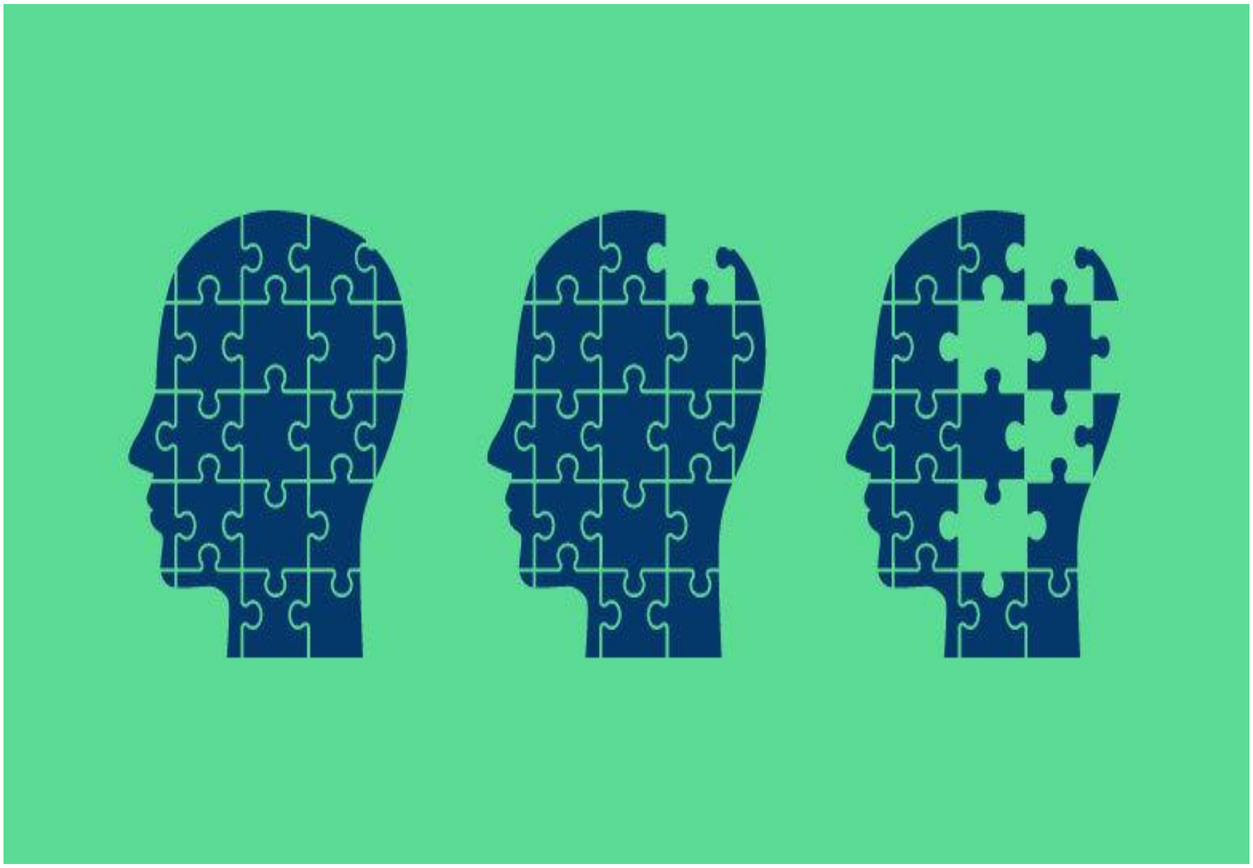
Medicare Training



Manual for Improving Outcomes in People with Dementia

During this module you will be asked some questions to simply provoke thought and test your current knowledge please have a note pad or supervision workbook to hand to make notes. Your performance will only be measured on the answers you select when completing the knowledge test at the end of the module.

Contents

Learning Outcomes

- Getting idea about what dementia is
- Knowing the most common types of dementia
- Understanding that individuals will have differing experiences of dementia
- Understanding approaches that improve wellbeing for people with dementia
- Understanding the roles of care givers and others in the support of people with dementia
- Understanding factors influencing communication and interaction with people who have dementia
- Understanding how a person-centred approach encourages positive communication
- Understanding the ways of working to ensure that diverse needs are met

Complementary Manuals

- Introducing Person-Centered Approaches
- Promoting Dignity and Compassion in Care
- Challenging Behavior

Chapter One

Definition of Dementia

‘Dementia is a progressive disorder that affects how your brain works and in particular the ability to remember, think and reason. It is not a disease in itself – but a group of symptoms that may accompany conditions that affect your brain.’

www.ageuk.org.uk

Dementia in the UK:

- There are around 800,000 people with dementia
- Around 17,000 of these are under 65
- The national cost is around £23 billion a year

Personal Opinion

Dementia probably isn’t new to you but it’s worth spending a few moments considering what you know already before you start the course.

- How many of the clients you care for have been diagnosed with a form of dementia?
- What types of dementia are you aware of?
- In your experience what are the common symptoms of dementia?
- What challenges might clients with dementia face on a day to day basis?

Dementia classification

There are many different types of dementia but most (around 90%) can be put into three main categories:

1. Alzheimer’s type
2. Vascular type
3. Mixed (the first two in combination)

Dementia is a progressive illness, it gets worse with time. Alzheimer’s disease develops steadily while vascular dementia results in stepped deterioration, i.e. the person can lose abilities overnight.

If you are caring for someone who has been diagnosed with Alzheimer’s disease and they experience a sudden significant change, they should be referred to their doctor as there may be an underlying treatable cause such as an infection.
Although dementia becomes more common with age, an increasing number of people under the age of 65 are affected by it. As nearly 60% of sufferers may be undiagnosed more of your clients may be affected than you realize.

Alzheimer's

The progression of Alzheimer's is commonly divided into 3 stages:

In the early stage people may:

- Forget things, particularly recent events
- Repeat themselves
- Have difficulty concentrating
- Become confused
- Lack motivation

At this point the person, and their loved ones, may become aware that something is wrong; but it may not be obvious to others and can be frustratingly difficult to diagnose.

In the middle stage people can:

- Get lost while out
- Experience hallucinations and problems understanding their environment
- Do 'odd' things without realising
- Create risk through forgetfulness e.g. by not locking their front door, or leaving pans unattended on the hob

The increase in severity of the symptoms will make the person's condition more noticeable and they may become dependent on others to ensure their safety and maintain their personal hygiene and wellbeing.

In the late stages people can experience significant problems that have a serious effect on their independence and quality of life; common symptoms include:

- Eating and swallowing problems
- Difficulty communicating
- Loss of mobility
- Incontinence

None of these symptoms are inevitable; no one should ever be written off as beyond help. Although dementias are currently incurable the symptoms they cause are not necessarily untreatable. Good care and understanding can significantly improve people's wellbeing.

Vascular dementia

Vascular dementia is the result of mini strokes, as strokes occur they cause irreversible damage to the brain. The way they affect the person will depend on where in the brain they happen and how serious they are. People with vascular dementia may go for months, or years, without further deterioration, or they may experience frequent strokes or be affected by Alzheimer's as well resulting in steady decline.

Common symptoms associated with vascular dementias include:

- Poor concentration
- Loss of ability to reason
- Visual and perception problems
- Anxiety and depression
- Loss of physical strength or ability
- Forgetfulness

Confusing conditions for dementia

There are a number of conditions that may cause signs or symptoms similar to those of dementia. When a person is elderly it is all too easy to assume that problems with memory or odd behaviours are the result of dementia, however, they must always be referred to a doctor as they may have other conditions which might require medical attention or even psychiatric care.

Infections, particularly of the urinary tract, chest or blood can cause significant confusion and altered behaviours. These may come on suddenly and will improve as the infection is dealt with.

Sensory problems; difficulty seeing or hearing, may also cause people to appear confused or to experience problems with perception. All clients must be regularly assessed to determine their support needs and if hearing aids or spectacles are required they should be used properly and kept in good condition.

Age related memory impairment (also known as mild cognitive impairment) is a condition causing forgetfulness and memory loss not considered significant enough to require a diagnosis of Alzheimer's. People who experience this condition are at an increased risk of developing dementia but may never progress beyond this mild impairment.

Delirium (acute confusional state) is a condition which develops suddenly and causes severe confusion and cognitive problems. It can be caused by physical and mental health problems including infections and hip fractures. It is a serious condition requiring immediate medical attention.

Older people are at increased risk of delirium so particular attention should be paid to elderly clients who suddenly show signs of confusion or reduced mental function.

Depression can lead to mental impairment and lack of motivation resulting in self-neglect. Department of Health figures suggest that up to 40% of new admissions to care may be suffering from depression. Depression may be caused by physical health problems including strokes, diabetes and heart disease and may also accompany dementias. There are a range of possible medical and psychiatric interventions available to improve the mental health and wellbeing of individuals with depression.

Summary

Dementia is an increasingly common condition which is under diagnosed and often dismissed as an inevitable fact of ageing. Dementias are incurable but good care can improve outcomes and medical assessment may discover other, treatable, conditions are responsible for an individual’s mental decline.

When it is suspected that people may be developing dementia it is important that they are referred to a doctor for appropriate diagnosis in order to:

a. Rule out other conditions

b. Identify medicines and treatments which may be useful

c. Plan future care needs

d. Give the patient and their loved ones the opportunity to find out more about the disease and how it might be expected to progress

Chapter Two

Individuality and Dementia

There is a great deal of fear associated with a diagnosis of dementia; it's vital that you have a positive outlook and believe that good care can lead to improved outcomes. People with dementia can experience good quality of life and can be happy and fulfilled.

There is a common misconception that people with dementia have in some way ceased to be themselves; certain common symptoms challenge our understanding of personhood:

- Communication difficulties – if they are unable to make their feelings known it can be hard for people around to empathise or to understand what their experience of dementia might be
- Difficulty understanding – the person with dementia may find it hard to follow normal conversation or to interpret events which occur around them; this can cause them to act in ways which seem inappropriate, to withdraw into themselves or to experience anxiety
- Memory loss – chronic memory loss can mean that the person fails to recognise their loved ones, is unable to recall recent events and can no longer carry out simple tasks because they can't remember how to do them. These problems and the fact that the person may to some degree regress to a time in the past that they can remember can lead us to compare caring for a person with dementia with caring for a child. This identification of 'childlike' qualities in the person with dementia can be dangerous as it prevents us from seeing them as the adults they are and treating them with the respect they deserve

When the people around a person with dementia lack understanding of the condition they may act in ways which make situations worse. Around 25 years ago a gentleman called Tom Kitwood started to investigate new ways of caring for people with dementia – his work identified the importance of taking a person-centred approach to care. He argued that negative views of dementia led to poor care practices which in turn increased the severity of symptoms experienced by people living with dementia.

Every person with dementia will be affected in a different way because dementia does not take away who they are, it affects the way they experience and respond to the world around them. As importantly, it also affects the way that people treat them and expect them to act. Low expectations and a lack of understanding can mean that the individual's loved ones and care givers focus on what they can't do rather than exploring what they are able to do and ways in which their lives might be enriched.

People often have the best intentions but cause harm through ignorance. Consider the scenario below:

Mr Carlton's wife has been diagnosed with Alzheimer's disease; he loves her very much and worries about her future. Mrs Carlton struggles with everyday household chores and her husband decides to employ a personal assistant to keep the house clean and tidy and prepare meals.

Mrs Carlton reacts badly to the presence of a stranger in the house; she tries to stop her working, shouts at her and eventually physically assaults her.

Mr Carlton wonders what has happened to his gentle, friendly wife; he concludes that her illness has changed her making her unreasonable and aggressive; he grieves for the apparent loss of his wife.

The main problem in this situation is that no one has actually considered how Mrs Carlton might feel. Her perception of this situation is that a stranger has moved into her house and is taking her place. She doesn't want to be replaced; she wants to feel useful, valued and loved. She wants to understand what is happening to her and be supported to find a way to cope with her illness and to maintain her independence.

Behaviours that can have a negative effect on people with dementia include:

- Infantilisation – being treated like a child
- Bullying / intimidation – people with dementia are at increased risk of abuse
- Dishonesty – care givers use deception or mislead clients to gain compliance; they do this because they do not believe that the clients will understand or remember what they have done; this erodes trust in the relationship
- Invalidation – the client's emotions are ignored; statements are made such as 'don't listen to her, she talks rubbish'
- Outpacing – issuing instructions or giving information too quickly for the person to process causing confusion for the clients and leading care givers to label them as 'difficult', 'slow' or 'uncooperative'
- Objectification – treating the person as a 'thing' e.g. moving them from bed to chair without seeking consent, communicating or taking action to protect dignity (adapted from Kitwood 1997)

Understanding the Impact of your ***behaviors***

Imagine that you have poor physical mobility and require help to get around; how do you think you would feel if your care givers talked to each other but never to you, acted without preparing you and ignored anything you said?

How would you feel?

How might you act?

People who feel ignored and whose sense of self is threatened may become increasingly desperate to be heard and to be treated as human beings; ask yourself if you have witnessed any of the following behaviors.

People with dementia may react to poor care by:

- Shouting or screaming; perhaps repeatedly calling for help
- Lashing out when surprised or touched unexpectedly

- Constantly searching for a friendly face or a place which feels safe
- Expressing anxiety through repetitive physical or verbal tics
- Becoming increasingly withdrawn

Who are you?

Think for a few moments, even grab a piece of paper and write down some of the ways in which you would answer the question 'Who are you?"

There are many ways in which people can define themselves, and they may choose to answer the question 'Who are you?' differently to different people.

Even just answering with our name gives us a few possibilities:

- I am John
- I am John Smith
- I am Mr Smith
- I am Dr Smith

Our name might tell you whether we are being friendly, or formal, it could give away our marital status or our job. We might want to be addressed differently by different people depending on our relationship with them.

We might use a variety of characteristics to define ourselves, including any of the following:

- Age
- Gender
- Sexual orientation
- Marital status
- Culture / race
- Religion
- Background / experiences
- Personality

None of these things can be taken in isolation; their importance will be affected by the situation we are in and how we want to present ourselves.

As a care giver you have a duty to treat each client appropriately, if they have difficulty communicating you need to do some detective work to find out who they are. In chapter 4 we will look further at person-centred care; for now have a think about different ways in which you could find out about a person. Think about how you could make sure that you use this information correctly; for example:

Mrs Philippa Potts is known to all her friends and family as Pip
Pip is recorded in her care plan as her 'preferred name'
Mrs Potts does not feel that she has a close personal relationship with her care givers and is offended and upset that relative strangers, many of whom are decades younger than her, address her in such a familiar way.

Chapter Three

Care in communication

Before you start this chapter why not take some time to think about and write down some barriers to communication e.g. people use different languages

Barriers to communication cause misunderstandings and frustration; we have all experienced problems at one time or another, dementia makes communication more challenging because of the way it can affect people's physical and mental abilities.

Information processing

People with dementia may have difficulty understanding information or keeping up with conversation. Memory loss and reduced mental speed can mean that they are unable to take in more than one idea or instruction at a time. If people speak quickly or give several instructions at once this can lead to confusion and frustration.

The person talking may become annoyed that they are not receiving appropriate responses, while the person with dementia becomes increasingly confused and irritated that the person speaking to them is not giving them a chance to understand and respond.

Memory loss

Chronic forgetfulness is common to all types of dementia; all of us forget words sometimes, for people with dementia the loss is permanent, and it becomes increasingly difficult to pass on information, express emotion or ask for things.

If simple words are forgotten people need to find other ways of saying what they want; they may use long winded descriptions or become more reliant on gestures and other non-verbal forms of communication.

Sight and hearing dificculties

Don't forget that people with dementia may also be affected by other physical problems which make communication more difficult, including sight and hearing difficulties. It's important to make sure that clients have regular medical check-ups to identify and treat any sensory deterioration. Glasses, hearing aids etc. must be being used and kept in good condition.

Non-verbal Expression

The words we use are often only a small part of the way we communicate; our body language, voice, facial expression and gestures are also extremely important. As individuals' conscious understanding of verbal communication deteriorates they rely more on the visual and aural cues they receive. Ensure that your manner and tone of voice are open and friendly and consider the following alternatives to speech:

- Use flashcards or pictures
- Agree signs or gestures that you and the client can both use and understand
- When giving an instruction ‘act out’ your meaning e.g. mime drinking while asking ‘would you like a drink’
- Use gentle and appropriate touch to give comfort and to help the client to focus on you
- Write down key information if this will be useful to the client e.g. simple instructions for regular tasks, labels for drawers

Promoting communication

Individuals with dementia need the people around them to be patient and compassionate to promote on-going communication. Without support people with dementia may feel that they can no longer express themselves verbally and may use behaviours to communicate feelings and needs.

Behaviours used when care givers fail to support communication may include:

- Shouting apparently meaningless words / phrases in an attempt to get people’s attention
- Following care givers / other clients around – this may be an attempt to seek comfort or conversation
- Moaning / screaming / head banging – may all be expressions of unrecognised pain
- Aggressive / violent acts may be responses to being ignored or neglected

Attention seeking is seen as negative behaviour but if you are being ignored, if your needs are unmet and your emotions disregarded, attention seeking is an understandable response to your situation. Think about your last few days at work; how often do you give clients your undivided attention? How regularly do your interactions with clients go beyond ‘hello Mrs Jones, how are you today?’

Common good practices:

- Minimise background noise – television, radios and general chatter and clatter will make speech more difficult to hear
- Position yourself in a way that makes the other person feel comfortable – where they can see you, at arm’s length to give them space, on the same level i.e. if they are sitting, sit or crouch, if they are standing, stand with them
- Move closer and use touch only when you know it is appropriate – if you need to provide comfort and the person is at ease with you, you may move closer and gently place your hand on their shoulder or forearm (avoid touching legs or any part of the body that might be considered ‘intimate’)
- Make sure that your facial expressions and posture are open and friendly
- Gestures such as thumbs up and nods can be useful, but take care to avoid any that might cause offence e.g. shrugging, pointing
- Speak clearly without slang, swearing or jargon
- Use active listening skills to show you are interested – use encouraging words and noises ‘go on’, ‘I hear you’; maintain regular, not constant, eye contact; occasionally ask questions to check that you have understood.

Supporting individual communication

Clients' care plans must include information about their communication needs. These should be individually assessed through talking to the client, getting information from their loved ones, reading their medical history and observing their interactions.

A valuable exercise for developing person-centred ways of supporting communication is to create a life book with the client. This has 3 other main benefits:

- It teaches care givers about the client and helps them to see a person instead of a condition
- It becomes a tool for reminiscence allowing the client to reflect on their past without relying on memory
- It can help family members and friends to reconnect with their loved one and share memories and feelings

Life books can include labelled photographs, postcards of familiar places, accounts of life events, dates of celebrations, and anything that will have meaning for the client. Pictures, including those of everyday objects or old adverts, can trigger memories and help clients and care givers to find new ways of connecting. As time goes on remember that abilities will deteriorate, and communication needs will change; be sensitive to the clients' increased dependence on you.

Advocacy

Many people receiving care would benefit from access to advocacy services to support them in understanding choices and contributing to decisions. It's important that you are familiar with advocacy services available in your local area and that you know how to put your clients in touch with them.

Advocates can help to break down communication barriers between clients and care givers and can represent clients' views in an unbiased independent way. Details of advocates with experience of working with people with dementia can be found at www.alzheimers.org.uk or www.dementiauk.org

Interaction promoting

While it is extremely important that your clients have regular opportunities to talk with care givers, it's also beneficial for them to interact with each other. While some clients may prefer their own company, most would probably appreciate the opportunity to form new friendships.

To give clients the best chance to chat to each other arrange furniture in comfortable groups so that they can see and hear each other; introduce activities that encourage conversation and organize mealtime seating to encourage social interaction.

People in the later stages of dementia are likely to need more help than those who are just developing the disease. Be patient yourself and encourage clients to be patient and tolerant of each other.

Expertise help

To ensure that clients are given the best support possible to communicate it may be necessary to work with other health professionals:

- Speech and language therapist – may be able to give ideas for improving communication and help with any physical problems
- Occupational therapist – may suggest activities that would enable the client to interact with other people
- Audiologist – diagnoses and treats hearing problems
- Optometrist – diagnoses and treats sight problems
- Social worker – may have relevant knowledge of the client and their family

Chapter Four

Positive Care Practices

In 2009 the Department of Health began to implement a national dementia strategy under the banner “Living well with dementia”; as part of this it commissioned a guidance document ‘Common Core Principles for Supporting People with Dementia.

A guide to training the social care and health workforce’. This was based on 8 core principles.

The common core principles for supporting people with dementia

Principle 1 - Know the early signs of dementia.

Principle 2 - Early diagnosis of dementia helps people receive information, support and treatment at the earliest possible stage.

Principle 3 - Communicate sensitively to support meaningful interaction.

Principle 4 - Promote independence and encourage activity.

Principle 5 - Recognise the signs of distress resulting from confusion and respond by diffusing a person’s anxiety and supporting their understanding of the events they experience.

Principle 6 - Family members and other care givers are valued, respected and supported just like those they care for and are helped to gain access to dementia care advice.

Principle 7 - Managers need to take responsibility to ensure members of their team Are trained and well supported to meet the needs of people with dementia.

Principle 8 - Work as part of a multi-agency team to support the person with dementia.

(Skills for Care 2011)

These principles represent best practice for dementia care; they highlight the importance of person -centered approaches and recognize that people’s needs do not exist in isolation, nor can they be met by any one person or organization. Dementia affects everyone who cares for or works with the individual; and adequate care requires individuals, their loved ones, care givers and health professionals to work in partnership.

Supporting the rights of people with dementia The Mental

Capacity Act 2005

The Mental Capacity Act 2005 was designed to protect the rights of potentially vulnerable adults who might otherwise be prevented from making their own choices and decisions.

Before the Mental Capacity Act was introduced there was no way of ensuring that people who required care and support were being treated as competent adults. It is all too easy to make assumptions based on a person's behaviour or medical history and to believe that it will be in their best interests for you to act or make decisions on their behalf.

The Act is based on five key principles which together ensure that individuals are respected as competent adults; given every opportunity to make their own decisions and choices; treated fairly without prejudice or discrimination and supported to be as independent as possible.

The statutory principles

1. A person must be assumed to have capacity unless it is established that he lacks capacity
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action
   (Mental Capacity Act 2005 Code of Practice)

For the Mental Capacity Act to apply to an individual they must have a disturbance of their mind or brain which is affecting their ability to make a decision. The symptoms of dementia may be a 'disturbance of the mind or brain'; we would then want to consider whether the person can:

1. Understand information given to them about the decision
2. Retain the information for long enough to make the decision
3. Weigh up the information i.e. consider the pros and cons
4. Communicate their decision

Competence must be assessed properly in order to ensure that you are not acting on prejudices or assumptions. The code of practice accompanying the Act states that 'A person's capacity must not be judged simply on the basis of their age, appearance, condition or an aspect of their behaviour.' Therefore, just because someone has been diagnosed with dementia it does not mean that they cannot make their own decisions.

Each decision should be independently assessed, so inability to make one decision does not automatically mean that the person can't make any decision. For further information read Approved Care Training Limited's manual 'The Mental Capacity Act 2005.'

Active participation

The principle of active participation is essential to the provision of person-centered care. All clients are to be encouraged to take an active role in planning for their own care needs, identifying ways in which their mental and spiritual wellbeing can be supported and influencing changes to the environment in which they live.

By enabling clients to actively participate in making decisions about all issues that might affect them you help to ensure that they are having their needs met in a way which suits them; this reduces the likelihood of abuse in the following ways:

- Needs are met in ways that suit individuals' cultural, religious etc. requirements
- Care needs are less likely to be overlooked
- People feel empowered to voice their own opinions and know that these will be given due consideration
- People know that they can speak out about practices that they feel to be discriminatory or otherwise abusive
- The environment reflects the diversity of the individuals within it reinforcing each one's sense of self and demonstrating that everyone is of equal value

The following resources might be helpful if you want to find out about personalisation and active participation:

- www.scie.org.uk
- www.skillsforcare.org.uk
- Approved Care Training Limited manual 'Person-Centred Approaches to Care'

The Human Rights Act 1998

Human rights legislation exists to protect all of us from the actions of public bodies like councils and NHS trusts. There are some rights which are particularly relevant to the provision of care and they are summarized below:

- Article 2 – right to life
- Article 3 –protection from torture or inhuman or degrading treatment
- Article 5 –the right to liberty and security of person
- Article 6 – the right to a fair trial
- Article 8 - the protection of private and family life
- Article 9 –freedom of thought, conscience and religion
- Article 10 –freedom of expression
- Article 14 –freedom from discrimination

Collectively these rights mean that individuals in your care should be protected from abuse and undignified treatment; they should not be unnecessarily restrained or have their freedom of movement restricted. They must be able to complain about the treatment they receive and be supported to understand and defend their rights.

People receiving care have the right to maintain a family life and have their privacy respected and they must be allowed to practice and express their religious beliefs.

For good practical examples of how this Act might affect your life or the lives of your clients download 'Ours to Own Understanding Human Rights' from www.equalityhumanrights.com

The Human Rights Act 1998 has been used to challenge health authorities' use of blanket policies such as 'no lifting'; these have been found to be unlawful as they do not allow for differences between individuals, they remove freedom of choice and they may be discriminatory. (Ref The Queen v. East Sussex County Council 2003).

Equality

The Equality Act 2010 protects people with various characteristics which may make them vulnerable to discrimination at work or from service providers. There are 9 protected characteristics; these are:

- Age
- Disability
- Gender reassignment
- Marriage and civil partnership
- Pregnancy and maternity
- Race
- Religion or belief
- Sex
- Sexual orientation

People with dementia are classed as having a disability because their condition affects their ability to perform everyday tasks; their rights are, therefore, protected by the Equality Act.

Person-centered values

The Care Quality Commission is committed to promoting the benefits of person-centred approaches to care. They believe that to appropriately meet people's care needs you must know and understand them as individuals and adapt care provision accordingly. The individual becomes the most important part of a care partnership, working to find creative ways of maintaining their physical and mental wellbeing and improve quality of life.

Person-centered approaches to care are based on several core values which include:

- Independence
- Dignity
- Privacy
- Rights
- Choice
- Respect
- Partnership
- Individuality

By working in a way that reflects these values care givers should also be promoting equality, diversity and inclusion. by using person-centered approaches employers ensure that people’s needs are being met appropriately in a way that respects their individuality; care givers are not restricted by ‘this is how things are normally done’ attitudes but are free to find creative solutions to meeting client needs.

Risk management

Risk assessment is the process of identifying and controlling workplace hazards with the aim of protecting workers and others who may be harmed. Care providers have to maintain awareness that their work environment is their clients’ home and anything that is done to ensure safety has an impact. For example, emergency exits have to be signposted but it’s not ‘normal’ to have signs all over your house and they can make the premises look institutional.

It’s important that you do not limit clients’ freedoms unnecessarily; you have a duty of care to protect them but this has to balance with their rights. You cannot use health and safety concerns or your own personal feelings to limit clients’ lives. You must take a positive approach; listen to what the client wants and focus on how it can be achieved **not** the reasons why it might be difficult.

Good risk management maintains clients’ safety without affecting their freedoms. Suitably trained care staff must risk assess clients’ activities and make appropriate decisions about any potential dangers. These risk assessments should be done with the intention of enabling the activity to go ahead; they must not be attempts to find reasons why something shouldn’t happen.

Risk assessment has to be carried out on an individual basis in order to support equality and fairness; assessments must not rely on stereotypical ideas of client’s conditions. People with identical diagnoses will be completely different in terms of abilities and disabilities so while one may be able to live independently another may require a significant amount of support.

Decision making must be without prejudice or assumption; whoever carries out risk assessments must be confident in their abilities and unafraid of legal penalties. Good record keeping is essential so that if an individual does come to harm the reasons for allowing them to take actions are properly documented.

Chapter Five

Daily Improvement

Dementia can affect every aspect of a person's life; it's important that you look at ways in which you can support your clients to experience the best quality of life possible. That means helping them to cope with daily frustrations in a way that encourages independence, protects dignity and demonstrates understanding of the person as an individual.

If people's needs are misunderstood or ignored or if they are treated without respect or compassion they may behave in ways which put themselves or others at risk. It's important that people are supported to control their own lives and are able to make their own choices and do things in ways that are suitable for them. People with dementia may no longer remember, or be able to communicate their own beliefs but that doesn't mean that we can ignore their wishes. They should be supported to maintain their normal way of life for as long as possible.

The better you know a person and their history, the more appropriately you can care or them. People with dementia need familiarity, their religious beliefs, cultural background, employment history, family life etc. will all influence their expectations and normal habits.

Think about the clients you support and how you would complete the table below: Select a few tasks and choices and consider what you would need to know about the client to understand their needs and how you could support them to make choices or carry out tasks. (Make some notes in your workbook)

Daily tasks / choices	**What I would need to know about the client to understand their needs**	**How can I support them to make choices / carry out task**
e.g. getting out of bed	When do they normally get up? How mobile are they?	Provide physical help as necessary at an appropriate time

Individual hygiene care

How we look is a very important part of who we are; most of us like to maintain certain standards of hygiene and appearance particularly if we are spending time with other people. Whether it's a quick wash and a comb through our hair, or a perfumed bath, followed by full make up and a manicure we all have our own rituals and preferences when it comes to bathing and personal grooming.

It’s important that you understand the individual needs of your client including any cultural or religious requirements that may affect this area of their care. People who have dementia may forget what they need to do; they may become less interested in their personal appearance; or they may self-neglect, particularly if they are also affected by depression.

You need to recognize the client’s needs and act in their best interests if they can’t do things for themselves; find out what is appropriate and provide the right equipment and help. Be sensitive to the fact that people can be embarrassed if they need help washing and may be reluctant to admit to any difficulties they have. Ensure dignity at all times and do all you can to make the client feel comfortable and respected.

How to ensure good personal care:

- Make bathrooms warm, safe and ‘domestic’ – they are not store rooms and should not look institutional
- Find out what the client’s regular habits are and what’s important to them – e.g. if they are resistant to bathing they may be encouraged to do so if family are visiting
- Use familiar products that may trigger good memories – scent can aid reminiscence
- Use towels / flannels to cover intimate areas, keep staff to a minimum and protect the individual’s privacy
- Learn any special grooming techniques – ask the client or their family to teach you

Clothing

The clients you care for have a right to have their personal possessions, including clothing, properly cared for. There is no excuse for putting clients in other people’s clothes or regularly damaging them when doing laundry.

Clients should have enough clean and tidy garments to dress appropriately every day. It’s important to allow people to choose their own clothes, to help them to make decisions it may be necessary to take some clothes out of their wardrobe and ask them to pick an outfit.

If people want to wear clothes that are ‘odd’ or unsuitable for the situation or season, consider whether they will actually come to any harm if they are allowed to wear what they have chosen. If you feel that it is necessary to persuade them to wear something else do so gently using good communication techniques and highlighting personal benefits.

Tips:

- Store clothing so it’s easy to find – label cupboards / drawers, keep outfits together
- Lay out outfits in the order they are to be put on – undo fastenings, make sure everything’s the right way around
- Talk through the process of dressing one step at a time
- Chat and allow plenty of time so that the person feels calm and relaxed and is less likely to become confused or upset

- If you have to help ask the client’s permission and only do what they can’t; don’t make them more dependent on you than necessary

Eating

There are many reasons why a person with dementia may experience difficulties at mealtimes; some are physical e.g. problems handling cutlery, difficulty swallowing; others may be caused by mental deterioration e.g. they no longer recognize the need to eat or remember what to do.

Clients should be given every possible help to eat independently; consult professionals such as speech and language therapists or occupational therapists who can assess the client and suggest equipment or adapted diets that are suitable. Monitor the client, look for reasons why they might be uncomfortable at mealtimes and consider what might be done to improve their appetite and eating:

- Find out about previous habits – are they getting familiar food, do they usually eat at a table or are they used to eating with a tray on their lap in front of the tv?
- Are they avoiding certain foods because they are worried about making a mess e.g. rice, soup? Would equipment help?
- Would they eat more if they were given smaller meals more often?

Every effort should be made to enable clients to feed themselves but if this isn’t possible follow the guidance below:

Tips

- Make sure the client is fully awake and ready to eat – mouth is clean , dentures are in
- Make sure the food is attractive, appetising and a suitable temperature – ask yourself ‘would I eat this?’; if the answer is no don’t expect your client to eat it either
- Make sure that the client is comfortable and relaxed, support them in an upright position using pillows if necessary
- Sit by the client, where they can see you – make allowances for any visual problems, if they have a blind side don’t sit on it

Eating instruction

- Give the client as much time as they need, rushing will increase the risk of choking and make the meal an unpleasant experience
- If foods need to be warm and the client takes a long time consider having food ‘little and often’ instead of three times a day
- Make sure that the client is able to do as much as possible for themselves e.g. taking the fork or spoon from you when you have put the food on it
- Describe the food as you offer it so that the client knows what to expect with each mouthful

- Offer a small amount at a time (it may be best to use a teaspoon) and ensure that the client has finished one mouthful before offering another
- Maintain the client's dignity throughout; talk to them (but discourage them from talking and eating at the same time), help them to keep clean and tidy (but don't treat them like a baby, no bibs) and allow them to take the lead about what they are eating and when

When they have finished

Offer fluids to rinse their mouth out and encourage them to remain upright for half an hour to aid digestion

Environment

The environment that a person lives in can have a great impact on their physical and emotional wellbeing; it needs to:

- Be accessible
- Promote equality and diversity
- Be fit for purpose
- Support independence
- Be safe
- Reduce the likelihood of visual problems and confusion

The care environment needs to be designed to allow people to move around without staff support for as long as possible; signage needs to be clear and understandable, a mixture of words, pictures and even 3d objects may help. Signs need to be positioned at the right height for the clients; their eye line may be lower than yours, particularly if they are elderly or use a wheelchair.

Doorways and carpets need to be suitable for wheelchairs to move easily and level flooring and regular rest stops may be helpful to people who have difficulty with balance or find walking tiring.

The décor and furniture used should reflect the needs and diverse backgrounds of the client group; all clients should have a say when work is done as they need to feel 'at home'. People with dementia often want familiarity, it's particularly important that their bedrooms reflect their personal tastes and that they bring with them objects, bedding, photos etc.

Furniture used in communal areas needs to be the right size and type to meet client needs, it will probably be necessary to have different sizes and types of chair for everyone to be comfortable. The layout of rooms needs to allow for ease of movement and there must be enough space for care givers to work safely.

People with dementia may experience problems interpreting the world around them; the use of rooms should be well defined so that people are given clues as to what they might be expected to do in them. Contrasting colors may be used when it is important to define objects

e.g. toilet seats, or differentiate between different surfaces e.g. bed spreads should contrast with carpets.
Mirrors can cause fear and confusion if the person does not recognize their own reflection, be careful with their use. Patterned carpets, wallpaper / shiny surfaces etc. can create illusions of obstacles or water; try to keep décor simple. Light, bright colors are likely to suit the tastes of clients without being institutional.

Personal feeling

Everyone needs to feel that they have a purpose in life; people feel valued when:

- They work and earn money
- They do housework /die
- They provide a service to someone else
- They express themselves creatively
- They are needed by someone else

Your clients need to be given the opportunity to feel useful; they need to know that their life is worth something and that they are not a burden. Many care providers are experimenting with new ideas for improving their client's quality of life, what works for one person may not work for another; the better you know your client the more insight you will have into what is likely to improve their wellbeing. Ideas that have had some success include:

- Providing space and equipment – e.g. desks and files to remind people of their working days
- Supporting art projects, choirs, drama groups
- Bringing young and old people together to share skills and experiences
- Using client skills e.g. knitting, baking to raise money
- Encouraging clients to do work around the home e.g. preparing meals, decorating
- Creating a vegetable garden and helping people to get involved e.g. by having raised boxes for wheelchair users
- Keeping animals e.g. chickens for eggs

Abnormal behaviors

Sometimes people with dementia act in ways that seem irrational, inappropriate or violent. Often behaviors which are interpreted as 'challenging' can be a response to poor care or unmet needs; it's important to look at why a person may be acting in a certain way; what are they responding to? How are they feeling? What are they trying to communicate? Further information on understanding and influencing behaviors can be found in Approved Care Training Limited's manual 'Challenging Behavior'.

Conclusion

People with dementia can experience good quality of life if the people around them are able to support their needs appropriately. To care for someone with dementia we have to know who they are, what they value and what makes them feel happy and loved. Clients who are treated with dignity and respect and are supported to maintain their independence are more likely to experience wellbeing than those whose care givers ignore their individuality and take away their rights to make decisions and take actions for themselves.

References

Nothing Ventured Nothing Gained

Risk guidance for people with dementia
Issued by Department of Health 2010

Common Core Principles for Supporting People with Dementia

A guide to training the social care and health workforce
Skills for Care / Skills for Health 2011

Living Well with Dementia

A National Dementia Strategy
Issued by Department of Health 2009

Dementia Out of the Shadows

Alzheimer's Society 2008

Dementia Reconsidered

The person comes first
Tom Kitwood

Sources of Help and Support

www.ageuk.org.uk

www.nhs.uk

www.alzheimers.org.uk

www.dementiauk.org