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Enable rights and choices of individuals with dementia whilst minimising risks (DEM 304)



Assessment of this unit

Developing your knowledge, understanding and skills so that you can enable the rights and choices of individuals with dementia is very important, but minimising exposure of these service users to risk and harm should also be a priority. Take every opportunity to become fully acquainted with the legislative practices and agreed ways of working within your care environment.

The aim of this unit is gain knowledge and understanding of key legislation and to learn skills that support the rights and choices of individuals with dementia and that involve carers and others in decision-making.

The assessment of this unit is knowledge and skills based. You will need to:

1. Understand key legislation and agreed ways of working that support the fulfilment of rights and choices of individuals with dementia whilst minimising risk of harm.
2. Maximise the rights and choices of individuals with dementia.
3. Involve carers and others in supporting individuals with dementia.
4. Maintain privacy, dignity and respect of individuals with dementia whilst promoting rights and choices.

In order to successfully complete the unit, you will be required to produce evidence of your knowledge, understanding and skills in key legislation relating to individuals with dementia, their rights and their choices, as shown in the charts opposite. Your tutor or assessor will help you to prepare for your assessment; the tasks suggested in the chapter will help you to create the evidence that you need.

AC What you need to know

- 1.1 Explain the impact of key legislation that relates to the fulfilment of rights and choices and the minimising of risk of harm for an individual with dementia
- 1.2 Evaluate agreed ways of working that relate to rights and choices of an individual with dementia
- 1.3 Explain how and when personal information may be shared with carers and others, taking into account legislative frameworks and agreed ways of working

AC What you need to do

- 2.1 Demonstrate that the best interests of an individual with dementia are considered when planning and delivering care and support
- 2.2 Demonstrate how an individual with dementia can be enabled to exercise their rights and choices even when a decision has not been deemed to be in their best interests
- 2.3 Explain why it is important not to assume that an individual with dementia cannot make their own decisions
- 2.4 Describe how the ability of an individual with dementia to make decisions may fluctuate
- 3.1 Demonstrate how carers and others can be involved in planning and support that promotes the rights and choices of an individual with dementia and minimises risk of harm
- 3.2 Describe how a conflict of interest can be addressed between the carer and an individual with dementia whilst balancing rights, choices and risk
- 3.3 Describe how to ensure an individual with dementia, carers and others feel able to complain without fear of retribution
- 4.1 Describe how to maintain privacy and dignity when providing personal support for intimate care to an individual with dementia
- 4.2 Demonstrate that key physical aspects of the environment are enabling care workers to show respect and dignity for an individual with dementia
- 4.3 Demonstrate that key social aspects of the environment are enabling care workers to show respect and dignity for an individual with dementia

This unit also links to the following units:

- CMH 302** Understand mental health problems
- DEM 301** Understand the process and experience of dementia
- DEM 312** Understand and enable interaction and communication with individuals who have dementia

Some of your learning will be repeated in these units and will give you the chance to review your knowledge and understanding.

Understand key legislation and agreed ways of working that support the fulfilment of rights and choices of individuals with dementia whilst minimising risk of harm

The impact of key legislation

Key legislation was enacted to protect the rights and choices of many individuals, including those with dementia, while ensuring that the risk of harm is minimised. The rights of individuals are protected by these legislations:

- ▶ Human Rights Act 1998
- ▶ Mental Capacity Act 2005
- ▶ Adults with Incapacity (Scotland) Act 2000 and 2007
- ▶ Mental Health Act 2007
- ▶ Disability Discrimination Act 1995
- ▶ Safeguarding Vulnerable Groups Act 2006
- ▶ Carers (Equal Opportunities) Act 2004.

The Human Rights Act 1998

The Human Rights Act (1998) applies to all health and social care service users including individuals with dementia; service users with long-term conditions have rights too. However, these rights can be overruled by care workers or relatives if the individual poses a risk or is unable to make a decision regarding their own welfare.

Individuals should be kept informed of their rights, including the right to access legal support if that is required, until they no longer have the capacity to take decisions or make choices. A list of human rights includes the **right** to:

- ▶ life
- ▶ a good death
- ▶ be respected
- ▶ liberty
- ▶ be treated in a dignified way
- ▶ respect for private and family life
- ▶ be protected from danger and harm
- ▶ express beliefs
- ▶ experience these rights and freedoms without discrimination.

Your assessment criteria:

- 1.1** Explain the impact of key legislation that relates to fulfilment of rights and choices and the minimising of risk of harm for an individual with dementia.

Key terms

Rights: the legal freedoms or entitlements that people have



The Human Rights Act includes the right to life, to be respected, and to be protected from danger and harm

The Mental Capacity Act 2005

Every care worker should be aware of the five principles that underpin the Mental Capacity Act (2005):

- ▶ A presumption of capacity – every adult has the right to make his or her own decisions and must be assumed to have the **mental capacity** to do so unless proved otherwise
- ▶ The right to be supported to make decisions – individuals being supported to make their own decisions must be given all practicable help before anyone concludes that they cannot make their own decisions
- ▶ The right to make eccentric or unwise decisions – individuals should be able to make such decisions without being judged as lacking in capacity
- ▶ Best interests – when acting on behalf of an individual without capacity, anything done must always be in their best interests
- ▶ Preservation of rights – anything done for or on behalf of a person who lacks capacity should be the least restrictive intervention in terms of their basic rights and freedoms.

So, the Mental Capacity Act (2005):

- ▶ safeguards and protects people with dementia
- ▶ supports and protects individuals who are no longer able to make decisions regarding their lives
- ▶ allows carers to be involved in decision-making
- ▶ provides a clear framework and code of practice to support family and professionals.

The Mental Health Act 2007

The Mental Health Act (2007), The Mental Capacity Act (2005), Adults with Incapacity (Scotland) Act 2000, amended 2007 and the Disability Discrimination Acts of 1995 and 2005 are of particular relevance to people with dementia. Implementation of care under these Acts may have implications for an individual's human rights; for example when individuals are admitted to a care setting subject to the Mental Health Act, restrictions may be placed on their personal liberty. This act is largely concerned with the circumstances in which an individual with a mental disorder can be detained for treatment. It also sets out the processes that must be followed and the safeguards that ensure patients are not inappropriately detained or treated without their consent. New changes were made to the Act in 2007 so that it is no longer possible for individuals to be compulsorily detained or for detention to be continued unless appropriate medical treatment is available to that individual.

Key terms

Mental capacity: having the ability to make and communicate decisions about aspects of one's life

Investigate

The Mental Health Act Commission:

- ▶ is an independent body that supervises the implementation of the Mental Health Act
- ▶ specifically safeguards and promotes the rights of individuals
- ▶ makes planned and unplanned visits to every mental health facility to inspect practices related to individuals detained under the Act.

Find out more about the Mental Health Act Commission by going to Google and inserting the website www.cqc.org.uk/_db/_documents/report – focus on the role of the Commission in promoting and safeguarding the rights of the individual and the planned and unplanned visits made to every mental health facility that detains individuals under the Mental Health Act.

Adults with Incapacity (Scotland) Act 2000 and 2007

The Adults with Incapacity (Scotland) Act 2000 (Amended 2007):

- ▶ allows the individual to retain as much independence as possible
- ▶ presumes that capable adults are able to make their own decisions regarding medical care
- ▶ judges an adult incapable if he or she is unable to make decisions, communicate decisions, understand decisions and retain a memory
- ▶ allows adults to appoint a welfare attorney to make decisions for them in case their condition deteriorates to the point of being without capacity
- ▶ any intervention in the care of an incapacitated adult either by a professional or welfare attorney or guardian must benefit the individual, taking account of their wishes and the views of others involved in their care.

The Disability Discrimination Act 1995

The Disability Discrimination Act 1995, updated in 2005, prohibits discrimination against a disabled person. People with dementia, being disabled, are protected. The Act places a duty on public authorities to promote equality of opportunity for disabled people.

Safeguarding Vulnerable Groups Act 2006

The Safeguarding Vulnerable Groups Act (2006) applies to England, Wales and Northern Ireland whilst the Protection of Vulnerable Groups Act (2007) applies specifically to Scotland. Both Acts restrict contact between children and vulnerable adults and those who might harm them. The Act is complex but the underpinning principles are straight forward:

- ▶ Unsuitable people should be barred from working with children or vulnerable adults (including people with dementia).
- ▶ Employers should be able to check that a person is not barred from working with people in these two groups.
- ▶ Assessment of suitability to work with vulnerable people should be on-going, not a one-off procedure.

Unfortunately, individuals with dementia are occasionally subjected to abuse and neglect by care workers, other professionals or family members in residential care settings or at home. However, the Safeguarding Vulnerable Groups Act requires that organisations have systems and procedures in place to protect the individual. Good practice includes following policies and procedures on, for example, reporting, referrals, and investigation of incidents.

Your assessment criteria:

- 1.1** Explain the impact of key legislation that relates to fulfilment of rights and choices and the minimising of risk of harm for an individual with dementia.



Individuals should be supported in their rights and choices, maintaining as much independence as possible

The Carers (Equal Opportunities) Act 2004

The Carers (Equal Opportunities) Act 2004 gave carers new rights and a clear legal status. Under the Carer's Act 2004 individuals who provide or intend to provide a substantial amount of care on regular basis are entitled to an assessment of need. Councils must take into account the following issues when assessing a carer's needs:

- ▶ whether the carer works or wishes to work or is undertaking or wishes to undertake education, training or leisure activities
- ▶ support that can be provided from housing, health and education departments.

The Act also sets out the right for carers to request flexible working hours and the right for carers to access information regarding the individual, as long as **confidentiality** is maintained. The carer has a right to obtain some information regarding the person's condition, such as whom they are caring for in order to provide better quality care.

Rights, choices and managing risk

Managing risk in a care setting is a complex issue. What is an acceptable level of risk for each individual? Low, moderate or high? Does this depend on whether the person is being cared for in their home or in a practice setting? Care workers have to weigh up the individual's right to make independent choices and to control their own affairs against the person's vulnerability to risk. Every organisation should have risk management procedures in place to help carers assess risk and take appropriate action.

There are standards that address risk assessment and risk management in the workplace:

- ▶ Ten Essential Shared Capabilities (Department of Health, 2004) – this document promotes safety and positive risk taking by empowering people to decide on the level of risk they are prepared to take
- ▶ National Occupational Standards (Skills for Health, 2007) – this document requires carers to assess individuals' needs and circumstances and to evaluate the risk of abuse, of failure to protect and of harm to self and others.

Key terms

Confidentiality: non-disclosure of personal information

Investigate

Using online and library sources, investigate the key legislation that is relevant to individuals with dementia. Consider how this legislation supports the fulfilment of rights and choices for individuals with dementia.

Knowledge Assessment Task

1.1

The manager of your work setting has asked you to write a short leaflet that can be given to individuals and families who are interested in using the services offered by your care organisation. Your leaflet should focus on how the rights and choices of people with dementia are promoted and safeguarded in your work setting. In particular the leaflet must:

- ▶ explain the impact of key legislation that relates to fulfilment of rights and choices and the minimising of risk of harm for an individual with dementia.

You should retain a copy of the leaflet as evidence for your assessment.

Evaluate agreed ways of working

It is important for care settings to have systems in place that encourage **anti-discriminatory** practice for individuals with dementia by promoting their rights and choices. Care workers should always follow the policies and procedures of the institution in promoting these rights and choices, thereby adhering to the relevant legislation and ensuring that these policies become embedded in practice.

There are situations within the care environment where the individual's rights can be promoted; for example, care workers should be aware of an individual's privacy, knocking on the door before entering, and they should speak up about poor practice, alerting the person in charge.

Your assessment criteria:

1.2 Evaluate agreed ways of working that relate to rights and choices of an individual with dementia.

Key terms

Anti-discriminatory: an approach to care practice that challenges prejudice and unfair discrimination

Investigate

Ask the person in charge of your practice placement if you can look at the systems within the organisation that promote rights and choices for the individual. Then look for examples where these rights and choices have been embedded in practice in the care setting. Make notes on your observations.



Care workers should follow policies and procedures in promoting the rights and choices of individuals with dementia

Sharing personal information

If you handle personal information, you have a number of legal obligations to protect that information under the Data Protection Act 1998. You should also be aware that an individual has the right of access to their personal information, according to a timescale that is determined by the Act. UK law regarding patient confidentiality is largely based on the EU directives such as EC Directive 95/46/EC which the UK implemented in October 1998. Following consultations with the NHS, the UK Data Protection Bill came into force in March 2000.

The increased use of technology to transmit patient information, described as 'telemedicine', is currently under discussion with a view to a European Commission Staff Working Paper being issued.

Data protection law is very complex and continually developing. A key point to note is that healthcare professionals must comply with the common law duty of confidentiality with regards to patient data. Guidance of this can be found in 'The NHS Confidentiality Code of Practice' (HSG (96) 18, Department of Health, 2010).

Agreed ways of working

Within every practice setting there should be clear guidance on how information can be shared with carers and others. The NHS Service Delivery and Organisation programme (2006) suggests that the type of information that can be shared depends on the individual's circumstances. This includes whether the information is:

- ▶ general information that is already in the public domain
- ▶ personal information related to the person's condition, for example a diagnosis or information regarding medication
- ▶ sensitive personal information, for example regarding abuse or views about family members.

Consent should be obtained before information is shared with carers; the use of advance agreements, as highlighted by the NHS Service Delivery and Organisation programme (2006), is helpful because it allows an individual to say what care they would like in the future when they are no longer able to say. These agreements also allow the carers to have general and personal information in order to carry out their role of caring.

Your assessment criteria:

- 1.3** Explain how and when personal information may be shared with carers and others, taking into account legislative frameworks and agreed ways of working.



Good practice in sharing information

Some good practice initiatives to involve service users and others in sharing of information are:

- ▶ that involvement of the carer in sharing information should not undermine the individual who should retain a voice in decisions being made
- ▶ individuals should be invited to carer's meetings (rather than being excluded) so all parties are involved and are aware of what is taking place
- ▶ if a professional is unable to share personal information with carers and others because the individual has not consented, the professional should give a supportive explanation to prevent a perceived barrier to communication between the professional and carers
- ▶ policies should be put in place within the practice setting on sharing confidential information with carers and others
- ▶ clear boundaries regarding sharing of information and an understanding of the individual's need for privacy are essential
- ▶ it should be documented in notes whether the individual has given consent or not; consent should be informed, written, voluntary and recent.

Assessing the mental capacity of an individual with dementia to make a decision about sharing information with carers and others may be difficult for the care worker. With earlier diagnosis and new treatments, people are retaining capacity for much longer but for those who are no longer capable, the Mental Capacity Act (2005) provides principles and guidance to for sharing information.

Your assessment criteria:

- 1.3** Explain how and when personal information may be shared with carers and others, taking into account legislative frameworks and agreed ways of working.



Case study

Martin is admitted to your practice placement for the second time, confused and in a state of neglect. He has been living on his own but is failing to cope.

A neighbour, Sally, has been visiting daily and providing meals. Martin refuses for staff to share any information with the neighbour, yet he wants to return home. However, Sally needs support in managing him so that he does not get into this neglectful state again.

1. What information could you share with Sally?
2. How could the Mental Capacity Act (DCA 2005) assist you in helping Martin to share his personal information with Sally?
3. Review the policy on sharing information in your practice placement. What does it state? Share this information with fellow students in your practice setting.
4. What rights and choices does Martin have?

Investigate

Find out what policies are in your practice placement for sharing confidential information regarding an individual and their carers/others. Discuss with others and your tutor how consent is managed by the care practitioner, and make notes in your journal.

Knowledge Assessment Task

1.2

1.3

Health and social care practitioners should always be thinking about the effectiveness of the policies, procedures and agreed ways of working that influence their practice. This is a way of ensuring that individuals' interests are always at the centre of care practice. In this activity you are asked to:

1. Identify and describe two agreed ways of working in your work setting that relate to the rights and choices of individuals with dementia.
2. Evaluate each of the agreed ways of working by creating a table that lists the strengths and benefits of each way of working and the weaknesses or limitations of each way of working in relation to the rights and choices of individuals with dementia.
3. Explain how and when personal information about individuals with dementia may be shared with carers and others, taking into account legislative frameworks and agreed ways of working.

You should keep a copy of the written work that you produce for this activity as evidence towards your assessment.

Be able to maximise the rights and choices of individuals with dementia

The best interests of the individual

The best interests of an individual with dementia must always be considered when planning and delivering care and support. The Mental Capacity Act (DCA 2005) does not define what is meant by 'best interests' because every individual case is different, but it provides a list of factors that must be considered when deciding what is in a person's best interests:

- ▶ the individual's past and present wishes and feelings, beliefs and values
- ▶ if the person could regain capacity and the issue is not urgent, then the decision should be delayed
- ▶ the views of relatives and partners, as well as those of an attorney
- ▶ no **discrimination** based on age, appearance, condition or behaviour
- ▶ **advanced statements**
- ▶ **advanced directives**.

The Mental Capacity Act (DCA 2005) states that every effort should be made to encourage the individual to take part in making a decision about the following issues:

- ▶ finances
- ▶ health
- ▶ emotional and social wellbeing.

Advanced statements and directives

Advanced statements are clear instructions made by the individual before losing capacity. Advanced directives, also known as living wills, deal specifically with the individual's wishes regarding future medical care – for example, refusal of treatment when their condition deteriorates. In order to make an advance directive the individual must be:

- ▶ competent at the time of the declaration
- ▶ informed about the procedure and what will be involved
- ▶ free from any undue influence.

Your assessment criteria:

- 2.1** Demonstrate that the best interests of an individual with dementia are considered when planning and delivering care and support.

Key terms

Discrimination: treating one particular group of people less favourably than another

Advanced statement: a statement about future decision-making when the individual loses capacity

Advanced directive: a 'living will' dealing with medical care



Discuss

Discuss with a colleague in your practice setting how the best interests of individuals with dementia are being addressed. Talk about whether advanced directives are being used in practice and how they could be used to maximise individuals' rights and choices.

Exercising individual rights and choices

It is important to recognise that an individual should be given the opportunity to exercise their rights and choices, even when their decision is not necessarily in their best interests. Some negotiation may have to take place and a **compromise** reached if the desired choice could put the individual at risk of harm. When this occurs, the level of risk posed by a decision should be considered; risk is evident in all aspects of everyday life and a certain level of risk may be acceptable. The Department of Health's 'Ten Essential Shared Capabilities' (DH 2004) states that there is a tension between promoting safety and positive risk-taking. Essentially, the care team must be aware of risks, taking appropriate action when required, thus avoiding negligent practices.

Managing risk

Assessment and management of risk should be the core components of a risk management policy that is linked to the **Care Programme Approach** (Department of Health, 1999b). The report 'Best Practice in Managing Risk' (Department of Health, 2007) outlines the practice and strategies that should be put in place in the placement setting. The Health and Safety Executive focuses on wider safety strategies within the work environment.

Assessment of risk should not be carried out in isolation. It should be a multi-professional approach and the individual with dementia should be involved in the process. When conducting a risk assessment, the following should be considered systematically:

- ▶ History of previous risky behaviours – ask the individual themselves and research other information including letters written regarding previous behaviour; involve carers and partners
- ▶ Patterns of any risky behaviour – are any behaviours repeated?
- ▶ Recent risky behaviour – are there any recent incidents relating to the identified risk?
- ▶ Documentation of risk – how is the risk being documented; is there a policy in place?
- ▶ Communication of risk – who needs to be informed?

Regular risk assessments

Risk assessments are carried out on regular basis to monitor, for example, clinical and environmental risks in the workplace setting. The care practitioner needs to identify where the risk assessments are located within the workplace setting, who has responsibility for conducting the risk assessments and auditing them, how often they are conducted and who carries out the relevant actions. The assessments should be made available to all care practitioners and should not be a paper exercise – findings should be acted upon. In small settings the audit may be carried out by the manager of the care setting.

Your assessment criteria:

- 2.2** Demonstrate how an individual with dementia can be enabled to exercise their rights and choices even when a decision has not been deemed to be in their best interests.

Key terms

Compromise: establishing a mutually agreed objective where each side has to make concession/s until agreement has been finally made

Care Programme Approach: providing a programme of care for an individual with mental health needs, abbreviated to CPA

Risk assessment: a process that aims to identify potential risks to the health, safety and security of all people at a specified location

Investigate

Using online and library sources, investigate the information on risk assessment and risk management. Find out what information is available in your practice placement regarding risk management. Summarise your findings in about 100 words and file as evidence.

Don't assume individuals can't make their own decisions

It should not be assumed that an individual with dementia cannot make their own decisions. Everyone has the capacity to make their own decisions until proven otherwise. A **person-centred approach** encourages a positive attitude to decision-making; the focus is on the individual's abilities and strengths rather than on their long-term condition. Person-centred care will consider the whole person, including whether that individual still has the ability to make decisions regarding their care. When the individual can no longer make decisions, their mental capacity is assessed by the caring team. The Mental Capacity Act (DCA 2005) provides principles and guidance to assist assessment. The Act suggests that the individual should be given all necessary help to make supported decisions before it can be concluded that they can no longer make their own decisions. There is a two-stage test of mental capacity:

1. Does the person have brain impairment or is there something affecting how their brain works? Dementia is considered to be relevant here.
2. If so, is the person unable to make a decision regarding the question that is being asked?

Different kinds of decisions

The Mental Capacity Act (2005) supports a 'functional' or 'decision' test which recognises that an individual's ability to make decisions could vary from time to time, depending on the stage of their dementia and type of decision that is being requested. Some decisions are more difficult to make than others; for example, deciding what to wear is easier than trying to manage one's financial affairs or selling one's home. So, individuals may be able to make some decisions in their lives but a failing memory may prevent them from making others.

An advanced directive is also known as a 'living will'. This enables the individual to make very important decisions regarding their future medical care. If these decisions are not made when they have the capacity, decisions could be made by others that go against their wishes.

Your assessment criteria:

- 2.3** Explain why it is important not to assume that an individual with dementia cannot make their own decisions.



Key terms

Person-centred: a therapeutic relationship that focuses on the person's strengths and shows them respect

Reflect

Reflect on how the Mental Capacity Act can assist you in helping an individual to make decisions regarding their life.

- ▶ Refer to examples that you have observed in practice
- ▶ Discuss with your tutor and make notes in your journal.

Fluctuating decision-making ability

An individual with dementia may find that they can make decisions in more **lucid** moments, even if these are fleeting. This may depend on the type of dementia they have and the stage of the disease. Those who have Alzheimer disease do experience these moments, but these can be upsetting times if the individual realises their mental capacity is declining. Even if the individual has memory loss and generally only recalls past events, they may suddenly become fully aware of their present circumstances and may feel able to make important decisions – encourage them to be cautious. Carers should be aware of individuals' beliefs and values as these may influence decisions they wish to make.

Considering advanced directives

During periods of awareness, the individual could be asked to consider advanced directives to plan for their future medical care. This will depend on how often the individual has these periods of heightened awareness and whether they feel able to make such vital decisions.

Your assessment criteria:

2.4 Describe how the ability of an individual with dementia to make decisions may fluctuate.

Key terms

Lucid: clear thinking, rational and aware

Case study

Stephen is an 80-year-old man who lives with his wife, Jean. Stephen lived an active life until about six months ago when Jean noticed a change in his behaviour. He no longer went fishing, was neglecting his personal hygiene and was becoming increasingly forgetful. As Stephen has become increasingly difficult to manage at home, Jean has asked for respite care. However, he has refused to be admitted.

1. What risks does Stephen pose by being at home in his current state?
2. How could you support Jean using the person-centred approach?
3. How can the Mental Capacity Act and advanced directives help Stephen in making decisions regarding his future care?

Practical Assessment Task

2.1

2.2

2.3

2.4

Maximising the rights and choices of individuals is an important element of good practice in dementia care. You should focus your work for this activity on your own practice in relation to providing care for an individual with dementia. You will need to:

1. demonstrate that the best interests of an individual with dementia are considered when planning and delivering care and support
2. demonstrate how an individual with dementia can be enabled to exercise their rights and choices even when a decision has not been deemed to be in their best interests
3. explain why it is important not to assume that an individual with dementia cannot make their own decisions
4. describe how the ability of an individual with dementia to make decisions may fluctuate.

Your evidence must be based on your practice in a real work environment and must be witnessed by or be in a format acceptable to your assessor.

Be able to involve carers and others in supporting individuals with dementia



Your assessment criteria:

- 3.1** Demonstrate how carers and others can be involved in planning support that promotes the rights and choices of an individual with dementia and minimises risk of harm.

Involving carers in planning support

Carers commonly worry about individuals with dementia, such as what could happen if they leave the person unattended and how to cope with challenging behaviours. Carers have to cope with changing demands and unpredictable outcomes. Therefore, they require a lot of support and sensitivity.

As discussed, the individual's best interests and preferences must take priority and be placed at the centre of all provision. This can also be difficult for carers who may feel that their own needs are neglected. Care planning should involve carers along with members of the multi-disciplinary team, and the plan should:

- ▶ promote the rights and choices of the individual
- ▶ minimise risk and harm
- ▶ provide equitable and individualised care, treating each person as an individual
- ▶ adhere to equal opportunities legislation and good practice
- ▶ recognise and value **diversity**
- ▶ promote anti-discriminatory practice
- ▶ adhere to the Human Rights Act (DCA 1998) (individuals should be informed of their rights).

Carers should be made aware of the confidential nature of the individual's personal information through involvement in care planning.

Key terms

Diversity: variety, such as in social characteristics



Individuals with dementia have rights and choices, though some decisions may need assessing against the risk involved

Conflicts of interest

Although carers should always try to impress on individuals with dementia that they have rights and choices, they will be aware of their dependence and can feel very vulnerable as a result. Nonetheless, most individuals want to retain some control over their lives, especially with regard to making decisions.

Balancing rights and risk

Carers may face a dilemma when they believe that they know what is best for a person, but the individual has conflicting ideas. However, carers should accept that the individual needs to retain some independence by taking control of some aspects of their life, even though they may be vulnerable to risk.

Individual choice and opportunity

Individuals with dementia and their carers are entitled to:

- ▶ opportunities to enhance their abilities
- ▶ participation in decisions that will affect their daily lives, now and in the future
- ▶ opportunities to participate in the wider community
- ▶ assessment of their general, medical and social needs.

Your assessment criteria:

- 3.2** Describe how a conflict of interest can be addressed between the carer and an individual with dementia whilst balancing rights, choices and risk.

Reflect

Reflect on the dilemmas that you have observed while on your placement between an individual and their carer. How were these managed within the care setting? Make notes of 100 words, record these in your journal and keep as evidence.

How to enable complaints without fear of retribution

Every organisation should have a complaints procedure and an individual with dementia, carers and others should feel able to complain without retribution. There are a number of national organisations that have complaints procedures, for example, local authority social services departments, the NHS and the Care Quality Commission (DH 2009), the independent regulator of health and adult social care in England. The NHS Constitution (DH 2010) explains patients' rights when making general complaints about services within the NHS system. These include to:

- ▶ have a complaint dealt with efficiently and for it to be properly investigated
- ▶ know the outcome of any investigation into a complaint
- ▶ take the complaint to the Independent Parliamentary and Health Services Ombudsman if the patient is not satisfied with the way the NHS has dealt with it
- ▶ make a claim for a judicial review if the patient has been affected by an act or by a decision
- ▶ receive compensation following any harm.

It is important that any complaint is made as soon as possible and within 12 months of the event happening. Complaints can be made directly to the service in question or to the local Primary Care Trust that commissioned the care.

Since April 2009, each hospital or trust runs a simple complaints process. A Patient Advice and Liaison Service (PALS) provides advice, helping relatives and carers on a wide range of issues that can be resolved quickly and easily. The PALS usually encourages complainants to raise concerns with the member of staff concerned with the care.

Other services that can be accessed for support and guidance when making a complaint are:

- ▶ the Independent Complaints Advocacy Service, a national service
- ▶ the Citizens Advice Bureau, which provides support for complaints about the NHS, social services and local authorities.

Your assessment criteria:

- 3.3** Describe how to ensure an individual with dementia, carers and others feel able to complain without fear of retribution.



Investigate

Using online and library sources, investigate the NHS and local authority complaints procedures that carers, others and individuals with dementia can access for information. Find out how your practice placement handles complaints. Make notes in your journal.

Case study

Rita is 76 years old and lives at home with her husband, Angus, who has vascular dementia. If possible, she wants to continue caring for him at home. Although they both attend a local support group once a week, Rita recognises that they both need more support, especially as Angus's mental capacity is deteriorating. He is becoming more confused. He has been admitted to a care home for assessment.

1. How would you support Rita in planning care for Angus, ensuring that he still exercises his rights and choices?
2. How would you manage the dilemmas of their conflicting interests regarding what he feels he needs and what she thinks he needs?
3. What advice would you give Rita if she decides to complain about his care?

Reflect

Reflect on how your practice placement manages complaints.

- ▶ Consider whether the policies that have been put in place to manage this process are effective
- ▶ Suggest ways that the process can be improved.

Make notes in your journal.

Practical Assessment Task

3.1

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Effective, person-centred care for individuals with dementia requires everyone involved with an individual to participate in the planning and delivery of care. Involving carers and others in supporting an individual with dementia requires a range of skills and abilities. In this practical activity, you need to should that you have these abilities. Focusing on your own care practice you should choose an individual with dementia with whom you work and:

1. demonstrate how carers and others can be involved in planning support that promotes the rights and choices of the individual whilst minimising risk of harm
2. describe how a conflict of interest can be addressed between the carer and an individual with dementia whilst balancing rights, choices and risk
3. describe how to ensure an individual with dementia, carers and others feel able to complain without fear of retribution.

Your evidence for this task must be based on your practice in a real work environment and must be witnessed by or be in a format acceptable to your assessor.

Be able to maintain the privacy, dignity and respect of individuals with dementia whilst promoting rights and choices



Your assessment criteria:

- 4.1** Describe how to maintain privacy and dignity when providing personal support for intimate care to an individual with dementia.

Key terms

Dignity: being worthy of respect

Privacy: free from being observed by others

Intimate care: associated with exposure of bodily functions and sexual parts of the body

Reflect

Give this activity plenty of thought before you start to address it. Reflect back on the occasions when you have given intimate care in your practice placement. Then complete the following sentences:

1. I offer dignity by ...
2. I uphold privacy by ...

Maintaining privacy and dignity

Maintaining **dignity** and **privacy** is extremely important for an individual, especially when **intimate care** is being provided. To provide dignity, the care worker needs to demonstrate respect, valuing the person's uniqueness and upholding privacy at all times so that the individual cannot be observed by others.

What is intimate care?

Intimate care is:

- ▶ help with tasks of personal nature, for example toileting
- ▶ associated with bodily functions, e.g. elimination of urine/faeces
- ▶ help with personal hygiene, maybe including sexual organs.

Managing intimate care can be difficult; individuals may feel uncomfortable or humiliated, for example, if they are naked in close proximity to a carer who is bathing them.

Standards for intimate care in care settings should include:

- ▶ considering the individual's personal preferences, rather than making assumptions about their needs
- ▶ encouraging the individual to do as much of their intimate care as they can, recognising the need for support
- ▶ ensuring that the individual is free from danger, harm or abuse
- ▶ being aware of the boundaries involved in intimate care.

Key physical aspects of the environment

Key physical aspects of the environment that every practice setting should aspire to are:

- ▶ features that allow for privacy
- ▶ cleanliness
- ▶ spaciousness
- ▶ non-slip flooring
- ▶ accessibility of computers.

An environment that meets these quality standards enables care workers to show respect and dignity for the individual.

Promoting dignity in the environment

The Royal College of Nursing (RCN) conducted a study in 2009 and these are some of the findings regarding the promotion of dignity in the environment:

- ▶ Privacy – curtains, doors, screens and private rooms for consultations should be present.
- ▶ Aesthetic aspects – space, colour, music, furnishings, cleanliness and good lighting all enhance the environment.
- ▶ Accommodation – should be single-sex with space for clothes and including a toilet and washroom facilities.
- ▶ Curtains around beds – should be present and should not have gaps.
- ▶ Layout – a good layout includes easy access to common rooms and bathroom facilities.
- ▶ Use of signage – ‘do not disturb’ signs prevent intrusion and loss of physical privacy and dignity.
- ▶ Confidentiality – confidentiality of information is vital, especially when care is being discussed.



Your assessment criteria:

- 4.2** Demonstrate that key physical aspects of the environment are enabling care workers to show respect and dignity for an individual with dementia

Reflect

Review the layout of your practice placement and consider whether the environment meets the standard discussed above. If not, suggest how it can be improved. Share your findings with the setting manager. Write 100 words of reflection afterwards.



Your assessment criteria:

- 4.3** Demonstrate that key social aspects of the environment are enabling care workers to show respect and dignity for an individual with dementia.

Key social aspects of the environment

Key social aspects of the environment can enable positive interactions between individuals with dementia, so that their abilities can be enhanced. The whole team should adopt a relationship-centred approach when engaging with individuals with dementia. The focus should be on building therapeutic relationships with these individuals, fostering effective communication and interpersonal skills. The use of the following can enhance social relationships:

- ▶ use of appropriate eye contact
- ▶ a friendly approach
- ▶ good active listening skills
- ▶ realistic goals that have been mutually agreed
- ▶ facilitation of the individual's and carer's engagement with other services
- ▶ fostering an atmosphere of co-operation, even if the individual rejects the interaction
- ▶ an awareness of some of difficulties of holding a conversation with an individual who has a memory impairment or who becomes frustrated when unable to express themselves coherently and clearly
- ▶ an awareness of professional **boundaries**.

Professional boundaries set the limits in the relationship between the care worker and the individual who needs care. It is crucial for care workers to recognise the difference between a therapeutic relationship and a close and confiding friendship. In a professional relationship, there is mutual respect and the individual's dignity and privacy are safeguarded.

Key terms

Boundaries: limits

Setting your professional boundaries

It is not always easy to keep within the boundaries of a therapeutic relationship, especially if you find yourself in a situation where someone who is distressed needs comforting. However, it is important, as a care worker, to develop an awareness of when you are crossing a professional boundary. Seek help from your manager or the person in charge if this occurs.

Your employer will set the boundaries that describe what is expected of your role in that organisation.

Discuss

Discuss with a colleague why it is important for care practitioners to set professional boundaries when engaging in a therapeutic relationship with an individual.

- ▶ What would you do if problems arose?
- ▶ Who should seek support from?

Make notes in your journal.

Case study

Mary is 75 years old and lives with her husband, Henry, who is her main carer. He says that he can no longer care for her and has visited several care homes to find the best one for her. He has mixed feelings regarding the decision to place Mary in a care home but realises that she needs more expert care.

1. How would you maintain dignity and privacy for Mary in her new care home?
2. What physical aspects should Henry look for in the environment when viewing homes for Mary?
3. Identify the social aspects of the environment that you should consider when caring for an individual like Mary.

Practical Assessment Task

4.1

4.2

4.3

Individuals with dementia gradually lose their self-care skills, independence and ability to make decisions. As a result it is very important that care practitioners act to maintain the privacy, dignity and respect of people who are no longer able to do this for themselves. In this assessment activity you need to show that you act to safeguard and maintain the privacy, dignity and respect of the individuals with whom you work. In relation to your own practice you should:

1. describe how you maintain privacy and dignity when providing personal support for intimate care to an individual with dementia
2. demonstrate that key physical aspects of the environment are enabling care workers to show respect and dignity for an individual with dementia
3. demonstrate that key social aspects of the environment are enabling care workers to show respect and dignity for an individual with dementia.

Your evidence for this task must be based on your practice in a real work environment and must be witnessed by or be in a format acceptable to your assessor.

Are you ready for assessment?

AC	What do you know now?	Assessment task	✓
1.1	Explain the impact of key legislation that relates to the fulfilment of rights and choices and the minimising of risk of harm for an individual with dementia	Page 7	
1.2	Evaluate agreed ways of working that relate to rights and choices of an individual with dementia	Page 11	
1.3	Explain how and when personal information may be shared with carers and others, taking into account legislative frameworks and agreed ways of working	Page 11	



Bibliography:

'Best Practice in Managing Risk' (Department of Health, 2007)

Care Programme Approach (Department of Health, 1999b)

NHS Service Delivery and Organisation 'Sharing mental health information with carers: pointers to good practice for service providers' (National Co-ordinating centre for the service delivery and organisation research programme, 2006) see <http://www.sdo.nihr.ac.uk>

National Occupational Standards (Skills for Health, 2007)

'Defending dignity' (Royal College of Nursing, 2009) see <http://www.rcn.org>

Ten Essential Shared Capabilities (Department of Health, 2004)

AC	What can you do now?	Assessment task	✓
2.1	Demonstrate that the best interests of an individual with dementia are considered when planning and delivering care and support	Page 15	
2.2	Demonstrate how an individual with dementia can be enabled to exercise their rights and choices even when a decision has not been deemed to be in their best interests	Page 15	
2.3	Explain why it is important not to assume that an individual with dementia cannot make their own decisions	Page 15	
2.4	Describe how the ability of an individual with dementia to make decisions may fluctuate	Page 15	
3.1	Demonstrate how carers and others can be involved in planning and support that promotes the rights and choices of an individual with dementia and minimises risk of harm	Page 19	
3.2	Describe how a conflict of interest can be addressed between the carer and an individual with dementia whilst balancing rights, choices and risk	Page 19	
3.3	Describe how to ensure an individual with dementia, carers and others feel able to complain without fear of retribution	Page 19	
4.1	Describe how to maintain privacy and dignity when providing personal support for intimate care to an individual with dementia	Page 23	
4.2	Demonstrate that key physical aspects of the environment are enabling care workers to show respect and dignity for an individual with dementia	Page 23	
4.3	Demonstrate that key social aspects of the environment are enabling care workers to show respect and dignity for an individual with dementia	Page 23	