



Knowing Me!™

Dementia, Depression and Delirium - A person centered education and training resource



LIFE STORY NETWORK

Knowing Me! - Further Training

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Jean Tottie, Chair and Founding Director, Life Story Network

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Foreword



“*Knowing Me!* is the culmination of the passion and efforts of many people, past and present who wanted to make a difference to the lives of those affected by dementia, depression and delirium commonly known as the “3D’s”. This resource has a history with the first “toolkit”, called Let’s Respect, being developed in 2006. The content of this toolkit had been co-ordinated by the Care Service Improvement Partnership (CSIP), funded by the Department of Health. The toolkit was designed to raise the awareness and understanding of the 3D’s within Acute Hospitals and was followed by a similar resource titled “Do You See Me” designed for Care Home staff.

Knowing Me! is the result of the Yorkshire and Humber Clinical Network (CN) responding to local clinicians, health and social care providers and commissioners who, although they considered 'Do you see me' to be an excellent resource, thought it was the right time to “review and refresh” it. The CN have commissioned The Life Story Network, who now own the intellectual property rights to the resource, to undertake this work and to deliver two main aims:

- Firstly, update the resource to reflect recent developments in the awareness and understanding of the 3D’s.
- Secondly, to format the content into an accessible resource to enable its wide dissemination and uptake through digital and web formats.

The objectives of this new *Knowing Me!* remain the same in that by raising awareness and understanding of the 3D’s improvements in the standards of care, experience and outcomes can be achieved for those affected by the 3D’s. *Knowing Me!* is not however a stand alone resource aimed at a particular staff group or a particular care environment but should be seen as a complementary resource to raise the awareness and understanding of the 3Ds. *Knowing Me!* builds on the values and principles of person centered care and support to improve the quality of life and provides useful and practical ways in which improvements can be made to really make a difference. Knowing the person is the cornerstone of delivering person centered care and support.

If you are a family carer using this resource then you may be interested in joining 'tide - together in dementia everyday', which is the voice, friend and future of carers, and former carers, of people with dementia (www.tide.uk.net). Other additional learning modules can be found on the 'Life Story Network' website.



A handwritten signature in purple ink that reads "JTottie".

Jean Tottie

Chair and Founding Director, Life Story Network



Getting Started

Getting Started

Learning Statement



After reading and reflecting on *Knowing Me!* you:

- Will better understand how health and wellbeing impacts on quality of life.
- Will have a better understanding of the distinctive features of dementia, depression and delirium.
- Will have a better understanding of the differences between dementia, depression and delirium.
- Will have a broader understanding of “person centred care”.
- Will have a broader understanding of the issues surrounding the end of life.
- Will have a broader understanding of issues surrounding being a carer.
- Will have a broader understanding of Human Rights and surrounding legislation.
- Will have a broader understanding of measuring success.
- Will have a better understanding of the issues surrounding being a staff member employed to care and support someone with dementia, depression and delirium.

What is *Knowing Me!*?

Knowing Me! is a quality improvement resource. Quality improvement is about making things better so by engaging with this resource your knowledge and understanding will be improved so you too can help make things better when caring for and supporting someone with dementia, depression and delirium.

This education and training resource has a simple and clear focus; to raise the awareness and understanding of dementia, delirium and depression referred to as the 3D's. The focus will primarily, but not exclusively, concern the older adult and will involve not just the person diagnosed with the illness or the disease, but their carers, loved ones and families too.

It is hoped that by being aware and by understanding the issues around the 3D's the stigma often associated with them can be reduced and then people can hopefully help and support more. In turn if people can help and support more then the life experience and outcomes for the person living with the illness or disease can be improved.

Who is *Knowing Me!* for?

Knowing Me! is designed for anyone who needs to be aware of and understand the 3D's including health and social care staff whether permanent, part time or bank staff, independent and voluntary sector staff, general community service staff, businesses and the community in general. We also expect that people living with dementia, delirium or depression and their carers and families may also find this resource useful.

The resource does not attempt to present all the information and knowledge currently available regarding the 3D's but will provide the required information to build on any basic awareness of the 3D's to develop a better understanding. However, throughout, the resource will also sign post to and refer to further information that will support an increased knowledge and understanding as required.

This resource complements other information available but reference should be made to the specific dementia, depression and delirium pages found on the Yorkshire and Humber Clinical Networks website: www.yhscn.nhs.uk/mental-health-clinic.

How can *Knowing Me!* be used?

Knowing Me! can be used in a variety of ways:

- An information and reference resource for anyone who wants to understand a little more than just the basic awareness of the 3D's.
- A staff induction aid to be used for new staff, who are likely to come across or work with people living with dementia, delirium or depression.
- A staff training aid on the specific topics of dementia, delirium and depression.
- A quality improvement aid either in staff or group discussions or with individual supervision, where reflection is required and learning can be improved.

Principles and Value Statements



Principles and Value Statements

Learning Statement



After reading and reflecting on this section you will:

- Know what “protected characteristics” are and how they relate to equality.
- Understand the difference between equality and equity.
- Understand the basic person centred care principles.
- Understand what stigma means and what promotes stigma.

Knowing Me! aims to build on the principles of Human Rights (1), Equality (2) and those person centered principles captured by specific guidance such as those associated with dementia (3).

Equality and Health Inequalities Statement

Promoting equality and addressing inequalities are at the heart of the Human Rights Act and thus Health and Social Care values. Throughout the development of this resource we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (cited under the Equality Act 2010) and those who do not share it; and;
- Given regard to the need to reduce inequalities for people in their access to information and services, delivery and outcomes from those services and to ensure services are provided in an integrated way where this might reduce health inequalities.

The Protected Characteristics mean people should not be disadvantaged because of their age, gender, sexual preference and assignment, race, religion and belief, marital and civil status, pregnancy and maternity and disability.

What is the difference between Equality and Equity?

From a person centered care perspective it is important to understand the difference between equality and equity. There is a quote to help understand this difference that states:



Equality is giving everyone a shoe.
Equity is giving everyone a shoe that fits



From a person centered perspective and in the context of this resource people should not be disadvantaged, disenfranchised or dis-empowered because of an illness or a diagnosis. **Knowing Me!** promotes person centered care and the basic principle of involvement, “nothing about me, without me”. Many statements have been produced over the last few years to capture these principles such as those surrounding disability, cancer and more recently dementia and are often referred to as “I” statements or “We” statements.

As this resource aims to be inclusive then the “We” statements as presented by the Dementia Action Alliance (4) will be used as a basis throughout. These statements were developed by people living with dementia and their carers. The person with dementia is at the centre of these statements. They represent everyone living with any type of dementia regardless of age, stage or severity. The “we” used in these statements encompasses people with dementia, their carers, their families, and everyone else affected by dementia. These rights are enshrined in the Equality Act, Mental Capacity legislation, Health and care legislation and International Human Rights law.

- We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.
- We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.
- We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how our illness or disease affects us. This must meet our needs, wherever we live.
- We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.
- We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.

What is Stigma?

Stigma refers to attitudes and beliefs that lead people to reject, avoid, or fear those they perceive as being different. Stigma is a Greek word that in its origins referred to a kind of mark that was cut or burned into the skin. It identified people as criminals, slaves, or traitors to be shunned.

People with illness, particularly mental illness and dementia, have long been stigmatised, mainly due to a lack of understanding and appreciation of the particular illness and disease.

While “stigma” is an attitude or belief, “discrimination” is behavioral because of those attitudes or beliefs. Discrimination occurs when individuals or institutions unjustly deprive others of their rights and life opportunities due to stigma. In the case of the 3D’s an example would be depriving someone of choice simply because they had dementia, depression or delirium. Things like attitudes, language and imagery can increase stigma so this resource will use words and images that reflect and represent fairly and positively the impact of the 3D’s. For more on language and words please see the work done by the Dementia Engagement and Empowerment Project (DEEP) and the Dementia Action Alliance Words Matter campaign (5).

“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

Helping to understand stigma

The parable of the cracked pot is a good way of understanding stigma associated with ageing and in particular to dementia. The parable is all about the flaws in perfection and the perfection in flaws, as well as a reflection on re-framing our own imperfection (6).

Things to remember from this section



- Everyone is an individual
- Everyone has rights
- Everyone has choices
- Words and attitudes can create stigma which can prevent good care and support

Additional Resources

- www.skillsforcare.org.uk/Learning-development/Care-Certificate/Care-Certificate
- www.myalzheimersstory.com

References

1. *Humans Right Act, 1998*. See <https://www.legislation.gov.uk/id/ukpga/1998/42>.
2. *Equality Act, 2010*. See <https://www.legislation.gov.uk/ukpga/2010/15/contents>
3. *National Dementia Declaration, 2010*. (updated 2017) See www.dementiaaction.org.uk/nationaldementiadeclaration
4. www.dementiaaction.org.uk/nationaldementiadeclaration
5. <http://www.dementiaaction.org.uk/dementiawords>
6. <https://bible.org/illustration/cracked-pot>

Health and Wellbeing



Health and Wellbeing

Learning Statement

After reading and reflecting on this section you will:

- Know what we mean by health and wellbeing
- Know the Five Ways to Wellbeing
- Know how to improve the health and wellbeing of people affected by dementia, depression and delirium.



What is Health and Wellbeing?

Wellbeing is about how people feel about themselves, feeling healthy, happy and well off. Having a good self-concept or “liking yourself” gives an individual a feeling of wellbeing.

Health is having a state of sound body and mind.

Health and Wellbeing is made up of four factors, physical, intellectual, emotional, and social. These are the factors that help us through the day and keep us going. Many people connect emotional wellbeing with a possible fifth factor which is spiritual health where people's religion and faith can influence and support how they feel.

Public Health England have produced an excellent resource that details the Five Ways to Wellbeing (1).



TALK & LISTEN,
BE THERE,
FEEL CONNECTED



DO WHAT YOU CAN.
ENJOY WHAT YOU DO.
MOVE YOUR MOOD



REMEMBER
THE SIMPLE
THINGS THAT
GIVE YOU JOY



EMBRACE NEW
EXPERIENCES.
SEE OPPORTUNITIES.
SURPRISE YOURSELF



Your time,
your words,
your presence

How do we improve the health and wellbeing for people living with dementia, depression and delirium?

The table below gives a little more information about each of the five ways to wellbeing specifically in relation to the 3D's:

	<p>Staying connected helps prevent isolation and loneliness. Having someone to talk with and share your thoughts feelings and experiences helps keep people involved and engaged with life and people around them. Being lonely can cause depression and people affected with dementia can often feel alone especially if people around them are not aware of and understand what dementia is and how it can affect someone's life.</p>
	<p>Exercise makes you feel good! This can be as little or as much as people want but by knowing someone, activities can be that they have enjoyed in the past, or still do. Doing activities with other people can help connections and physical health. People with depression may not feel like being active and people with delirium and dementia may not be well enough but this does not mean activities cannot be considered as part of a plan to improve and maintain health and wellbeing. Activities should be aimed at providing real opportunities to improve physical, social and mental wellbeing.</p>
	<p>Being aware of the world around you, reflecting on what you have done and seen, what you are doing and seeing now and what you may do and see helps to keep people in touch with their surroundings. Helping and supporting people with the 3D's to reflect and talk about experiences will help you appreciate what is important to them and therefore know them better.</p>
	<p>"We learn something everyday" is the saying commonly heard. Learning is not just for children and formal education. Learning new things or rediscovering things people have done before can be challenging or fun and can help build confidence.</p>
	<p>Giving is not just about donating money. Giving can refer to many things, such as giving your time, giving appreciation, giving respect and consideration and simply giving a smile. To receive often starts with giving so when you are with people affected by the 3D's think how you can help them give by giving something yourself. Giving makes people happy and helps them stay connected.</p>

When we think of health and wellbeing in later life the Mental Health Foundation (2) provide ten things to consider. We have summarised these in to ten key messages about mental health in later life.



Changes - Everyone has mental health just as they have physical health and this can change over time. As mental health and wellbeing are influenced by so many factors it can change over time. Big events such as retirement, moving home, being ill, moving to residential care and losing a loved one can have a huge impact. Loss of sense of purpose can have a huge impact on a persons wellbeing. Understanding these changes and helping people to deal with them will help their health and wellbeing.



Good to Talk - Conditions such as the 3D's are not an inevitable part of growing old but growing old does increase the risk of becoming depressed or getting dementia. Managing problems, difficulties and worries become easier if we talk about our concerns. It's a good thing to start thinking about how we feel. Talking can make people feel supported and not alone.



Ask for Help - Many people feel as they get older asking for help is a sign of losing independence but everyone needs help at some time. People with dementia, delirium and depression may not be able to ask for help so by knowing the person, help can be offered at the right time in the right way, when help is required.



Planning - A national inquiry into mental health (3) found certain factors that were important in relation to promoting good mental health in later life: not experiencing discrimination; planning activities; having good social connections; good physical health; and having enough money. These factors should be included in a person's "Care Plan" or "Plan of Care" if they are receiving care, support or services.



Caring - Caring for others and being cared for provide connections that can have positive impacts for both parties. Having an understanding of this can promote positive relationships that impact on wellbeing. Being a carer can also place a huge burden on people and we will be looking at the needs of carers in more detail further in the resource under Being a Carer.



Friendships - Most people have a friend or even a best friend or someone they are really close to. These can be the most important of relationships and often provide the space for honesty and disclosure of true feelings. Good mental health is not the same as happiness. Good mental health can help people cope with what life brings and having friends to help with life's challenges is good. Understanding a person and their friendships can help in understanding and knowing the person.



Be Active and Sleep Well - Often the more active a person is the better they sleep, both are as equally important to good health and wellbeing in later life. Being active can be as simple as walking or doing the garden. Sleeping poorly can effect concentration, make people irritable, give people low mood and lower their immune system so they are susceptible to infections. Knowing the person and what activities they like and what helps them sleep will help promote their health and wellbeing



Eat and Drink Sensibly - Eating a balanced diet, staying hydrated, drinking alcohol in moderation and not smoking (4) all effect how we physically and mentally feel. Knowing what people like and dislike can help to promote a healthy diet and lifestyle.



Do Things You Enjoy - People with good mental health can still experience mental health problems, for example bereavement. However, poor mental health can increase vulnerability to mental illness and slower recovery from any life incidents or accidents. Knowing what people have enjoyed or still enjoy can help to support people and give them a sense of wellbeing. Spirituality, faith, religions and cultures must not be overlooked.



Find Time to Relax and Rest - Taking a break, having a rest and relaxing are just as important to health and wellbeing as being active. "Recharging the batteries" letting the body and mind rest can help people feel refreshed. What is relaxing for one person could be an activity for another so getting to know the person will help support this. Some people may use their spiritual preferences to relax and may find their faith or religion as a source of relaxation.

Things to remember from this section



- Health and wellbeing are made up of several factors.
- Five ways to wellbeing: Stay Connected, Be Active, Take Notice, Keep Learning and Give.

Additional Resources

- www.nice.org.uk/guidance/ng32
- www.fingertips.phe.org.uk/profile/older-people-health
- www.england.nhs.uk/ourwork/ltc-op-eolc/older-people/
- www.england.nhs.uk/ourwork/ltc-op-eolc/older-people/improving-care-for-older-people/
- www.scie.org.uk/publications/guides/guide03/framework/wellbeing.asp

References

1. <https://www.gov.uk/government/publications/five-ways-to-mental-wellbeing>
2. <https://www.mentalhealth.org.uk/publications/how-to-in-later-life>
3. https://www.mentalhealth.org.uk/sites/default/files/promoting_mh_wb_later_life.pdf
4. <https://www.gov.uk/government/publications/the-eatwell-guide>

Quality of Life



Quality of Life

Learning Statement

After reading and reflecting on this section you will:

- Know what we mean by Quality of Life.
- Understand how certain factors can impact on Quality of Life.
- Understand how quality of life can be improved for people affected by dementia, depression and delirium.



Quality of Life

Someone's quality of life is the extent to which their life is comfortable or satisfying. Of course what makes people feel they have a good quality of life can vary and differ from one person to the next. People have different backgrounds and experiences, different likes and dislikes, and different views. Understanding and appreciating these will help improve the quality of life.

The Joseph Rowntree (1). Foundation presents three core factors that influence the quality of life; somewhere to live, something to do/some purpose and to love or to be loved.

Knowing Me! will now present some broad themes, (some of which have already been mentioned), which should be considered when thinking of improving someone's quality of life in association with the 3Ds.

The Impact of Nutrition and Hydration

Eating and drinking are key indicators to tell you if someone is well. They are more than just essential in maintaining a healthy body; they are also great social activities that people can enjoy. Knowing the person, their likes and dislikes, where when and how they like to eat are important in delivering good care and support. Done well meal times can be an enjoyable and rewarding experience; done badly and the person can be left frustrated, embarrassed, isolated and undervalued. This can often lead to isolation, poor nutrition and hydration and illness such as delirium.

Older adults and especially those with the 3Ds, disabilities and sensory loss may need assistance while promoting independence to ensure good nutrition and hydration. Considerations for good nutrition and hydration:

- **Knowing Me!** Knowing the person and their preferences regarding eating and drinking.
- How the food is presented, does it look and smell attractive to eat. Should it be hot or cold?
- What type and colour of crockery are used to help identify the food; for example white mash potato on a white plate may be hard to see.
- What type of utensils should be used to support the person to eat and drink well but maintain independence.
- Ensuring privacy where necessary to maintain dignity with no interruptions or distractions.

The Impact of Sleep

Sleep is important for a quality of life, to rest the body and mind and “to recharge” the batteries. Lots of research has been done on how important sleep is on the body and the brain, with some research suggesting the brain “cleans” itself during sleep helping to protect itself from disease (2).

Preparing for sleep is important to enable a good sleep. We all may have different ways of preparing for sleep and getting to know someone’s routine can help care and support them better.

Light and noise in the sleeping environment can be responsible for night time awakening. A sleeping environment that is too warm or too cold can also make sleeping difficult. An early morning truck, a streetlight outside the bedroom window, street noises and similar disturbances can make it hard to fall asleep and stay asleep. These external elements can be the easiest to identify, and the simplest to remedy.

Physical pain from disability and conditions like arthritis and other conditions that accompany the aging process can make it difficult to fall asleep and stay asleep.

Dehydration, infections, stimulating the body before retiring to bed with television or caffeine from drinks, are all well documented factors that can have an effect on a good sleep.

Some medications and drug interactions can also interfere with natural sleep cycles and it is always a good idea to frequently ask the person's GP to review prescribed medication.

Sleep Disorders

Sleep disorders and disturbances come with a variety of characteristics and have many causes. Some of the sleep disorders that are common in people with dementia include:

- increased frequency and duration of night time awakening
- daytime napping
- decrease in the time spent in deep sleep. This can lead to increase in awakenings
- difficulty falling asleep and insomnia
- “sun downing” – disorientation and confusion that often occur in people with dementia late in the day
- shifts in sleep/wake cycle – more time awake during the night and asleep in the day.

The Impact of Pain

Pain can be defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage. Pain is a feeling triggered in the nervous system which may be sharp or dull and it may come and go or be constant. Pain may be felt in one area, such as the back, stomach or chest or may be felt all over with aching muscles when someone may have flu.

Pain is usually referred to as acute or chronic, and these differ greatly:

Acute pain is the sudden pain experienced from a fall, an injury or an acute infection for example.

Chronic pain would usually be associated with arthritis or other long term conditions.

Pain is individual:

- It's what the person says "hurts."
- It's what the person describes and feels as pain.
- No other person can experience another's pain, or know what it feels like, or how it affects the person physically or emotionally.
- It may cause discomfort, distress or agony.
- Emotional pain can be as powerful and unpleasant as physical pain.
- Emotional pain can be caused by many things, for example loss, being lonely and not being able to fulfill spiritual, faith or religious practices.

Pain is not normal and is not a normal part of ageing. Pain can, if untreated or unmanaged, affect how a person can feel and behave. Pain can make people feel miserable or even depressed and if a person cannot communicate they are in pain, for example when they have dementia, depression or delirium, they may exhibit behaviours to show their distress. While noise may be the most obvious indicator of distress, it does not always indicate that a person is in pain. Equally, someone who is silent and socially withdrawn may also be in great pain.

Some common signs of pain can be (3):

- increased agitation
- hitting out
- shouting, repetitive calling
- repetitive movements
- tense muscles; decreased ability to function at the usual level
- changes in sleep patterns
- increased pulse rate, sweating
- grimacing
- withdrawal
- not eating or drinking

The National Council for Palliative Care (NCPC) have produced a useful guide for people living with dementia who may be in pain. A useful acronym has been devised for people who care and support people with dementia - **ALOA** (4):

- **A**sk the person what the matter is
- **L**isten to them
- **O**bserve their behaviour and what's going on
- **A**ct on what you've seen and heard

By knowing the person, changes in their behaviour and mood can be identified. When a change is noticed pain could be the reason! Ask the person if they have any pain. Never ignore pain and always consult the person's GP.

The Impact of Relaxation

Knowing the person and understanding what they did previously or do now to relax can help to plan good care and support. Some people find that soaking in a warm bath can work wonders when they are feeling stressed. The warm water can relax stiff muscles and also help people mentally relax. Sunlight and fresh air can also help people relax. Often something as simple as taking a short walk in the fresh air can help people relax. It is also known that certain smells can help people relax, the smell of lavender for example.

It's a proven fact that soothing music can be relaxing. Knowing the person and their favourite music can help plan activities to assist relaxation. The therapeutic effects of singing are well documented and can connect people with their self and their emotions, and provide a connection with others aiding communication.

Music therapy uses singing to engage people in an activity that promotes and maintains their quality of life. A person's enjoyment is typically increased as they move or sing with music. Music can also be linked to other memory-stirring activities such as looking at photographs, and can provide some sense of shared feeling and emotion. It can also stimulate a sense of belonging and of who we are or once were.

Massage and particular types of massage can be relaxing. Hand massage is a well known practice. Doing a person's nails and massaging their hands using rich hand cream can help people relax but also provides the opportunity to spend quality time with the person. Always check whether having a massage is something the person would enjoy; some people do not like to be touched in this way.

See sections on Quality of Life and The Impact of Spirituality to understand more on how a person's spirituality, faith or religious practices can often be the activity that helps a person relax.

The Impact of Falls

As people get older the risk of having a fall increases and people living with dementia, depression and delirium are at even higher risk. The result of falling is one of the main reasons for hospital admission for the elderly and lots can be done to help reduce the risk of falls.

The risk of falls is increased by:

- Having a long-term condition such as dementia, heart disease, diabetes and chronic chest conditions.
- Sensory impairment such as poor eyesight and hearing.
- Being easily startled with noises and distractions.
- Taking the wrong medication or the right medication at the wrong time.
- Not eating and drinking well.
- Having dizziness and balance or blood pressure problems.
- Wearing ill fitting shoes or slippers or the wrong footwear for the environment.
- Not using walking and balancing equipment like walking sticks and frames, when advised or instructed.
- Being in an environment that has hazards like steps, slopes, rugs, slippery surfaces and worn carpets.
- Being in an environment with poor lighting and obstructions like clutter and furniture.
- Living alone and being isolated.

Most areas in the country now have services to help people who are at risk of falls but the person's GP practice is a good place to start if advice and help is needed.

The Impact of Relationships

The importance of relationships has previously been presented in the Quality of Life section and more information can be found in the section on Person Centred Care. The issue of relationships is central to the *Knowing Me!* resource.

Relationships are central to who we are and are essential for our well-being and our survival; having relationships is a basic human need. Knowing the person and understanding the relationships important to them will assist the delivery of good care and support. Relationships can come in many forms from the usual loved ones and families to strong friendships and love for a pet or an activity.

Verbal communication is an important part of our relationships but non-verbal communication must not be overlooked especially when caring and supporting people living with dementia, depression and delirium.

Personal Relationships

Personal relationships, like the person, are very individual and assumptions again should not be made. It is often assumed the older adult is heterosexual, for example, and that sexuality and sex are no longer important. In a growing, diverse, tolerant and changing society, people are being accepted for who they are and not what they are. Age does not mean the factors that were important to people when they were younger are no longer important to them including sex and intimacy. Again knowing the person and the personal relationships that are/were important to them is important to planning and giving good care and support. This will also help to avoid discrimination and causing distress. Sexuality is a multi-dimensional concept (5) that describes:

- The desire and need for sex
- Sexual activity
- Sexual orientation
- Values and beliefs
- A person's self concept and self esteem
- A sense of sensuality

As we live in a predominantly heterosexual society (6) (93% ONS 2015), different forms of sexuality can be overlooked. We may shy away from discussing a person's sexuality, or even worse, ignore it. Statistics show that our society has an ever-increasing population of gay, lesbian, bi-sexual and trans-sexual people, currently predicted to be over 7%. If this number is applied to an older population, or specific populations such as those living with dementia, it can be estimated how many people are not heterosexual.

Health and social workers and providers of care and support need to consider the differing relationship needs of people. They also need to be culturally aware of how to support relationships that are not heterosexual.

The Impact of Spirituality

When caring for and supporting a person, spirituality can often be overlooked, classed as emotional wellbeing or mixed up with faith and religion. Spirituality is a more all-embracing concept (7) than emotional wellbeing, faith or religion. One metaphor describes spirituality as a journey with religions as different modes of transport. For some it can be the most important thing for them. Getting to know the person's spiritual needs can therefore be very important when giving care and support.

For people who believe in God, spirituality can mean one thing, for those who do not believe in God, it can mean another. However, spirituality can often compel people to ask questions about the meaning and purpose of life. It is impossible to know all the intricacies of every specific religious and spiritual belief (8). What is more important is treating them seriously with dignity and respect, knowing the person and trying to understand and support the individual's needs and wishes (see sections on Quality of Life, Life Story Work and End of Life Care). People do not need to be religious to have a sense of spirituality. It may help by asking or discussing the following questions with the person or their family:

- What do they value the most?
- What do they enjoy doing?
- What gives meaning to their day?
- How would they feel if they couldn't do what they enjoy and gives meaning to their day?

Religion

There are many religions. Religion creates a framework for people to make sense of the world and although often reassuring to the person can often cause distress especially if certain cultures and taboos that surround that particular religion are overlooked or ignored. Here are some examples to consider:

- Devout Muslims may not drink alcohol but some people who say they are Muslims may drink alcohol.
- Sikhs may regard having a bath as abnormal and prefer a shower.
- Jewish people and Rastafarians may refuse to eat pork.
- Sikhs do not eat Halal food.

The most important thing regarding religion is to understand if the person has religious beliefs and then to get to know their individual preferences and behaviours regarding that religion. It is important not to make assumptions about a person's culture and beliefs.

Things to remember from this section



- In older people, physical illness or medication side effects are more likely to result in poor mental health and warrant thorough investigation in every case.
- Every older adult should have a frequent (minimum annual) medication review and a targeted physical examination as required and according to symptoms.
- Being in pain and lack of good sleep can change a person's behaviours.
- Relaxation and relationships need to be considered when giving care and support.
- Not all older adults are heterosexual.
- Knowing and understanding the persons spiritual, faith and religious practices is important in giving good person centered care and support.

Additional Resources

- Alzheimer's Society; (2007) My name is not dementia. London.
- Alzheimer's Society; (2010) Dementia - Out of the Shadows. London.
- www.playlistforlife.org.uk/
- Cook-Daniels, L (2002) Lesbian, Gay Male Bisexual and Transgendered Elders. Elder Abuse and Neglect Issues
- www.skillsforcare.org.uk/Documents/Topics/Dementia/Dementia-and-diversity-a-guide-for-leaders-and-managers.pdf
- www.evidence.nhs.uk/Search?q=spirituality+mental+health+wellbeing
- www.spiritualcompetency.com/
- [/www.mentalhealth.org.uk/a-to-z/s/spirituality](http://www.mentalhealth.org.uk/a-to-z/s/spirituality)
- www.spiritandculture.org.uk/

References

1. <https://www.jrf.org.uk/report/better-life-what-older-people-high-support-needs-value>
2. <https://www.nih.gov/news-events/news-releases/brain-may-flush-out-toxins-during-sleep>
3. <https://www.scie.org.uk/dementia/advanced-dementia-and-end-of-life-care/end-of-life-care/pain.asp>
4. http://www.ncpc.org.uk/sites/default/files/How_Would_I_know.pdf
5. <https://www.psychologytoday.com/basics/spirituality>
6. <https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/sexuality/bulletins/sexualidentityuk/2015>
7. <http://www.tandfonline.com/doi/abs/10.1080/19325037.2009.10599074>
8. <https://www.scie-socialcareonline.org.uk/guidelines-on-spirituality-for-staff-in-acute-care-services/r/a11G00000017w6UIAQ>

Dementia



Dementia

Learning Statement



After reading and reflecting on this section you will:

- Know what dementia is.
- Know what causes dementia and what are the risks factors associated with dementia.
- Know how people are assessed for dementia.
- Know what the treatment for dementia is.
- Know what we mean by good dementia care and support and what factors and activities can improve that care and support.
- Have a broader understanding of Life Story Work and how to get to know the person.
- Understand what dementia mapping is.

What is dementia?

Dementia is not a disease in itself. It is a syndrome, or a group of symptoms that occur when brain cells stop working properly, and is caused by lots of different diseases. The word 'dementia' is just an umbrella term for the symptoms caused by these diseases.

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. Each person is unique and will experience dementia in their own way. The different types of dementia also tend to affect people differently, especially in the early stages of the disease. Other factors that will affect how well someone can live with dementia include how other people respond to them and the environment around them.

People with dementia can experience some or all of the following (1):

- memory loss
- language impairment
- disorientation
- changes in personality
- difficulties with activities of daily living and self neglect
- perceptual and sensory difficulties
- psychiatric symptoms such as depression and psychosis
- out-of-character behaviour such as aggression, sleep disturbance or dis-inhibited behaviour

Everyone's experience of dementia is different.

Dementia Statistics

There are many facts and statistics regarding dementia. A good source for up to date data on dementia is the Alzheimer's Research UK, Dementia Statistics Hub (2). However, here are some key facts and statistics:

- There are 850,000 people estimated to be living with dementia in the UK with almost 520,00 having a formal diagnosis.
- With a growing and ageing population the number of people expected to have dementia by 2025 in the UK is one million and two million by 2050.
- Dementia mainly affects older people, and after the age of 65, the likelihood of developing dementia roughly doubles every five years (3).
- Dementia and Alzheimer's disease became the leading causes of death in England and Wales in 2015 accounting for 11.6% of all deaths registered (4).
- Dementia can start before the age of 65, presenting different issues for the person affected, their carer and their family. There are estimated to be 40,000 people under the age of 65 with dementia.
- There are around 540,000 carers (5) of people with dementia in England (6). It is estimated that one in three people will care for a person with dementia in their lifetime. Half of them are employed and it is estimated that 66,000 people have already cut their working hours to make time for caring, while 50,000 people have left work altogether.

What causes dementia?

There are many causes of dementia. Alzheimer's disease is the most common accounting for about 60 per cent of dementia cases. Alois Alzheimer was a German Neurologist who in the early twentieth century discovered the specific brain damage of the disease that now bears his name. Around 20 per cent of cases are vascular dementia, which results from problems with the blood supply to the brain. Many people have a mixture of Alzheimer's disease and vascular disease. There are other less common forms of dementia, for example dementia with Lewy bodies and fronto-temporal dementia. There are some rarer types of dementia that may have a genetic link such as Huntington's disease (7).

Dementia Risk Factors

Alzheimer's Research UK and Public Health England have produced a booklet titled Reducing Your Risk of Dementia (8). There is evidence that more can be done to delay the onset of dementia by reducing risk factors and living a healthier lifestyle. Studies suggest it may be particularly important to maintain a healthy lifestyle in your forties and fifties to help lower the risk of dementia (9).

Although age is the biggest risk factor associated with dementia, it is not an inevitable part of ageing (10). The risks for heart disease are the same risks for dementia leading to the saying "***what is good for the heart is good for the mind!***"

Some guidance:

- Don't smoke.
- Keep active and exercise regularly.
- Maintain healthy weight.
- Eat a healthy balanced diet.
- Only drink alcohol within NHS guidelines.
- Keep cholesterol and blood pressure at a healthy level.

There is also evidence that other conditions can increase the risk of dementia. Parkinson's disease, stroke, type 2 diabetes, high blood pressure and Mild Cognitive Impairment (MCI) all increase the risk of dementia.

People with learning disabilities have a greater risk of developing dementia than other people and usually develop the condition at a younger age. This is particularly true of people with Down's syndrome, one in three of whom will develop dementia in their 50's (11).

There is greater prevalence of dementia among black and South Asian ethnic groups. In 2011, there were 25,000 people with dementia from black, South Asian and minority ethnic groups in England and Wales, according to the Alzheimer's Society. This number is expected to double to 50,000 by 2026 and rise to over 172,000 by 2051. These groups are more prone to risk factors such as cardiovascular disease, hypertension and diabetes, which increase the risk of dementia and contribute to increased prevalence.

There is also a growing body of research examining the effect of sleep, brain stimulating activities and social contact on cognitive decline and dementia (12).

Many people with dementia will have complex needs compounded by a range of co-morbidities. A recent survey found that 72 per cent of respondents were living with another medical condition or disability as well as dementia. The range of conditions varied considerably, but the most common ones were arthritis, hearing problems, heart disease or a physical disability (13).

How are people assessed for dementia?

Dementia assessment involves excluding any physical reasons for the presenting symptoms such as infections or cardio vascular problems. A detailed history involving the person with the symptoms and their carer/family, along with specialist tests, can then help form a diagnosis. An initial assessment is often performed by the person's GP, with many people then being referred to "Memory Services". There is no set model for a memory service and they can be found in many locations such as hospitals, community clinics and local surgeries. Diagnosis can be given by a variety of skilled professionals who follow clinical guidance produced by National Institute for Health and Care Excellence (NICE) (14).

What is the treatment for dementia?

Currently, dementia is not curable. However, medicines and other interventions can lessen symptoms for a period of time and people may live with their dementia for many years after diagnosis.

A person with Alzheimer's disease or mixed dementia in which Alzheimer's is the main cause may be prescribed drugs: donepezil may give temporary help with memory, motivation, concentration, daily living attention and possibly ease distressing or challenging behaviours.

Drugs can also be helpful for someone with dementia with Lewy bodies who has distressing hallucinations or delusions, or who has behaviours that can challenge such as agitation or aggression.

For a person with vascular dementia, drugs will be offered to treat the underlying medical conditions, which often include high blood pressure, high cholesterol, diabetes or heart problems. Controlling these may help slow the progression of dementia.

A wide range of other drugs may be prescribed at different times for a person with dementia. These include drugs for depression or anxiety, sleeping tablets or antipsychotics. Health professionals will generally recommend that a non-drug approach is tried first before prescribing medication, unless a person's symptoms are very severe.

There are a range of non-drug treatments, therapies and activities such as talking therapies and cognitive therapies that are available that can help someone to live well with dementia. The GP, memory service or local Alzheimer's Society are good places to start for more information on what is available however some of these will be presented in more detail within the next section.

Learning (Intellectual) Disabilities and Dementia

As the risk of dementia increases with age and the fact that life expectancy has increased significantly for those people born with learning disabilities, more and more people with learning disabilities are being diagnosed with dementia. Life expectancy for people with Down's syndrome and other learning disabilities has improved significantly in the past 30 years, thanks to advances in medical care. For example, the life expectancy of someone with Down's syndrome has risen from 25 years in 1983 to over 60 years in 2015.

People with learning disabilities, particularly those with Down's syndrome, are at an increased risk of developing dementia. If a person with a learning disability develops dementia, they will face different and additional challenges to people who do not have a learning disability (15).

A learning disability is a lifelong condition that affects someone's learning, communication and understanding. The person may require support with some aspects of their life, including planning, learning new skills and socialising. There are estimated to be about 700,000 people living with a learning disability in the UK. Down's syndrome is relatively common, with more than 40,000 people living with the condition in the UK.

There are different learning disabilities with various causes. Not all of them are well understood. Some learning disabilities, such as Down's syndrome or fragile X syndrome, occur before birth and are due to genetic disorders. Others occur after birth but before adulthood. These may be due to infection (e.g. bacterial meningitis), brain injury, lack of oxygen at birth or premature birth. The effects of a learning disability on the individual range from mild to severe to profound (very severe).

The current national learning disabilities strategy (16) focuses on ensuring people with learning disabilities and their families are empowered to be in control of their own lives and if care is needed it is the right care and received in the right place. This mirrors the ambitions of the Prime Minister's Challenge on Dementia 2020 ensuring people with learning disabilities and dementia are not disadvantaged.

What is good dementia care and support?

In July 2017 NHS England published the Implementation guide and resource pack for dementia care (17). This pack complements the Prime Ministers Challenge on Dementia 2020 (18) and should be read to support this section of *Knowing Me!*

The pack sets out what needs to be considered and done and provides the evidence for transforming dementia care; to make it better and to ensure dementia is considered and treated like other diseases. The dementia “journey” is described as a “Dementia Well Pathway” and focuses on five key areas where improvements can be made. The five key areas are:



The ambition is to ensure:

- people who are suspected of dementia are offered a timely and responsive assessment for diagnosis with the commencement of treatment that will be within six weeks from referral.
- everyone with dementia and their family/carers should have a co-ordinator of care.
- everyone with dementia should have an agreed care plan that includes an Advanced Care Plan as necessary (see section on Dementia and End of Life)
- that care plan should be fit for purpose, up to date and reviewed as appropriate and within 12 months.

It is also worth noting that NICE are reviewing the current Clinical Guidance on dementia known as “CG42” produced in 2006 and aims to consult and then publish new guidance in 2018.

Again, what is good care and support for one person may not be good for another. The meaning behind the title of this resource *Knowing Me!* reflects the necessity to see and know people as individuals and not group them or box them together as “people with dementia”.

“We must put the diagnosis of dementia to one side and find the person.” (19)

No two people with dementia or their carers are the same and individuals will have unique and differing needs. Tom Kitwood stated:

“Once you have met a person living with dementia, you have met one person living with dementia” (20)

Dementia Education and Training

The Dementia Core Skills Education and Training Framework (21) was commissioned and funded by the Department of Health and developed in collaboration by Skills for Health and Health Education England (HEE) in partnership with Skills for Care. The development of the framework was guided by an “Expert Group” and included a wide range of health and social care organisations, relevant Royal Colleges and education providers.

The Framework sets out the core skills and knowledge, which would be transferable and applicable across different types of service provision. It includes expected learning outcomes for training delivery, key policy and legal references and is aligned to related national occupational standards. The aim is to help ensure the quality and consistency of dementia training, and to help prevent unnecessary duplication of training.

The Framework comprises:

1. Dementia awareness
2. Dementia identification, assessment and diagnosis
3. Dementia risk reduction and prevention
4. Person-centred dementia care
5. Communication, interaction and behaviour in dementia care
6. Health and well-being in dementia care
7. Pharmacological interventions in dementia care
8. Living well with dementia and promoting independence
9. Families and carers as partners in dementia care
10. Equality diversity and inclusion in dementia care
11. Law, ethics and safeguarding in dementia care
12. End of life dementia care
13. Research and evidence-based practice in dementia care
14. Leadership in transforming dementia care

What is Life Story Work?

There is no consistent or set definition of Life Story Work. The term “Life Story Work” is used to describe a wide range of activities ranging from informal to formal activities putting a life into perspective through a therapeutic life review (22).

Although Life Story work can be a key activity when caring for and supporting someone living with dementia it can be an activity and pastime for anyone who has a story to tell or share.

Many people with dementia enjoy life story work, in which they are encouraged to share their life experiences and memories. Life story work is often associated with working with people with dementia but everyone has a life and a story to tell so it can be used when working with anyone, not just people affected by dementia.

As a person’s dementia progresses, they may also enjoy reminiscence. Reminiscence is usually done in group settings with people talking about their memories and listening to each other and often includes the use of general prompts such as photos, objects or music from past times. Such activities may help improve someone’s mood, wellbeing and mental abilities.

“The pastime of ‘scrapbooking’– making photo albums and sharing memories – is a common, everyday activity, which many people do to celebrate birthdays and anniversaries. It is part of the ‘remembering’ practices we all engage in throughout our lives. We all have a story.”

Life Story Network

Life Story work is a process. It is not just a form to be filled, but a process of getting to know a person, the key message of this *Knowing Me!* resource. Life Story work is not just about looking back on the past but also understanding current hopes and future dreams such as revisiting a past hobby, or holiday destination, going back to church or seeing family.

Life Story work is not a tool to resolve past or current problems and even though it can be found to be therapeutic it is not classed as a therapy. Life Story work is usually done on a one-to-one basis but does not have to result in a “book” – It can be a simple sheet of A4 paper, a presentation or film on a laptop or some pictures in a scrapbook.

The Aim of Life Story Work

Life Story work aims to improve the quality of life and wellbeing of people by enabling them to document and share their Life Story in whatever way is best for them. Examples include written script, photographs, a computer file, memory boxes, audio tapes or DVDs. It is their story and puts them firmly in the centre. It is a vehicle for purposeful and respectful communication between the individual concerned and staff who are working with them to provide personal care and support.

Benefits of Life Story Work to the Carer

Many carers of people living with dementia report the benefits of Life Story Work. (22) (23)

Benefits of Life Story Work for Family Carers:

- Life Story Work is an activity that can support communication.
- Life Story Work is an activity that can help support connections and the building of relationships.
- Life Story Work can be constructive, rewarding and therapeutic.
- Life Story Work is an activity that can help the person with dementia feel valued by focusing on their identity and improving self-esteem and wellbeing.
- Life Story Work is a resource that can be used by the carer to help health and social care staff to get to know the person so that they can support them better.
- Life Story Work can be a legacy resource to assist bereavement and to remember the person.

Benefits of Life Story Work for Paid Staff:

- Life Story Work can help paid staff to get to know the person living with dementia and thus provide person centred care and support.
- Life Story Work assists with carrying out formal assessments, planning care, providing care and reviewing its effectiveness.
- Life Story Work can be used to design activities in day and residential settings that are rewarding and enjoyable.
- Life Story Work can help paid staff develop new skills and competences.

Ways of getting to know the person

There are many ways of getting to know the person. Spending time with the person and sharing experiences are important. Remember that feelings are as important as facts and capturing someone's life story is not the same as taking a family history. Take the opportunity while you are helping people with personal care to talk about their lives.

Here are some top tips for questions that can help conversations and assist in getting to know the person but remember it is not an interview or inquisition. Try to illicit details through conversations which you start and encourage a response:

- Where were you born?
- What part of the country do you consider home?
- What is the place you like (or dislike) the most?
- What did your parents do for a living?
- Where did you go to school?
- Did you like school?
- What subjects did you like most?
- Where did you or have been on holiday? Which did you like the most?
- What makes you laugh?
- What makes you happy?
- Who do really admire?
- What are you really proud of?



Dementia Care Mapping

Dementia Care Mapping is an established approach to achieving and embedding person-centred care for people with dementia, recognised by the National Institute for Health and Clinical Excellence (24).

Dementia Care Mapping has been used for over 20 years by care practitioners to improve quality of life for people living with dementia in a range of care settings, including care homes and hospitals.

Dementia Care Mapping prepares staff to take the perspective of the person with dementia in assessing the quality of the care they provide. It empowers staff teams to engage in evidence-based critical reflection in order to improve the quality of care for people living with dementia.

N.B Dementia Care Mapping is a registered trademark.

The Importance of Environments

It is often assumed that people living with dementia mostly have problems with their memory. While memory problems are a symptom of dementia, people living with dementia also experience changes in the ways that they see or visualise their surroundings. The Kings Fund (25) has performed research on the importance of environments and produced a toolkit to help measure how dementia friendly an environment is, for examples Care Homes (26). It is important to consider what would be “dementia-friendly” when designing or changing environments where people with dementia will spend time. The Kings Fund have produced some environmental tools to help care and support staff to assess and consider environments to enable improvements to be made (27).



Use of Lighting

Poor lighting can of course make it difficult to see for anyone. For people living with dementia poor lighting can present further problems to orientation and avoiding potential hazards and obstacles.



Use of Flooring

In addition to the normal aging process, some areas of the brain that process information may have been affected by dementia so consideration needs to be given to the type and colour of flooring. If possible, maintain a constant colour of flooring. Walking over carpet grips or strips or onto a change of floor surface, can appear to be a step or a change in depth. This can lead to the risk of stumbles or falls and cause anxiety and even fear for the person living with dementia. Shiny floor surfaces may give the impression that there is water on the floor.

Use of Colour



Due to the changes in how the brain processes information it is important to think about how colour can be used to improve recognition. Having furniture the same colour as the carpet can make it difficult to identify seating so, for example, it is better to use contrasting colours. White crockery on a white tablecloth can create difficulties at mealtimes as the person living with dementia may find it difficult to distinguish between a plate and a tablecloth. The use of coloured crockery can help people with dementia recognise and identify food more easily and assist people with dementia to eat better. If possible use coloured beakers or if using a glass, fill with a coloured squash or cordial rather than water.

Use of Mirrors and Signs



Mirrors are obviously useful, but for people living with dementia, they can sometimes be frightening or disturbing because the reflection may not be recognised. It is common for reflections to be mistaken for a family member or a stranger. If the reflection is not recognized it may cause anxiety or fear and lead to behaviours that can create challenges for care and support staff. Culturally relevant images can be used instead of mirrors and pictures that can help identify different rooms like kitchens, dining rooms, bedrooms and toilets can help with orientation, a sense of location and perhaps may stimulate appetite.

Use of Images



It is common to put pictures of landscapes and flowers on walls as means of decoration but these types of images do not stimulate interaction or conversations. Pictures of people, places or objects that are meaningful can provide many more opportunities for discussion or distraction, particularly in difficult moments. Finding out about people's life history (see Life Story Work section) and matching these with appropriate images can help with identity and provide a focus for communication or activities. Appropriate images can help with signage to help people identify spaces too.

Use of Objects

Using objects that reflect a person's past can help with identity, provide reassurance and again provide a focus for communication or activity.

Use of Indoor and Outdoor Space

Space that is used well can provide a healthy and safe environment. Poor use of space can create anxiety and fear if people feel closed in and cannot walk about safely. Clutter and obstacles not only create safety hazards but may also be overstimulating for people with dementia. Outdoor spaces should be accessible so that people can enjoy fresh air and relax. Raised beds will encourage people to help in the garden. Spaces with dead ends can cause frustration and anxiety, whereas circular walks enable people to walk about without feeling hemmed in. Staff in hospital wards and care homes should think carefully about whether locked doors are necessary and consider whether other ways can be found to keep people safe.

Remember, these ideas can help most people, not just people living with dementia.

Things to remember from this section



- Dementia is not a natural part of ageing (28).
- Dementia is caused by disease of the brain.
- Dementia is not just about losing your memory.
- No two people with dementia are the same.
- There is a core skills, education and training framework for dementia
- Life Story Work is a valuable tool in providing individualised care.
- People can still live well with dementia. Life does not end with a diagnosis of dementia.
- Think of how the environment can improve a person's quality of life, their experience and their safety.

Additional Resources

- Case Studies NHS England website - <https://www.england.nhs.uk/mental-health/dementia/>
- <https://www.england.nhs.uk/mental-health/dementia/>
- <http://www.skillsforcare.org.uk/Documents/Topics/Dementia/How-to-identify-dementia.pdf>
- PHE Fingertips Tool - <https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia>
- Clinical Commissioning Group Improvement and Assessment Framework - www.england.nhs.uk/commissioning/ccg-assess/iaf/
<https://www.england.nhs.uk/stps/>
- NHS Right Care - www.england.nhs.uk/rightcare/intel/cfv/data-packs/
- Dementia United - <http://dementiaunited.net/>

- Dementia Advisers - <https://www.alzheimers.org.uk>
- Dementia Pathway - <https://parkinsonsacademy.co/2017/02/15/new-dementia-toolkit>
- NHS Benchmarking - <https://www.nhsbenchmarking.nhs.uk/>
- Modelling Dementia - <http://www.modem-dementia.org.uk>
- Care planning - <https://www.england.nhs.uk/mental-health/resources/dementia/>
- Prime Ministers challenge on dementia 2020 Implementation Plan- https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/507981/PM_Dementia-main_acc.pdf
- <https://www.england.nhs.uk/wp-content/uploads/2017/02/dementia-good-care-planning.pdf>
- <https://www.england.nhs.uk/wp-content/uploads/2017/04/toms-story-full-narrative.pdf>
- <https://www.ons.gov.uk/.../birthsdeathsandmarriages/deaths/.../deathsregisteredine ngland...>
- <http://www.lifestorynetwork.org.uk/>
- <http://www.southwestyorkshire.nhs.uk/quality-innovation/initiatives-projects/portrait-life-elearning/>
- Kreativitiy dementia series = [/vimeo.com/228785408](https://vimeo.com/228785408)
- Alzheimer's Society provides a range of books and factsheets that you may find useful. <http://alzheimers.org.uk/>
- Age UK offers a wide range of useful information. www.ageuk.org.uk/
- <https://www.kingsfund.org.uk/projects/enhancing-healing-environment-unforgettable.org>
- Alzheimer's and Dementia Professional Group pages on LinkedIn

References

1. <https://pathways.nice.org.uk/pathways/dementia#content=view-info-category%3Aview-about-menu>
2. <https://www.dementiastatistics.org/statistics-about-dementia/prevalence/>
3. *Dementia UK: The Full Report*, Alzheimer's Society, 2007.
4. Brayne C et al, *Dementia before death in ageing societies – the promise of prevention and the reality*, PLoS Med 2006;3;10
5. *Dementia 2014: Opportunity for Change*, Alzheimer's Society, Sept 2014.
6. A carer is somebody who provides support or who looks after a family member, partner or friend who needs help because of their age, physical or mental illness, or disability. This would not usually include someone paid or employed to carry out that role, or someone who is a volunteer.
7. *Dementia resources*, NHS Health Check.
8. <http://www.alzheimersresearchuk.org/wp-content/uploads/2015/01/RRD-0515-0517-Risk-Reduction>
9. <https://pathways.nice.org.uk/pathways/dementia#content=view-node%3Anodes-risk-factors-and-prevention>.
10. *Dementia UK Update*, second edition, Alzheimer's Society, November 2014
11. Alzheimer's Society. 2011 *Learning disabilities and dementia factsheet*.
12. <http://www.sciencedirect.com/science/article/pii/S1552526015001971>
13. <https://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-14>
14. <https://www.nice.org.uk/guidance/cg42>
(Note this guidance is currently being reviewed and due 2018)
15. https://www.alzheimers.org.uk/info/20007/types_of_dementia/37/learning_disabilities_and_dementia
16. <https://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf>
17. <https://www.england.nhs.uk/wp-content/uploads/2017/07/dementia-care-short-guide.pdf> Publications Gateway Reference: 06950.
18. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf
19. James, J, Cotton, B, Knight, J, Freyne, R, Pettit, J & Gilby L (2017) *Excellent Dementia Care in Hospitals*. JK Publications. London.
20. Kitwood, T. (1997) *Dementia Reconsidered: the person comes first*. Open University Press, Buckingham.

21. <http://www.skillsforhealth.org.uk/services/item/176-dementia-core-skills-education-and-training-framework>
22. Kaiser, P; Eley, R; (2017) *Life Story Work With people With Dementia. Ordinary Lives Extraordinary people.* Kingsley. London. (p108-117)
23. <https://www.bradford.ac.uk/health/dementia/dementia-care-mapping/>
24. <https://www.york.ac.uk/spru/projects/life-story-feasibility/>
25. <https://www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-design-dementia>
26. https://www.kingsfund.org.uk/sites/default/files/field/field_pdf/is-your-care-home-dementia-friendly-ehe-tool-kingsfund-mar13.pdf
27. <https://www.worcester.ac.uk/discover/kings-fund-environmental-assessment-tools.html>
28. https://www.alzheimers.org.uk/info/20000/about_dementia/847/five_things_you_should_know_about_dementia

Depression



Depression

Learning Statement



After reading and reflecting on this section you will:

- Know what we mean by depression.
- Know what causes depression and the risks factors associated with depression.
- Understand how people are assessed for depression.
- Know the treatment options for depression.
- Understand what we mean by good depression care and support and what factors and activities can improve that care and support.

What is depression?

Depression is a broad diagnosis that is central to a depressed mood and/or loss of pleasure in most activities (1). Depression is different from feeling unhappy or sad and is characterised by the length of time someone feels like this and the severity of the lowness of mood.

Depression is the most common mental disorder in older people. However, symptoms can be distinctly different to depression in young adults, and it is often missed (2).

To be diagnosed with depression symptoms would have to persist for more than two weeks and there would need to be daily symptoms of low mood, loss of interest and loss of energy. Again no two people will experience depression the same.

The most severe form of depression called psychotic depression is where the person may have delusions (false beliefs) such as feeling they have done something really bad and they need to be punished. People may hear negative voices and at its worst the person may stop talking, eating and drinking and moving altogether.

Depression Statistics

- One in five people will experience depression sometime in their life (3).
- Depression mixed with anxiety is the most common mental health issue in the UK (4).
- Depression is the leading cause of disability (5).
- Women are more likely to experience depression than men (6).
- Older people are more vulnerable to mental health problems and depression (4).
- You can get better from depression but depression can also return (3).

What Causes Depression?

There's no single cause of depression. It can occur for a variety of reasons and it has many different triggers often referred to as biological, psychological and social factors. For some people, an upsetting or stressful life event, such as bereavement, divorce, illness, redundancy and job or money worries, can be the cause. Different causes can often combine to trigger depression (5).

With an older person depression can be caused by life events such as retirement, bereavement or moving into residential care. Loneliness and illnesses are often associated with depression where people feel helpless and cannot adjust or accept to a changing lifestyle. The past is seen as bright and the future is seen as bleak; consequently, when working with people with depression we need to be sensitive to the person's past, present and future (6) (7).

Again ageing alone does not mean depression is inevitable but as life events are part of ageing and because the risk of illness increases with age the older adult can be at higher risk of getting depression.

Depression Risk Factors

The causes and risks of depression can be very similar but certain factors can mean people are more at risk of getting depression:

- Having a serious health event such as a heart attack, stroke or being diagnosed with cancer
- Having a serious illness or disability that affects the way people live like immobility, incontinence or Parkinson's Disease

- Having dementia
- Sensory loss such as hearing and vision can mean people are more at risk of getting depression
- Being lonely and isolated
- Having financial worries
- Drinking alcohol to excess or using illegal substances
- Taking certain medications like steroids that can have a depressive effect
- Stress

How are people assessed for depression?

As with other illnesses, including dementia, the best way to assess for depression is to take a good history of the person's symptoms. Feelings of depression experienced most of every day, for more than two weeks, would alert the doctor to the possibility of depression.

There are no physical tests for depression, but the GP may examine and carry out some urine or blood tests to rule out other conditions that have similar symptoms, such as an under-active thyroid.

Depression will affect a person's ability to work, enjoy their usual interests and social relationships. Depression in the older adult is the leading factor associated with suicide.

Diagnosing depression in the older adult can be difficult because of the high risk of other physical illnesses, which may affect their behaviour and emotions.

Looking for clues can help assessment and diagnosis. Things like:

- loss of appetite and changes in eating habits
- sleeping a lot and being tired and lethargic,
- neglecting personal hygiene and dress,
- not being sociable and active
- complaining a lot and being negative about themselves, others and life in general.
- refusing medication
- being forgetful

What is the treatment for depression?

Sometimes, when people are depressed it can be difficult to imagine that treatment can actually help. But the sooner people are assessed the sooner appropriate treatments can be prescribed and they will improve.

The treatment that will be recommended will be based on the type of depression diagnosed. As experiencing a low mood from time to time is quite normal, the doctor may do nothing initially; this is often referred to as “watchful waiting”. Only if symptoms persist, as described earlier in this section, may the doctor prescribe treatments.

Two thirds of older people have mild depression that will often respond to listening, explanation, reassurance, encouragement and simply taking notice of the person's needs.

Treatment for depression usually involves a combination of self-help, talking therapies and medicines but knowing and understanding the person can help tailor treatment options to ensure the best outcomes.

With the older adult, health and ability will also need to be considered but the following things have been proven to help:

- Exercise (8)
- Healthy eating and tailored diets
- Staying socially connected with people
- Talking therapies such as psychotherapy, cognitive behavioural therapy (CBT) and counselling
- Alternative therapies such as aromatherapy and massage
- Relaxation and any activities that help people feel relaxed

If moderate to severe depression is diagnosed then antidepressants may be prescribed. There are almost thirty different types of antidepressant. A summary on the pros and cons of treatments for depression can be found at www.nhs.co.uk (9).

What is good care and support for people who are depressed?

Being alert to the possibility of depression as a reason for changes in a person is essential. Do not ignore depression. Depression is not normal.

Care and support should take into account the person's needs and preferences. People with depression should have the opportunity to make informed decisions about their care and treatment, in partnership with their families and with support staff. If a person does not have the capacity to make decisions, health and social care professionals should follow the Department of Health's advice on consent and follow the code of practice of the Mental Capacity Act (See Know My Rights section)

Good communication between the person, the person's carers, family and support staff is essential. Communication should be supported by evidence-based written information tailored to the person's needs.

Treatment and care, and the information people are given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English.

If the person agrees, families and carers should have the opportunity to be involved in decisions about treatment and care. Families and carers should also be given the information and support they need. There is no evidence that talking about suicide increases the risk of it happening and questions about how people are feeling, far from planting ideas in a person's head, can give them opportunities to talk about their emotions, their feelings and their fears. If a person expresses feelings that life is not worth living, or of wishing they were dead, do not ignore them; seek help and advice from senior staff or the person's doctor.

Things to remember from this section



- Depression is not normal.
- Risks for depression can be identified so action can be taken to help prevent depression. Prevention is better than cure!
- Be alert to depression. Do not ignore depression.
- Depression is the leading factor for suicide among older adults. Alert senior staff or the person's doctor if you notice self-neglect, self-harm or statements of suicidal intent.
- Most people recover from depression or benefit from treatment.

Additional Resources

- <https://www.evidence.nhs.uk/Search?q=cbt%20in%20older%20adults>
- <https://www.nice.org.uk/guidance/ng32/resources/older-people-independence-and-mental-wellbeing-1837389003973>
- <https://www.ageuk.org.uk/sheffield/our-services1/case-studies/>
- <http://www.ageuk.org.uk/health-wellbeing/conditions-illnesses/depression/help-and-support/>
- <https://www.mind.org.uk/information-support/types-of-mental-health-problems/depression/>
- Chew-Graham, C., Baldwin, R. and Burn, A. The Integrated Management of Depression in the Elderly. Cambridge University Press. (2008).

References

1. <https://www.nice.org.uk/guidance/cg90/chapter/Introduction>
2. <https://www.england.nhs.uk/wp-content/uploads/2017/09/practice-primer.pdf>
3. <http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/depressionkeyfacts.aspx>
4. <https://www.mentalhealth.org.uk/statistics>
5. www.healthline.com/health/depression/facts-statistics-infographic
6. www.nhs.uk/Conditions/Depression/Pages/Causes.aspx
7. <https://www.nice.org.uk/guidance/cg90/chapter/Person-centred-care>
8. <http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/exercise-for-depression.aspx>
9. <http://www.nhs.uk/Conditions/Depression/Pages/treatmentoptions.aspx>



Delirium

Delirium

Learning Statement



After reading and reflecting on this section you will:

- Know what is meant by delirium.
- Know what causes delirium and the risks factors associated with dementia.
- Know how people are assessed for delirium.
- Understand the treatment options for delirium.
- Know what we mean by good delirium care and support and what factors and activities can improve that care and support.

What is Delirium?

Delirium, sometimes called 'acute confusional state', is a common health condition characterised by disturbed consciousness, confusion, difficulty in thinking straight and paying attention. Delirium happens quickly and can fluctuate in severity. It usually develops over one to two days. It is a serious condition that is associated with poor outcomes. However, it can be prevented and treated if dealt with urgently (1).

Delirium can occur at home, in hospital or in residential care and it's the risk factors associated with ageing that need to be considered and managed. Delirium can be hypoactive or hyperactive but some people show signs of both (mixed). People with hyperactive delirium can be restless, agitated and aggressive. People with hypoactive delirium become withdrawn, quiet and sleepy. Hypoactive and mixed delirium can be more difficult to recognise.

Delirium Statistics

- Older people and people with dementia, severe illness or a hip fracture are more at risk of delirium.
- The prevalence of delirium in people on medical wards in hospital is about 20% to 30%,
- 10% to 50% of people having surgery develop delirium.
- In long-term care the prevalence is under 20%.
- People with delirium are five more times likely to get dementia.
- Reporting of delirium is poor in the UK, indicating that awareness and reporting procedures need to be improved.

Compared with people who do not develop delirium, people who develop delirium may:

- need to stay longer in hospital or in critical care
- have an increased incidence of dementia
- have more hospital-acquired complications, such as falls and pressure sores
- be more likely to be admitted to long-term care from hospital
- be more likely to die.

What causes delirium?

Again age alone is not a cause of delirium but the risks of delirium are increased with age because of illness or lifestyle factors. There can be many causes of delirium, some more common than others. Pain, infections, commonly chest or urinary infections, constipation, poor nutrition, dehydration some medications and changes to the environment are the most common. Other causes can be lack of mobility, sensory impairment, sleep disturbance, alcohol and the withdrawal of some medications . In older people there may be more than one cause of delirium.

A good way of remembering the common causes for delirium is the acronym **PINCHES ME**.



Delirium Risk Factors

The most common risk factors for getting delirium are:

- Older age
- Falls
- Disorientation
- Poor vision and hearing
- Poor nutrition and hydration
- Having a urinary catheter in situ
- Physical and mental illness
- Immobility
- Loneliness and lack of stimulating activities

How are people assessed for delirium?

Assessment for delirium should be carried out by a trained professional who may use certain tools such as the Confusion Assessment Method (CAM) to confirm a diagnosis of delirium. If there is difficulty distinguishing between the diagnoses of delirium, dementia or delirium superimposed on dementia, treatment for delirium is given first (1).

Spotting delirium quickly is essential so look out for key symptoms such as:

- Sudden change in behavior
- More confusion over past few hours or days
- Confusion varies at different times of the day
- Difficulty in following a conversation
- Rambling and jumping from topic to topic
- More sleepy or agitated than normal

What is the treatment for delirium?

The most effective treatment for delirium is to tackle the common causes - pain, infection, nutrition, constipation, poor hydration, environment, sleep, medication and enzymes (PINCHES ME). Being aware of and understanding the causes helps to identify it quickly so that treatment can be started as soon as possible.

If a person is distressed, medications may be used for the short term only (usually no more than a week).

What is good care and support for delirium?

Delirium can be very distressing for the person, their carers, family and care and support staff. Knowing the person and what they are like from day to day will help to identify sudden changes in their behaviour or mental awareness. (See section on person centered care).

Providing care and support for the person's physical needs such as eating and drinking, toileting and sleep will help a quicker recovery from delirium.

Effective communication and reorientation (for example, explaining where the person is, who they are, and what your role is) can provide reassurance for people diagnosed with delirium. Consider involving the person's carer and family, friends to help with this.

It is much better to prevent delirium in the first place than to treat it. Here are some things that can be done to help reduce the risk factors associated with delirium:

- Support orientation – help people be aware of what time it is, what day it is and where they are using conversation and prompts such as calendars, clocks and up to-date information such as newspapers.
- Ensure people are drinking enough using favourite non-alcoholic drinks. The Institute of Medicine states that an adequate intake for men is roughly 13 cups of liquid a day and about 9 cups for women (5).
- Ensure people have a good balanced diet and if dentures are worn they fit correctly. Good mouth and dental care are important factors to be able to eat well.
- Avoid infections where possible. Older people should be encouraged to have the flu jab.

Look out for signs of infection and treat quickly. Using urinary catheters should be avoided wherever possible.

- Medications should be reviewed frequently. Many older people take several medications and some may not suit the person or cause problems when they are mixed (6).
- Encourage mobility. This helps prevent constipation and helps mental health and wellbeing.
- Ensure people can see and hear well especially if they wear glasses or hearing aids.
- Help support a good nights sleep (see section on sleep)
- Manage any pain (see section on pain)

After the Confusion

Delirium can be very frightening and distressing not just for the person experiencing its effects but those caring for the person. It is important to give the person the chance to talk about their experience if they want to. Many people who have had delirium worry that it might be a sign of mental illness or the start of dementia. Explaining the reasons after confusion can help them to understand their experiences, help reduce any worries and can help prevent further episodes.

Carers, relatives and friends may also need information to help them understand what happened to their loved one and may also be in need of reassurance and support afterwards.

Things to remember from this section



- Delirium can present within days or even hours
- Delirium is often mistaken for dementia or just old age
- Delirium can be prevented
- Delirium is reversible
- Delirium is a medical emergency
- SPOT IT, TREAT IT, STOP IT.

Additional Resources

- www.nice.org.uk/guidance/cg103/resources/awareness-workshop-session-plan-pdf-134609005
- www.europeandeliriumassociation.com/
- www.nutrition.org.uk/nutritionscience/life/dehydrationelderly.html
- www.youtube.com/watch?v=BPfZgBmcQB8
- www.youtube.com/watch?v=_c9M4FnDwOc&app=desktop

References

1. <https://www.nice.org.uk/guidance/cg103>
2. <http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/delirium.aspx>
3. https://www.alzheimers.org.uk/info/20029/daily_living/370/delirium
4. https://www.alzheimers.org.uk/info/20029/daily_living/370/delirium
5. www.theseniorlist.com/2014/08/how-much-water-do-i-need-to-drink/
6. <http://www.yhscn.nhs.uk/mental-health-clinic/Dementia/Delirium.php>



Is it
Dementia,
Depression
or Delirium?

Is it Dementia, Depression or Delirium?

Learning Statement



After reading and reflecting on this section you will:

- Know the major differences between dementia, depression and delirium

It can be difficult to distinguish between delirium and dementia and some people may have both conditions. If clinical uncertainty exists over the diagnosis, the person should be managed initially for delirium (1). Family carers, friends and neighbours can play an important part in helping to identify which of the 3Ds is present. They can provide essential information to clinical staff to help make an accurate diagnosis particularly if there has been a change in the individual's behaviour or how they are managing their daily life. Any changes to 'normal' daily activity and over what timeframe will help in making the accurate diagnosis.

Please see the next page for a useful identification chart.

	Delirium	Dementia	Depression
Onset	Sudden (Hours to days)	Usually gradual (Over months)	Gradual (Over weeks to months)
Alertness	Fluctuates (Sleepy or agitated)	Generally normal	Generally normal
Attention	Fluctuates (Difficulty concentrating and easily distracted)	Generally normal	May have difficulty concentrating and be easily distracted
Sleep	Change in sleeping pattern (Often more confused at night)	Can be disturbed (May be more confused and begin night time wandering)	Can be disturbed
Thinking	Disorganised, jumping from one idea to another	Problems with thinking and memory recollection, such as finding the right word	Generally normal
Perception	Illusions, delusions and hallucinations common	Generally normal	Generally normal

Things to remember from this section



- Dementia, depression and delirium can present very similarly.
- It could be dementia, depression or delirium or all three!
- If in doubt delirium should be treated first.
- Help the person, their carers and their loved ones talk about delirium after the confusion.

Additional Resources

- www.pasrrassist.org/sites/default/files/attachments/DementiaDeliriumDepression_PASRRwebinar_4.12.16.pdf
- www.youtube.com/watch?v=_c9M4FnDwOc&app=desktop

References

1. <https://www.nice.org.uk/guidance/qs63>

Person Centred Care and Support



Person Centred Care and Support

Learning Statement



After reading and reflecting on this section you will:

- Know what is meant by person centred care.
- Know what the benefits are of person centred care and support.
- Know how person centred care and support are delivered.

Knowing Me! so far has presented information that can help the awareness and understanding of the 3D's as a diagnoses and what makes them different. **Knowing Me!** now presents information concerning knowing the person. By understanding the 3D's and knowing the person there is a real opportunity to provide the best help, care and support which can make a real difference.

What is Person Centred Care?

Person centred care is putting people and their carers/families at the heart of decisions and viewing them as experts who, with trained professionals, can get the best outcomes and best experience. Person centred care was founded in early psychotherapy approaches and reflects a general move from a purely medical and health model to a biological and social approach to health and social care. The Health Foundation have produced an excellent quick guide titled 'Person Centred Care Made Simple' (1).

In relation to person centred care it is important to understand the basic principle of the Mental Capacity Act 2005 (2) which is that, irrespective of illness or diagnosis, every adult should be considered to have capacity unless proven otherwise. No one has the right to make decisions for another without consent or outside legal frameworks. **Knowing Me!** will discuss capacity and decision making further in the "Know My Rights!" section.

The Health Foundation presents four principles of person centred care (3). These may refer to health environments and patients, but the principles can be applied to any setting and to anyone in need of or receiving care and support.

The four principles of person-centred care



We must always:

- Respect the person's values, preferences and expressed needs.
- Co-ordinate and integrate care and support.
- Provide the right information and education at the right time.
- Consider the person's physical health and comfort.
- Provide emotional support and help reduce fear and anxiety.
- Involve and engage with carers, family and friends.
- Ensure there is continuity of care and support.
- Ensure fair and timely access to care, support and services.

What are the benefits of person centred care and support?

There is emerging evidence that person centred approaches to care and support are improving lives and improving service efficiency. This evidence is underpinned by NICE in fifteen Quality statements (4). All the statements focus on the rights and choices of people as individuals.

Person centred care can make a significant impact on the quality of care. Some examples are (5):

- Improved quality of life
- Better sleep patterns
- Less agitation
- Improved self esteem
- Improvements in a healthy lifestyle
- Joint decision making
- Reductions in the requirements for services
- Increased satisfaction for all involved

How do we give person centred care and support?

This question is at the very heart of *Knowing Me!* and the reason for choosing this title. To be able to give person centred care, you must get to know the person, but how do you do it?

Section 5 of *Person Centred Care Made Simple (1)* presents many initiatives, old and new, that can be used or applied to deliver person centred care. A recent initiative is "*Hello my name is...*" This is a national campaign that was founded by Dr Kate Granger. Kate died with terminal cancer but developed this campaign to encourage all staff to introduce themselves by name and profession when meeting a new patient. Kate said, "*In my mind it is the first rung on the ladder to providing compassionate care*" (6).



There are many documents, guidelines and books on person centred care but all refer to the basic activities of the acronym: **IT'S ME!**

I (Information)

Gather as much information as possible about the person: their past, such as their job, where they used to live and their family; the present, such as their current circumstances, their likes and dislikes; and the future, such as what they would like to do and wish could happen.

T (Together)

Discuss with the person and their family, if appropriate, and plan together what they would like to happen. These are often called goals, outcomes or objectives.

S (Share)

Make sure no activity is beyond the person's, or their family's, ability, experience or authority by sharing tasks and responsibility.

M (Meet)

Meet to discuss progress and make sure everything is going as expected. Do changes need to be made?

E (Evaluate)

How did it go? Did we achieve what we set out to achieve? Have we learnt anything?

Things to remember from this section



- Person centred care is personalised, co-ordinated and ensures treating the person with respect, compassion and dignity.
- I.T.S M.E.

Additional Resources

- Human Right Act,1998. See <https://www.legislation.gov.uk/id/ukpga/1998/42>.
- Equality Act, 2010. See <https://www.legislation.gov.uk/ukpga/2010/15/contents>
- National Dementia Declaration, 2010. See .
www.dementiaaction.org.uk/nationaldementiadeclaration
- www.dementiaaction.org.uk/nationaldementiadeclaration
- <http://www.dementiaaction.org.uk/dementiawords>
- www.dementiacarer.net
- Brooker, Dawn. (2007) Person centred dementia care – making services better. Kingsley, London.

References

1. http://personcentredcare.health.org.uk/sites/default/files/resources/person-centred_care_made_simple_1.pdf
2. Mental Capacity Act 2005. <https://www.gov.uk/government/uploads/.../Mental-capacity-act-code-of-practice.pdf>
3. <http://personcentredcare.health.org.uk/resources/eight-principles-of-patient-centred-care>
4. <https://www.nice.org.uk/guidance/cg136/chapter/personcentred-care>
5. Tritter, J. Koivusalo, M. (2013) "Undermining patient and public engagement and limiting its impact: the consequences of the Health and Social Care Act 2012 on collective patient and public involvement."
a. *Health Expectations: An international Journal of Public Participation in Health Care and Health Policy* 16, 2, 115 -118.
6. www.hellomynameis.org.uk

End of Life Care



End of Life Care

Learning Statement



After reading and reflecting on this section you will:

- Know what is meant by end of life care.
- Have a better understanding of issues relating to end of life and=
- dementia.
- Know what an Advanced Care Plans are and why they are so
- important.

What do we mean by end of life care?

End of life care refers to the care provided not only in the final days or hours before death, but to care for all of those with a terminal condition that has become advanced, progressive and incurable. Dying is part of life. Death is faced, celebrated and mourned in many ways within different cultures. Statistics (1) show deaths for the over 75's are slowing as people continue to live longer. As a consequence, and as age is linked to long-term conditions like dementia, more people are ending their lives with such conditions.

It can be difficult to be certain whether a person is dying, as the ways in which people deteriorate at the end of life can vary and depend on a person's condition. To help identify the last days of life, there are guidelines (2) that recommend healthcare professionals should assess for changes with certain signs and symptoms. These include agitation, deterioration in level of consciousness and increasing fatigue and loss of appetite. They should also be aware that, although appearance of these signs and symptoms might suggest that a person is dying, improvements can occur that indicate a person's condition is stabilising. People should be monitored for further changes at least every 24 hours, and the person's care plan should be updated accordingly.

The National Gold Standards Framework (3) (GSF) Centre in End of Life Care, is the UK's leading provider of training in end of life care for general frontline staff.

The GSF is a systematic, evidence-based approach to optimising care for all people approaching the end of life, delivered by general frontline care providers. Training programmes are also available that are designed to help to support all people approaching their last year/s or so of life in any setting.

Understanding end of life care and support

“How people die remains in the memory of those who live on”

Dame Cicely Saunders

Founder of the Modern Hospice Movement.

Talking about end of life care can feel difficult, to the point where families and care staff may even actively avoid conversations with people who are dying. Research (6) however tells us that most people (over 80 per cent at all ages) would want to be told if they are terminally ill. Although every individual may have a different idea about what would, for them, constitute a “good death”, for many it would involve:

- Being treated as an individual, with compassion dignity and respect.
- Being without pain and other symptoms that are distressing.
- Being in familiar surroundings with most wanting to die at home.
- Being in the company of loved ones and people that matter to them.

Having the conversation about death can be daunting. It is a common belief that talking about someone’s illness or end of life will upset them. In fact, many people at the end of life also felt that by talking about death would upset their loved ones. Many people are surprised to find that a person at the end of life wants to talk about what is happening to them. There is no right way or wrong way to talk about the end of life but by knowing the person conversations can be commenced taking the cue from the person. Having such conversations can take skill, training and experience and advice should always be sought from senior staff.

A person at the end of life may be angry, resentful, scared, sad, resigned, accepting or some combination of all. When discussing end of life with them:

- Do not judge what the person is feeling, as this may discourage them from continuing the conversation
- Do not offer advice: what you find helpful may not be so to others.
- Do not say things like “ I know how you feel” (you cannot possibly do so) or 'don't worry'
- Ask “How can I help”

The key message of this resource is **knowing** the person and **knowing** the person who is at the end of life well will help when discussing the person's wishes and making plans with them. Many people at the end of life have a plan called an Advance Care Plan and this will be discussed further in this section.

End of Life Care and Dementia

As discussed in the section on Dementia new data show dementia is the leading cause of death in England and Wales (4). Despite this fact data also show that despite 72% of people wanting to die at home, only 23% do so, with 48% dying in hospital, 21% in a care home and 6% in a hospice. This suggests that people with dementia are being disadvantaged when it comes to the choices surrounding death and dying.

People with a diagnosis of dementia (and learning disabilities) will end their life with the condition but may have other physical problems that may be wrongly ascribed to the dementia. This 'diagnostic overshadowing' can also happen for people with learning disabilities. Not being able to communicate with the person can mean symptoms like pain may be missed or underestimated or lead to decisions that result in invasive action like artificial feeding and hydration. Observing for signs that the person may be in pain is a key feature of compassionate end of life care. See previous section “The impact of pain”.

An approach to ensuring people at the end of life, including those with dementia, are cared for and supported with respect and dignity is the use of Advanced Care Planning.

What is Advanced Care Plans and why they are so important?

Advance care planning (ACP) is a voluntary process of discussion and planning about future care between an individual and their care providers, irrespective of discipline. If the individual wishes, their family and friends may be included (5). Having an ACP is not compulsory but it is best practice and many care and support providers insist that these are in place for people. An ACP means that everyone caring for the person will know what their wishes are for the end of life and be able to make sure they are followed.

Things to remember from this section



- People are living longer and with more complex illnesses and diseases.
- Everyone has the right to die with dignity and respect in a place of choice.
- Talking about the end of life with a person is often avoided but it is often something the person wants to talk about.
- People can be asked about pain, observing for possible signs of pain is as important.
- Advanced Care Planning is an empowering tool to ensure a person's end of life can be planned with the person and their family promoting dignity, control and choice.

Additional Resources

- www.rcnendoflife.org.uk/case-study/
- www.dyingmatters.org/gp_page/gp-case-studies
- www.nhs.uk/Planners/end-of-life-care/Pages/planning-ahead.aspx
- www.mariecurie.org.uk/help/support/terminal-illness/planning-ahead/advance-care-planning
- www.skillsforcare.org.uk/Documents/Topics/Dementia/Advanced-stages-of-dementia.pdf
- www.macmillan.org.uk/information-and-support/organising/planning-for-the-future-with-advanced-cancer/advance-care-planning-england-wales/planning-ahead.html
- www.gmcuk.org/guidance/ethical_guidance/end_of_life_advance_care_planning.asp
- www.compassionindying.org.uk/library/advance-care-plans/

References

1. <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths>
2. <https://www.nice.org.uk/news/article/new-guidelines-to-improve-care-for-people-at-the-end-of-life>
3. <http://www.goldstandardsframework.org.uk/>
4. <https://www.alzheimersresearchuk.org/new-figures-show-dementia-leading-cause-death-england-wales/>
5. <http://www.ncpc.org.uk/sites/default/files/AdvanceCarePlanning.pdf>
6. http://www.dyingmatters.org/gp_page/breaking-news

Caring for Carers



Caring for Carers

Learning Statement



After reading and reflecting on this section you will:

- Know what a carer is
- Know some key statistics about carers
- Understand more about how to assess the need of carers

What is a "carer"?

A carer is somebody who provides support or who looks after a family member, partner or friend who needs help because of their age, physical or mental illness, or disability. This does not include someone paid or employed to carry out that role, or someone who is a volunteer. Unpaid carers are sometimes referred to as 'informal' carers, but this diminishes the importance of their role and the term should be avoided. Many people don't recognise that they are a carer, or they think that because others do more, their own role in caring doesn't really count.

Carers play a critical role in reducing the need for paid care. They are often the lynchpin between the person being cared for, health and social care, the GP, and other professionals. They provide an important network of support from within the family, from friends, neighbours and the local community. Carers and the wider family should be seen as expert partners and actively involved in shaping how support is provided when it is needed (1).

Caring Statistics

(2)

- 1 in 8 adults (around 6.5 million people) are carers.
- By 2037, it's anticipated that the number of carers will increase to 9 million.
- Every day another 6,000 people take on a caring responsibility – that equals over 2 million people each year.
- 58% of carers are women and 42% are men.
- Over 1 million people care for more than one person.
- Carers save the economy £132 billion per year: £19,336 per carer
- Over 3 million people juggle care with work. Demands of caring mean that 1 in 5 carers are forced to give up work altogether.
- Carer's Allowance is the main carer's benefit and is currently £62.10 for a minimum of 35 hours (£1.77 per hour)
- People providing high levels of care are twice as likely to be permanently sick or disabled
- 625,000 people suffer mental and physical ill health as a direct consequence of the stress and physical demands of caring.
- Over 1.3 million people provide over 50 hours of care per week.

Caring for someone with dementia can, at times, be challenging, isolating and exhausting but it can also be very rewarding. There are about 670,000 carers of people living with dementia in the UK saving the state £11bn a year (3). Carers of people with dementia often report that peer support (spending time and talking with others in similar situations) is an important way of building their resilience (helping them to cope) (4).

Assessing the needs of carers

Many carers say that they do not have the services and support they need to help them carry out their caring role. Once identified it is every carer's right to be offered a carer's assessment, which is a formal assessment of need usually performed by local health or social care staff. A carer's assessment can help to identify who in the family is caring and what support is needed by everyone identified. It is important that assessors consider who else may be involved in caring for an individual; sometimes several family members can be caring for one individual.

Co-caring (sometimes called mutual caring), where the carer and person being cared for rely on each other to some extent is also common. Whole families may be co-caring, each supporting the others in some way. Many carers care for more than one person at a time. Some carers will not live with or near the person with care needs, caring at a distance, perhaps via the telephone or the internet, giving vital support, checking and reassurance and visiting when they can.

Most areas in the country now have a “Carers Strategy” following a National Carers' Strategy in 2010 (5).

Things to remember from this section



- Carers have their own needs
- Caring can be challenging and rewarding
- Peer support can help build resilience
- Every carer is entitled to be offered a carer's assessment

Additional Resources

- www.tide.uk.net
- www.skillsforcare.org.uk/...needs/assessment-and-eligibility-workbook.docx
- <http://www.rcgp.org.uk/clinical-and-research/clinical-resources/carers-support.as>
- http://www.dyingmatters.org/gp_page/supporting-carers-cope

References

1. <http://www.skillsforcare.org.uk/Documents/Topics/Supporting-carers/Assessing-carers-needs.pdf>
2. <https://www.carersuk.org/news-and-campaigns/press-releases/facts-and-figures>
3. <http://tide.uk.net/>
4. www.dementiacarer.net
5. <https://www.gov.uk/government/publications/recognised-valued-and-supported-next-steps-for-the-carers-strategy>

Know My Rights



Know My Rights

Learning Statement



After reading and reflecting on this section you will:

- Know what is meant by My Rights.
- Understand what is meant by managing risk.
- Have a broader understanding of the Mental Capacity Act and Deprivation of Liberty Safeguards.
- Have a broader understanding of the roles of institutions supporting law and acts.
- Have a broader awareness of the issues regarding restraint.

What are My Rights?

In the section on Principles and Value Statements, we presented the revised statements of the Dementia Action Alliance which are based on rights. These concern the basic rights of choice, being free from discrimination, the right to a timely diagnosis, being involved in care and respect.

Human rights have a place throughout history but more recently with the Human Rights Act in 1998 (1). The Human Rights Act is a UK law that allows people to defend their rights in UK courts and compels public organisations (including the Government, police and local councils) to treat everyone equally, with fairness, dignity and respect. The “articles” in the Human Rights Act include the following:

- Right to life
- Freedom from torture and inhuman or degrading treatment
- Freedom from slavery and forced labour
- Right to liberty and security
- Right to a fair trial

- No punishment without law
- Respect for your private and family life, home and correspondence
- Freedom of thought, belief and religion
- Freedom of expression
- Freedom of assembly and association
- Right to marry and start a family
- Protection from discrimination in respect of these rights and freedoms

Managing Risk

People do not lose their rights simply because they may be living with dementia, depression or delirium. However, managing the risks involved with supporting people with the 3D's to have choices and control within person centred care and support can be challenging. Organisations and individuals can find it very difficult to help people to have more control over their lives and can have an overly cautious attitude to risk, particularly with people with dementia or a learning disability.

Risk management starts with understanding what is important to the person – for example, their well being and their need for love, comfort and social inclusion.

It is important to develop a culture within a care home that recognises the strengths that each person has and builds on what a person CAN do as opposed to focusing on their disabilities. This is what is known as “risk enablement”.

Not everyone is at risk, nor is at equal risk – it depends on the person. Assessment of risk needs to be made before a plan to manage risk can be developed. Most people assess and manage risk automatically, for example crossing the road, but when people are ill, or have dementia, depression or delirium, they may lose this ability. Running alongside risk enablement is the legislation – ‘The Mental Capacity Act 2005 (2)’ including the ‘Deprivation of Liberty Safeguards (3) (DoLS).’ This is the legal part of enablement that underpins all the care and support that is given. It is about a whole-life, whole-person approach, linked to the end of life care and to dignity. It is important that legal issues are integrated into our everyday work and not regarded as JUST legislation.

Mental Capacity Act (MCA)

Mental capacity – or the ability to make decisions – is an issue that affects everyone. We all make decisions, big and small, all of our lives. Most of us are able to make these decisions for ourselves, although we may seek information, advice or support for more serious or complex decisions. However, illness, injury or disability, may have affected some people's mental capacity. This can prevent them from making certain decisions about their lives. This may be temporary or permanent, and therefore decisions may need to be made on their behalf. A lack of mental capacity could be due to:

- a stroke or brain injury
- a mental health problem
- dementia
- a learning disability
- delirium
- confusion, drowsiness or unconsciousness
- illness or treatment of an illness
- substance misuse.

The MCA was introduced to create a proper legal framework to support people to make their own decisions wherever possible but also to create legal processes and safeguards when decisions have to be made on their behalf.

Deprivation of Liberty Safeguards

The Deprivation of Liberty Safeguards (DOLS) are an amendment to the MCA 2005. They apply in England and Wales only and the key points are:

- The MCA allows restraint and restrictions to be used – but only if they are in a person's best interests.
- Extra safeguards are needed if the restrictions and restraint used will deprive a person of their liberty. These are called the Deprivation of Liberty Safeguards.
- The DOLS can only be used if the person will be deprived of their liberty in a care home or hospital. In other settings the Court of Protection can authorise a deprivation of liberty.

- Care homes or hospitals must seek permission from a local authority if they can deprive a person of their liberty. This is called requesting a standard authorisation.
- There are six assessments, which have to take place before a standard= authorisation can be given.
- If a standard authorisation is given, one key safeguard is that the person has someone appointed with legal powers to represent them. This is called the relevant person's representative and will usually be a family member or friend.
- Other safeguards include rights to challenge authorisations in the Court of Protection, and access to Independent Mental Capacity Advocates (IMCAs).

Applying for a DOLS is not to be seen as a negative action but an appropriate way of safeguarding and protecting a person who may be vulnerable. The DOLS Code of Practice (4) should be read alongside the MCA code of practice (5).

The Mental Capacity Act has five key principles:

- 1) Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so, unless it is proved otherwise.
- 2) People must be supported as much as possible to make a decision before anyone concludes that they cannot make their own decision.
- 3) People have the right to make what others might regard to be an unwise or eccentric decision.
- 4) Anything done for or on behalf of a person who lacks mental capacity must be done in their best interests – the Act explains how to determine a person's best interests.
- 5) Anything done for or on behalf of a person who lacks mental capacity should be the least restrictive of their basic rights and freedoms, providing it is still in their best interests.

According to the Act, a person's capacity must be assessed on a decision-specific basis. This is to prevent 'blanket' assessment of capacity – just because someone with dementia can't make a complex decision about medical treatment, for example, it should not be assumed that they lack capacity to make a decision about what they eat or wear. The Act also emphasises that assessments of capacity or deciding a person's best interests must not be done on the basis of their age, appearance, condition or behaviour alone.

The Mental Capacity Act says certain people must think about the code of practice (4) when they act or make decisions on the other person's behalf. This includes an attorney appointed under a lasting power.

Mental Health Act 1983 (MHA)

The MHA 1983 (6) makes provision for the assessment and treatment of people with a mental illness, or mental health needs not yet diagnosed. It allows for the detention without consent, for example in a hospital or a police station. The Act provides organisations and services to detain people without consent. This could be in a police station or a hospital setting for example. The Act sets out a number of legal safeguards to ensure the person's rights are protected and not violated. These safeguards include the right to have the person's detention reviewed independently and have access to the Independent Mental Health Advocacy Service (IMHAs) (7).

The roles and institutions of supporting the laws and Acts

The role of the **Independent Mental Capacity Advocate (IMCA)** (8) are a legal safeguard for people who lack the capacity to make specific decisions, including where they live and medical treatment options.

Attorneys appointed under Lasting Power of Attorney (LPAs) (9). This is a legal tool that enables one person (the attorney) to make decisions on behalf of another. The individual concerned must have the capacity to give the power of attorney and they can appoint more than one person. For finance and property LPAs, these can be registered with the Office of the Public Guardian and take effect before the person loses capacity. The Health and Welfare LPA can only take effect once the person has lost capacity. If an individual does not have capacity to make decisions and does

not have a LPA, then application must be made to the Court of Protection for authority to make decisions on their behalf.

Court of Protection (10) This court makes decisions on financial or welfare matters for people who can't make decisions at the time they need to be made (they 'lack mental capacity'). The court is responsible for:

- deciding whether someone has the mental capacity to make a particular decision for themselves
- appointing deputies to make ongoing decisions for people who lack mental capacity
- giving people permission to make one-off decisions on behalf of someone else who lacks mental capacity
- handling urgent or emergency applications where a decision must be made on behalf of someone else without delay
- making decisions about a lasting power of attorney or enduring power of attorney and considering any objections to their registration
- considering applications to make statutory wills or gifts
- making decisions about when someone can be deprived of their liberty under the Mental Capacity Act

Office of the Public Guardian (11) The Office of the Public Guardian (OPG) protects people in England and Wales who may not have the mental capacity to make certain decisions for themselves, such as about their health and finance. OPG is an executive agency, sponsored by the Ministry of Justice.

Issues Regarding Restraint and Seclusion

Restraint is a measure or condition that keeps someone or something under control. The Mental Capacity Act 2005 defines restraint as when someone "uses, or threatens to use force to secure the doing of an act which the person resists, OR restricts a person's liberty whether or not they are resisting".

Using restraint in care settings can lead to abuse and violate people's rights so people who provide care and support have a duty to minimise restraint and identify the least restrictive option if and when restraint is necessary.

This can be identified by:

- Knowing the person – Understanding the person and help reduce the need for restraint
- Use life story work to get to know the person and therefor help reduce the need for restraint.
- Performing good up to date risk assessments allowing and supporting the person to take risks as appropriate.
- Making sure that support plans are based on assets and what the person can do, rather than on deficits.

Things to remember from this section



- People do not lose their rights just because they have dementia, depression or delirium or any other condition.
- Capacity is decision specific and time limited.
- There is specific legislation to protect people when they do not have the capacity to make decisions.
- There are organisations and bodies to help people and their families when legislation has to be applied.
- Restraint when necessary should be least restrictive within the law.

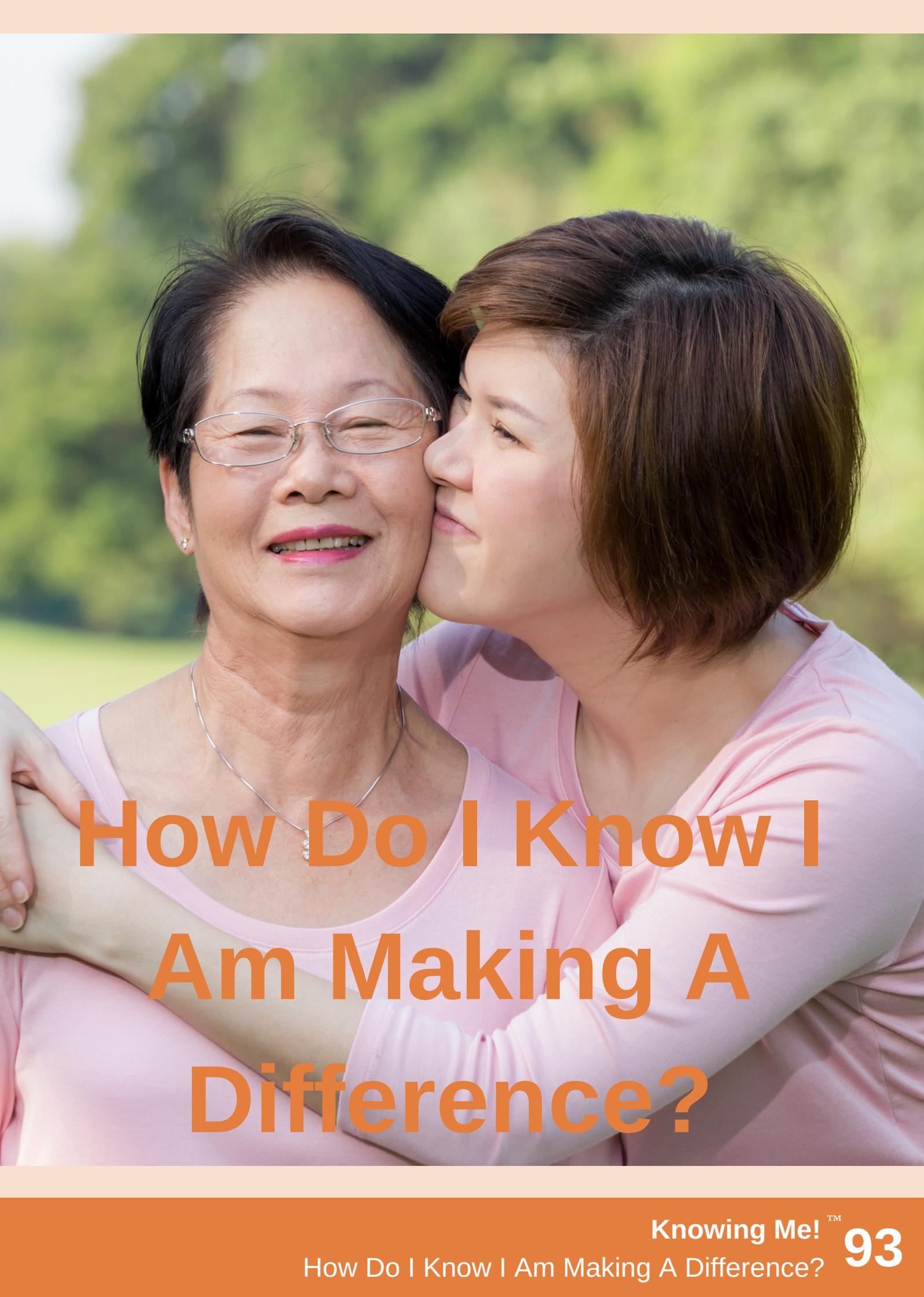
Additional Resources

- <http://www.communitycare.co.uk/2015/04/09/27-deprivation-liberty-cases-need-know-comply-landmark-ruling/>
- <https://www.tsoshop.co.uk/>

- <http://www.medicalprotection.org/uk/resources/factsheets/england/england-factsheets/uk-mental-capacity-act-2005-best-interests-tests>
- <https://www.scie.org.uk/mca/practice/best-interests/>
- <http://www.skillsforcare.org.uk/Standards-legislation/Mental-Capacity-Act/Mental-Capacity-Act.aspx>
- <http://www.skillsforcare.org.uk/Topics/Restrictive-practices/Restrictive-practices.aspx>

References

1. <https://www.liberty-human-rights.org.uk/human-rights/...human-rights/human-rights-act>
2. <https://www.legislation.gov.uk/ukpga/2005/9/contents>
3. <https://www.scie.org.uk/mca/dols/at-a-glance>
4. https://www.scie.org.uk/mca/dols/?gclid=EAIaIQobChMI-eaJ7qHS1wIVzZ3tCh2X1A-YEAAAYASAAEgKQS_D_BwE
5. <https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>
6. <https://www.legislation.gov.uk/ukpga/2007/12/notes/division/3/1>
7. <https://www.scie.org.uk/independent-mental-health-advocacy/resources-for-staff/understanding/>
8. <https://www.scie.org.uk/mca/imca/>
9. https://www.alzheimers.org.uk/info/20032/legal_and_financial/130/lasting_power_of_attorney/3
10. www.gov.uk/courts-tribunals/court-of-protection
11. <https://www.gov.uk/government/organisations/office-of-the-public-guardian>



How Do I Know I Am Making A Difference?

How Do I Know I Am Making A Difference?

Learning Statement



After reading and reflecting on this section you will:

- Know what we mean by “Quality Improvement”.
- Know some of the tools used for measuring improvement when caring for and supporting someone with dementia, depression or delirium.

Quality Improvement

Quality in health and social care is often defined as doing better than expected or “exceeding expectation” (1). A key feature of providing quality in health is that it is consistent and there are three key factors that influence this (2):

- quality planning – planning to make things better
- quality assurance – knowing improvements have been made
- quality control – learning and ensuring quality is maintained and continued

At the beginning of this resource we explained how *Knowing Me!* aims to improve awareness and understanding of the 3 D’s so you can better help and thus make a difference, but how would you know you have made a difference?

There are many ways of knowing you have made a difference, some simple ways and some more “technical ways”.

Asking the person for feedback on how they feel is probably the easiest way. Understanding a person's needs and working with them to plan and deliver ways of meeting those needs will mean you will be able to judge whatever you have done has been a success.

There will be times when people with dementia, depression or delirium cannot tell you how they feel or give feedback on whether things have improved. This is where the person's carer can really help. Carers will know the person much better and can help understanding of a person's needs and wishes. Involving carers as partners in care is of benefit to everyone.

There are also measurement tools that can be used to assess and help understand a person's need and the needs of their carers. These can also be used to measure improvements and whether an intervention within the given care and support has been successful. This is what is meant by 'outcomes'.

Measurement Tools

Tools used with dementia including tools that measure outcomes for carers

There are many measurement tools used in the assessment and care of people living with dementia. This includes: how a person thinks, solves problems and remembers things (cognition); how they manage normal activities of living; how they perceive their quality of life; and how satisfied they are with their experiences (3). Measuring how a carer feels about their quality of life will also help us to understand if their needs are also being met. The most common tools used are:

- The mental state examination (MSE or MMSE for the mini mental state examination) (4).
- Neuropsychiatric Inventory (NPI) (5).
- Bristol Activities of Living Scale (6).
- Quality of life scales for both the person with dementia (QoL-AD) (7) and the carer (QoL-AC) (7) .

Depression

Again there are many tools to assess if someone is depressed and how severe that depression may be. With the older adult the Geriatric Depression Scale (8) is the most commonly used.

Delirium

The Confusion Assessment Method (CAM) (9) is the most common tool to assess if someone has delirium and how severe the delirium is.

Things to remember from this section



- Quality improvement is about making things better.
- Planning, reviewing and learning from improvement actions can help maintain and further improve the care and support given.
- There are specific tools to help care and support staff to understand and demonstrate if improvements have been made.

Additional Resources

- www.improvement.nhs.uk/improvement-hub/quality-improvement/
- www.health.org.uk/blog/reflections-hospital-doctor-challenges-maintaining-high-quality-care-current-climate?gclid=EAIaIQobChMllv2ekq_S1wIVbbXtCh0-
- www.professionals.carers.org/triangle-care-dementia
- www.health.org.uk/blog/reflections-hospital-doctor-challenges-maintaining-high-quality-care-current-climate?gclid=EAIaIQobChMllv2ekq_S1wIVbbXtCh0-NQyoEAAYANQyoEAAYA
- www.rcn.org.uk/professional-development/quality-and-safety/quality-improvement

References

1. <http://www.health.org.uk/publication/quality-improvement-made-simple>
2. <https://www.kingsfund.org.uk/topics/quality-improvement>
3. <http://www.ichom.org/medical-conditions/dementia/>
4. https://www.alzheimers.org.uk/info/20071/diagnosis/97/the_mmse_test?gclid=EAlaIQobChMluZueobbS1wIVK7HtCh00rwwjwEAAYASAAEgKDyf
5. <https://www.ncbi.nlm.nih.gov/pubmed/9153155>
6. <http://www.wellnessofmind.com/wp-content/uploads/2015/12/Bristol-Activities-of-Daily-Living-Scale.pdf>
7. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC155631/>
8. <http://www.sabp.nhs.uk/moodhive/Documents/Geriatric%20Depression%20Scale%204.pdf>
9. <https://www.nice.org.uk/guidance/cg103/chapter/1-guidance>

Staff and Health



Staff and Health

Learning Statement



After reading and reflecting on this section you will:

- Understand that caring for and supporting for someone with dementia, depression or delirium can be challenging and stressful as well as rewarding.
- Have a broader understanding of the benefits of workplace wellbeing.
- Understand the difference between workplace stress and burnout.
- Be aware of the Three R Approach for dealing with burnout.

Wellbeing at Work

Caring for and supporting someone with dementia, depression or delirium can be challenging both emotionally and physically. The importance of reflecting on experience and learning from it is crucial not only to improve practice but to help maintain the health of the paid carer worker. This also applied to the unpaid carer.

Many individuals and organisations are much more aware today of the importance of workplace wellbeing. There are now workplace well being charters, a workplace and well being index and even award ceremonies for the best workplace wellbeing employers (1). Well being starts with the individual but employers are now appreciating the benefits of supporting well being in their employees; “a happy ship is an effective ship” (2).

The Quality of Life section presented the Five Ways to Wellbeing that apply to all, but the impact on the workplace can include:

- Increased job satisfaction.
- Increased job performance
- Improved morale
- Improved communication and relationships with work colleagues
- Reduced workplace stress and anxiety
- Reduced rates of sickness and absenteeism
- Reduced workplace incidents, accidents and injuries
- Improved workplace image as a “mindful employer” (3)

Words like “workplace stress” and “burnout” are often used when there are excessive demands on the worker. Everyone can get stressed at times and some levels of stress can be quite normal and healthy but increasing and unrelenting stress can have serious effects on someone’s wellbeing and is often referred to as “burnout” (4). Stress can often be managed and improved by simple measures and there is hope for improvement as the primary effects are physical like lack of energy. Burnout however is much more serious leaving people with emotional distress, feelings of exhaustion, feelings of emptiness, lack of motivation and even physical symptoms like poor sleep and poor appetite.

The best way to deal with burnout is to prevent it in the first place; however, the “Three R’s Approach” can be used (5).

Recognise - Watch for the warning signs of burnout (see above).

Reverse - Try and manage the stress and seek support from friends, colleagues, managers, supervision and mentorship.

Resilience - Resilience is the ability to cope. Managing stress and taking care of your wellbeing will help to build resilience.

Things to remember from this section



- Caring and supporting the person with dementia, depression and delirium can be stressful and challenging.
- Wellbeing starts with the individual's responsibility but organisations and employers have responsibilities too.
- Remember the Five Ways to Wellbeing and the Thee R Approach.
- Staff and worker health is important and needs to be considered, assessed and managed to support the delivery of effective care and support.

Additional Resources

- www.mindtools.com/pages/article/recovering-from-burnout.htm
- www.skillsforcare.org.uk/Topics/Mental-Health/Resilience.aspx
- www.cipd.co.uk/pm/peoplemanagement/b/weblog/archive/2017/01/13/five-things-that-must-be-on-your-workplace-wellbeing-radar-in-2017.aspx
- www.bhf.org.uk/health-at-work/get-started/workplace-wellbeing-charter
- www.hse.gov.uk/pubns/misc743.pdf

References

1. <https://www.mind.org.uk/workplace/workplace-wellbeing-index/>
2. <https://books.google.co.uk/books?id=at2HzlSD4HkC&pg=PA37&lpg=PA37&dq=a+happy+ship+is+an+effective+ship&source=bl&ots=tOzXnq9dZV&sig=13T>
3. <http://www.mindfulemployer.net/>
4. <https://www.helpguide.org/articles/stress/burnout-prevention-and-recovery.htm>
5. <http://pharmacist.com/fight-burnout-three-rs>

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Fiona MacMillan, Skills for Care

Danielle Farrar, previous Health Education England, Dementia lead

Joanne Hirst, Nurse Consultant, RDaSH NHS Foundation Trust

Kathryn Penrith, Dementia Nurse Consultant, Making Space & Consultation Group

Murray Forest, NHS North Kirklees, Clinical Commissioning Group

Adrienne Lucas, North Yorkshire County Council

Rob Moore, Home Instead

Kate Tufnell, Commissioner, Rotherham Clinical Commissioning Group





Life Story Network CIC is a fully registered Community Interest Company (CIC) in England and Wales. Life Story Network (LSN) works with a range of partners, and stakeholders, to promote the value of using life stories to empower and improve the wellbeing of often overlooked communities or people. The work of Life Story Network considerably enhances the quality of care, and support, delivered through embedding a human-rights based approach.

Life Story Network also hosts 'tide - together in dementia everyday' which is the UK wide involvement network of carers of people with dementia.

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