

Dementia Skilled - Improving Practice

Learning Resource

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Introduction

Introduction

Welcome!

Welcome to the Dementia Skilled – Improving Practice Learning Resource. This resource is designed to help you to develop your ability to support people with dementia, their families and carers. It will help you to improve your skills and to feel more confident about the work you are doing. The resource contains the *Informed about Dementia: Improving Practice DVD* and you should watch this DVD before you start this learning resource. We are building from the knowledge and skills presented in the DVD and, sometimes with the same cast of characters, we will be presenting more detailed, and sometimes more challenging issues for you to work through. We hope you find the style of this action focused resource supports you to learn, and to enjoy the process!

Who is this learning resource for?

This learning resource is for people who work directly with people with dementia, their families and carers and also for people who have substantial contact with people with dementia, their families and carers. The learning will help ensure you have the knowledge and skills set out at the Dementia Skilled Level of **Promoting Excellence: A framework for all health and social services staff working with people with Dementia, their families and carers**. It's designed particularly for the health and social services workforce, but may be valuable to other groups working in related services or organisations.

This resource will help you to develop your understanding about dementia and to think differently about the people with dementia you may work with whether they're living at home, living in a care home, attending a day centre or in a hospital ward. People with dementia have rights and they have abilities, rich histories and experience. All of this must be recognised in the way we provide care and support.

Why is Dementia so important?

As people live longer, there are more and more people living with dementia in Scotland. Statistics from Alzheimer Scotland in 2011 showed dementia affects about:

- 2% of people aged 65 to 70
- 5% of people aged 70 to 80
- 20% over 80

82,000 people in Scotland have dementia and this figure is expected to double over the next 25 years.

Dementia is not just a condition affecting older people, people in their 40s or 50s or even younger can have dementia, and it is sometimes only one of a range of conditions people may be living with, for example:

- Dementia and depression
- Dementia and learning disability
- Dementia and heart disease

Dementia has a profound impact on the families, friends and neighbours of people with dementia. They need our support to help people to have the best quality of life as they journey through their illness. Wider communities also have a role in keeping people with dementia connected to the life and activities they value. We are all part of communities and our lives will be increasingly affected by dementia personally, in our work settings, families or communities.

What is the background to this resource?

In June 2010, the Scottish Government launched Scotland's National Dementia Strategy which set out a range of commitments in relation to dementia care, support and education. One year later, in June 2011, Scottish Government launched *Promoting Excellence*: a framework for all health and social services staff working with people with dementia, their families and carers and Standards for Dementia Care in Scotland. *Promoting Excellence* describes the minimum knowledge and skills required by ALL of the health and social services workforce whether you work in a care home, in a clinic or community hospital or whether you work in someone's own home. Groups such as pharmacists, consultant psychiatrists and mental health officers will need very detailed knowledge in relation to their specialist areas of work but all their training and learning will build from the information, aspiration and principles outlined in *Promoting Excellence*. The Standards outline what people can expect from the services they receive so together these documents represent a means of making sure that improving the quality of life for people with dementia is at the heart of what we do.

How is the resource structured?

This learning resource has 5 Modules and this introduction. It is important that you work through

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Module 1 first to make sure you have a strong knowledge base about dementia. The learning outcomes for the Modules and the learning activities have been written to reflect Level 7 of the Scottish Credit and Qualification Framework. Each Module includes links to further learning for people who choose to explore issues in greater depth.

The Modules are shown below.

The learning resource modules

- Module 1: Understanding dementia
- Module 2: Promoting person and family centred care and community connections
- Module 3: Promoting health and well being
- Module 4: Meeting the needs of the person with dementia who is distressed
- Module 5: Supporting and protecting people's rights

Throughout the resource we use learning activities that help you reflect on how you can best support people with dementia and put this learning into practice.

How should this resource be used?

We want you to use this resource in the way that best suits you, your team or your organisation. The activities that appear throughout each of the Modules will play a key part in helping you further develop the knowledge, skills and attitudes that are central to your role. The focus is on practical applications of the learning, reflective practice and putting your learning into action.

You can use the resource for individual learning, learning as a group or team, in a facilitated learning event or in a mixture of all of these approaches. You can:

- focus on one Module at a time, using the variety of activities we have provided
- use the resource to discuss your thoughts and responses with your colleagues, e.g. in team meetings, workshop or study sessions
- use the resource for individual study, reflecting on the activities in your own time
- use the resource with a facilitator in dedicated learning sessions
- build a portfolio of evidence which may support you to gain qualifications
- confirm your progress against the key learning points at the end of each Module

- check out links to other resources to enhance your development
- involve colleagues from a range of disciplines or agencies in joint learning
- use the resource as part of your supervision

Whichever approach you favour, we recommend that some opportunities for group discussions are offered to help to put individual experiences into a broader context and enhance learning.

If you have already seen the DVD or used it in a learning session, you may want to refresh your memory as it identifies a starting point for this resource. If you haven't seen it, you should watch it now as it will introduce you to some of the people you will encounter as you work further through this resource.

Next, we'll introduce you to the people with dementia who feature in this resource. These are fictitious characters although their stories and experiences reflect those of real people with dementia. You have been introduced to 4 of them, George, Ellen, Jim and Margaret in the DVD 'Informed about Dementia: Improving Practice' and worked through the questions we posed in it. All of them are living lives rich in experience, have loved and been loved and have pursued their individual interests, often with great passion and commitment. As people who care for and support others, you will already know that your commitment to the people you work with makes a difference to their lives. Being equally committed to developing your learning and improving the skills you already demonstrate will benefit people with dementia, their families and carers even more. Recognising the rich and varied backgrounds and interests people with dementia have, helps you to understand them better and ensure that their lives remain valued and meaningful.

Introducing you to:

George

George is 55 and lives at home. He was married and worked in the housing department of the local council for 30 years until he was retired 12 months ago on the grounds of ill health. Around the same time his wife left him and George has since found it difficult to engage with the community groups he once loved - the community council, the heritage group and the bowling club. He has one son, Barry, who lives with his partner in the North of England. George is very proud of his son and sees him two or three times a year.

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Ellen

Ellen is 80 and lives at home. Her husband died 6 years ago and she has 3 children and 4 grandchildren. Her sons both live at a distance and her daughter Carolyn lives nearby and visits every evening. While raising her own children, Ellen worked by keeping accounts for her husband John's car repair business and was a treasurer of the local WRVS. She has always been busy and enjoyed using her skills to support the family business and organise their home life and she particularly enjoys cooking.

Jim

Jim is 84 and a retired art teacher. He was passionate about art and it provided a focus for his working life and his spare time. He enjoyed teaching at the local college and taught a small art class in the local village. Fond of many styles of art, he would travel across the country to exhibitions and would often spend weekends in the west of Scotland painting landscapes and seascapes. He had never married and had few close friends.

Margaret

Margaret is 90 and she comes from, and had, a large family. The wife of a dock worker, she has lived all of her life in Glasgow and believes in the value of family and community. Margaret kept an immaculate home in spite of limited finances and 5 children and took great pride in cleanliness. One of her children died following a heart attack 10 years ago however her other children are in contact, as are some of her 11 grandchildren. She has few interests other than television.

Donald

Donald is a 68 year old retired joiner who is married to Sheila. They have 3 children and 4 grand children. He has been very active and involved in his local golf club and 20 years ago he was captain of the golf team and was secretary to the club committee for 10 years. Acting as secretary to the committee was a significant part of his life. Donald is very physically fit and has continued to attend the club regularly to play a round of golf. Donald is also a keen reader and is extremely interested in Scottish history. Donald was recently diagnosed with dementia.

Millie

Millie is 85 and has lived in the same small Scottish town all her life, as have her daughters. Millie is part of a close and sociable family. Millie hardly spent any time on her own until the death of her husband 8 years earlier. Millie was very active in the local church and at various stages she led the Sunday school, Guides and Brownies and latterly, the Women's Guild.

Participating in the life and work of the Church is very important to Millie.

Who will benefit?

We use the stories of people with dementia and their families and carers throughout this resource to support you to apply your learning. You may recognise aspects of their journeys from your own experience. We want you to consider how the quality of their experience can be improved through you using your knowledge and skill. All of us continue to learn and develop and the value of skilled practice to people with dementia is immeasurable. You will benefit from this course of learning and therefore people with dementia, their families and carers will be supported and cared for in the best possible way.

We can make a difference to people with dementia:

'What I would say to the professionals is that – you can pull me back, give me my life back and pull me into the light and by the same token, ignorance, arrogance, couldn't care less, you can shove me down into the darkness and just cast me away. I can't do it. I need your help to do it.'
(Through our Eyes, a life with dementia – Scottish Dementia Working Group)

Related links

The following links will lead you to key resources to help you further understand the background to this resource. We strongly suggest you familiarise yourself with the Standards of Care for Dementia in Scotland and the Promoting Excellence Framework.

Scotland's National Dementia Strategy <http://www.scotland.gov.uk/Resource/Doc/324377/0104420.pdf>

Promoting Excellence - a framework for health and social services staff working with people with dementia, their families and carers <http://www.scotland.gov.uk/Publications/2011/05/31085332/0>

Standards of Care for Dementia in Scotland <http://www.scotland.gov.uk/Publications/2011/05/31085414/0>

It is important that you familiarise yourself with these documents.

Module 1: Understanding Dementia

Module 1 - Understanding Dementia

Introduction

As life expectancy rises in the developed world, more cases of dementia are being diagnosed. There are currently approximately 82,000 people with dementia in Scotland (overall, approximately 5% of people over the age of 65 years experience dementia, with the risk of developing dementia increasing with age).

In this module, we will look at some of the more common types of dementia and examine their prevalence, how they affect the brain, and what signs and symptoms are likely to occur as a result. There is no single cause of dementia and it can affect a diverse range of people. However, there are a number of factors that can increase or decrease the risk of developing dementia. We will look at some of these risk factors and consider what can be done to reduce the risk of developing dementia.

We will also consider the stages of the dementia journey. Key to understanding dementia is the recognition of the impact on people's communication skills and the impact of the environment on people with dementia. Finally we consider the importance of equality and diversity in dementia care and support.

Learning outcomes

By the end of this module you will be able to:

1. Identify and describe the different causes and types of dementia, and understand the symptoms and difficulties people will experience.
2. Understand the concept of the dementia journey and its different stages.
3. Understand the impact of a diagnosis of dementia on the person and their family.
4. Distinguish between dementia, depression and delirium.
5. Explain the risk factors relating to dementia.
6. Reflect on the factors that can influence communication with people who have dementia.
7. Understand the impact of the environment on people with dementia.
8. Recognise the importance of equality, diversity and inclusion when working with people with dementia.

What is dementia?

Dementia is a term used to describe the symptoms that occur when the brain is affected by specific diseases and conditions. There are many types of dementia, each caused by a different disease affecting the brain. Among other things, these affect people's memory, relationships and their ability to communicate.

There is currently no cure for dementia and although there are medicines that can improve some symptoms or temporarily slow progression, the condition is terminal. All types of dementia are progressive, though in some less common types the progression can be halted. Some symptoms are common to all types of dementia, while other symptoms are more likely to occur in one specific type.

It is important to understand that many people with dementia are able to live well with dementia, and lead active and fulfilling lives for a number of years after they first experience difficulties and receive a diagnosis. Health and social care workers can also take a lot of positive action to ensure people with dementia can have the best possible quality of life as their dementia progresses, and these are issues we will explore through out the other modules in this learning resource.

While there are many similarities experienced by people with different types of dementia, no two people will experience dementia in exactly the same way and the rate of progression of dementia also varies greatly between people.

Module 1 - Understanding Dementia

Types of dementia

Alzheimer's disease	
Prevalence	Alzheimer's disease is the most common cause of dementia, accounting for around 62% of those with a diagnosis and affecting around 465,000 people in the UK.
Age groups affected	Approximately 98% of people with Alzheimer's disease are over the age of 65 and the risk of developing Alzheimer's disease increases with advancing age. Less commonly, Alzheimer's disease can also develop in younger people, affecting approximately 5,000 people under the age of 65 in the UK.
Typical symptoms	Alzheimer's disease involves a general decline in a range of cognitive abilities. Typical symptoms include poor memory for recent events, impaired concentration, decision-making difficulties, disorientation and difficulty in carrying out everyday tasks.
Progression	Alzheimer's disease is progressive, but the rate of progression differs widely between individuals.

For further information see the Alzheimer's Society factsheet available at: www.alzheimers.org.uk/factsheet/401

Vascular dementia	
Prevalence	Vascular dementia is the second most common type of dementia, affecting around 112,000 people in the UK.
Age groups affected	The risk of vascular dementia increases with age, but it is one of the most common types of dementia among the 15,000 younger people with dementia in the UK.
Typical symptoms	These include problems with concentration and verbal communication, memory problems (though this may not be the first symptom), periods of acute confusion, and epileptic seizures. People with vascular dementia may experience physical symptoms of stroke, such as physical weakness or paralysis. In this type of dementia, people often have good awareness of their difficulties and, partly due to this, depression can be quite common.
Progression	Vascular dementia can often involve a 'stepped' progression, with symptoms remaining at a constant level and then suddenly deteriorating.

Mixed dementia

Some people with dementia have a diagnosis which means that the progressive damage to the brain is being caused by both Alzheimer's disease and vascular dementia.

Module 1 - Understanding Dementia



Remember

Some people may be affected by more than one type of dementia – experiencing the difficulties associated with one type of dementia does not exclude the possibility that the person may also experience the difficulties associated with another type.

Dementia with Lewy bodies	
Prevalence	Dementia with Lewy bodies (DLB) accounts for about 10 % of those with a diagnosis and affects approximately 25,000 people in the UK.
Age groups affected	As with all forms of dementia, it is more prevalent in people over the age of 65, but in rare cases people under 65 may develop DLB.
Typical symptoms	These include, in common with most other dementias, memory loss, shortened attention span, disorientation and verbal communication difficulties. Additionally, people with DLB will often experience Parkinsonian symptoms (for example, tremor and muscle stiffness), visual hallucinations, and fluctuations in symptoms from day to day or within the same day. People may also be prone to fainting or unexplained falls.
Progression	DLB is a progressive disease. This means that over time the symptoms will become worse. In general, DLB progresses at about the same rate as Alzheimer's disease, typically over several years.

For further information see the Alzheimer's Society factsheet available at:
www.alzheimers.org.uk/factsheets

Fronto-temporal dementia	
Prevalence	Fronto-temporal dementia (including Pick's disease) is a relatively rare type of dementia, affecting approximately 11,000 people in the UK.
Age groups affected	Fronto-temporal dementia is more likely to affect people under the age of 65.
Typical symptoms	Earlier on in the condition, it is typical for memory to remain intact, but personality and behaviour tends to change. People may lack insight, lose the capacity to empathise with others, behave in inappropriate, disinhibited or occasional aggressive ways, or become withdrawn and lacking in motivation. Additionally, people will often experience verbal communication difficulties, spatial disorientation, a shortened attention span, and may develop compulsive behaviour, such as over-eating.
Progression	The rate of progression of fronto-temporal dementia varies enormously, ranging from less than two years to more than ten years. As the condition progresses, the damage to the brain becomes more generalised and symptoms become similar to those of Alzheimer's disease.

For further information see the Alzheimer's Society factsheet available at:
www.alzheimers.org.uk/factsheets

Module 1 - Understanding Dementia

Other types of dementia

Approximately 23,000 people in the UK have a rarer form of dementia. Two of these are conditions caused by alcohol: Korsakoff's syndrome and alcohol-related dementia. These are serious brain disorders but will only be progressive if the person continues to drink alcohol. There are some other rarer types of dementia that can be stopped from progressing, including those caused by deficiencies of thyroid hormone, vitamin B12 and folic acid. Most types of dementia are, however, progressive. Some of the more widely known of the rarer dementias include Creutzfeldt-Jakob Disease (CJD) and Huntington's disease. Between 15-30% of people with Parkinson's disease will develop a type of dementia closely resembling Dementia with Lewy bodies.

The effects of dementia on the brain

Every type of dementia involves progressive physical damage to the brain. The main areas affected in most types of dementia are the temporal, parietal and frontal lobes. Damage to each lobe will lead directly to problems related to the function of the particular lobe.

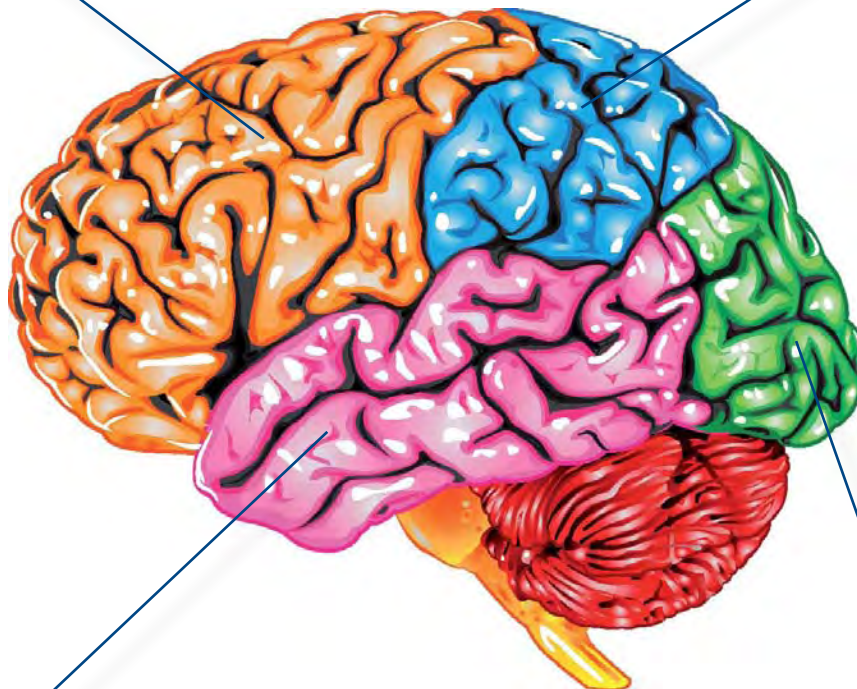
The Brain

Frontal Lobe:

Helps to regulate behaviour

Parietal Lobe:

Organises your body in space



Temporal Lobe:

Stores new information

Occipital Lobe:

Makes sense of visual information

Module 1 - Understanding Dementia

Some examples of the potential impact of damage to specific lobes of the brain are outlined below:

Parietal Lobe

As the Parietal lobe helps people to organise their body in space, damage in this area:

- Can often lead to people having problems in processing visual information, for example, difficulty in recognising faces and objects.
- Can lead to people having problems in carrying out a sequence of actions, for example getting dressed.
- Can affect people's body sense - that is knowing which part of your body is where,
- Can affect people's spatial awareness – this means knowing where objects are relative to their own body.

Frontal Lobe

As the Frontal Lobe helps people to organise and control their behaviour, damage in this area:

- Means a lack of inhibition might develop
- Means people might experience initiating actions difficult
- Means people can experience problems with planning, decision-making and abstract thinking, making it very difficult for a person to make a choices in certain situations
- Means people often experience problems with reasoning.

Temporal Lobe

As the Temporal Lobe helps people to store new information, damage in this area:

- Can cause problems for people in understanding and producing speech
- Can cause problems in remembering recent events
- Can cause problems with more recent memories, but memories from the past can remain intact
- Means people experience a short attention span.

For further information - the Open Dementia Programme from Social Care Institute for Excellence (Module 3) may help you understand the effects of damage in different areas of the brain in dementia. This can be accessed at the following web address <http://www.scie.org.uk/assets/elearning/dementia/dementia03/resource/flash/index.html>

When dementia causes damage to the brain, a person will most likely experience problems with carrying out day-to-day activities. If we understand a little about how the brain works, this can help to explain some of the problems that the person with dementia is facing. Having an accurate diagnosis of the disease or disorder causing the dementia can help us to understand the symptoms and difficulties people might be experiencing. This can be helpful for making plans for the future.

Later in this module we will look at the impact of a diagnosis on people with dementia and their families and carers.

Although the brain damage in dementia is progressive and therefore people's abilities may deteriorate over time, there are many additional factors related to other aspects of people's lives that can influence their journey through dementia both positively and negatively. The role you can play as a worker in improving a person's quality of life will be considered throughout this learning resource.



Remember

Some behaviour changes in dementia are due to damage to the brain. Staff can help and support people with dementia to take steps to help them cope with and compensate for these changes. Staff can also adapt the environment or their own behaviour to help people cope and develop new strategies.



Remember

There are many additional factors related to other aspects of people's lives that can influence their journey through dementia both positively and negatively. There is always the potential for improvement in a person's quality of life.

Module 1 - Understanding Dementia

The dementia journey

Dementia is a journey that has a recognised pathway of progression. The Promoting Excellence framework is designed around this pathway, as the priorities and needs of a person with dementia and their family and carers will differ at different stages of the pathway. Staff need to be able to recognise and respond appropriately to support people with dementia and their families and carers across the whole dementia journey.

Promoting Excellence identifies 4 stages of the dementia journey and these are:

Keeping well, prevention and finding out it's dementia

While acknowledging the life changing impact, challenges and difficulties that often surround receiving a diagnosis of dementia, the framework recognises that receiving a diagnosis is not the starting point for that person in the dementia journey. Striving to prevent the onset of dementia, maintaining good health and maximising well-being are general ambitions for all of us in an ageing and health conscious society.

Diagnosing dementia can be difficult and should be timely to reflect the wishes of the person. It may take some time before it is formally recognised that the difficulties the person is experiencing are in fact due to the development of dementia. However long the process has taken, receiving a diagnosis of dementia is life changing for the person and their family. It can be a frightening and emotional time for everyone involved. It is crucial, that the appropriate services and supports are in place and easily accessible during this stage of the journey.



Remember

“I have the right to a diagnosis”

Standards of Care for Dementia in Scotland (2011)

Living well with dementia

There are many ways to live well with dementia and no two people will experience the journey in the same way, or have the same care or support needs. During this stage of the journey, people with dementia should be fully involved in any decisions about their care and actively encouraged to stay as physically healthy as possible. It is important that people remain as active, independent and in control as their abilities allow and are fully enabled to exercise their rights.

Living well with increasing help and support

As the dementia journey progresses, people will need additional support in carrying out their day to day activities. This support might be from health and social services but these should be flexible enough to complement personal and community supports which surround the person and their family. The necessary support and care provided must be tailored to the needs of the person, including recognising their rights and being respectful of any cultural, spiritual, religious and belief needs they may have.

End of life and dying well

Dementia is a progressive condition. Palliative and end of life care needs for someone who has dementia are often complex. Their families and carers may need a different approach to support them after what may be many years of caring for their loved one.



Remember

No two people will experience dementia in exactly the same way, and people's experience through the various stages of the dementia journey will be unique to them.

Common difficulties people with dementia will experience

Every person is unique and dementia affects people differently - no two people will have symptoms and difficulties that develop in exactly the same way. A person's personality, general health and environmental and social situation are all important factors in determining how this will affect them.

Nevertheless, while no two people will experience dementia in exactly the same way, there are some relatively common symptoms that many people will develop at some point in their dementia journey. In Module 3 we will look at some of the other health and well-being issues experienced by people with dementia.

The following section outlines some of these common symptoms and the experiences of people affected by them.

Memory loss or forgetfulness

One of the most common symptoms of dementia is memory loss, often more noticeable in relation to short term memory. Many people's memory can become a little worse as they grow older and they may notice more frequent memory lapses. However, when someone has dementia, they may experience difficulty in retaining new information or even forget the names of familiar people such as family members, as well as strangers. They may forget appointments, the content of recent conversations or forget whether they have eaten lunch.

George's Story

We met George in the *Informed about Dementia DVD* and here you can learn more about him.

You might like to revisit Chapter 2 of the DVD to remind you about some of the difficulties George has been experiencing.

George is 55 and lives at home. He was married and worked in the housing department of the local council for 30 years until he was retired 12 months ago on the grounds of ill health. Around the same time his wife left him and George has since found it difficult to engage with the community groups he once loved - the community council, the heritage group and the bowling club. He has one son, Barry, who lives with his partner in the north of England. George is very proud of his son and sees him two or three times a year.

George has recently been experiencing difficulties remembering things like GP appointments. In the DVD, we saw that this had been quite frustrating for George but that, with a bit of support from the GP receptionist, he was supported to overcome his memory difficulties in that situation.

Unfortunately George's memory problems were affecting quite a few of his everyday activities. On Barry's recent visit, George's neighbour had mentioned that on a few occasions he had noticed that George had left the front door open when he had gone out and he had sometimes needed to remind George quite late in the evenings that his door was open. Barry had also noticed that there were piles of unpaid bills and unopened letters on the table and out of date food in the fridge. Barry, feeling quite concerned for his father, spoke to George about this situation. George became quite upset but acknowledged that he was forgetting quite a lot of things these days but he did not know what to do about it.



Reflection

1. How did reading about George's difficulties make you feel?
2. How would you feel if you were experiencing these difficulties?
3. How do you think George and his son feel about these difficulties?
4. What problems could be caused by these kinds of memory difficulties?
5. What practical support might people need with correspondence, appointments and household organisation?

Record your answers here:

As the dementia journey progresses, people's problems with their memory will cause them more difficulty. They will often find it difficult to remember what happened only a few hours or minutes earlier but can recall, often very accurately, events from decades ago. Sometimes they may repeat the same question because of their memory difficulties but will be unaware they are doing this. Often the memories that people with dementia hold have strong emotional connections for them they will remain intact although a person may need support in recalling them.

Because people with dementia often have difficulty in remembering recent events, they are more likely to retain memories with strong emotional connections. If they become upset in a particular situation they are likely to retain this feeling even after they have forgotten what happened. If someone has had an enjoyable experience, they may forget what they have done but are likely to remember the pleasant emotions.



Remember

It is important to try to make sure that our contacts and communications with people with dementia are likely to create positive feelings.

Module 1 - Understanding Dementia

Difficulties with everyday tasks

It is common for people with dementia to experience some difficulty in undertaking everyday tasks such as cooking, cleaning, organising or even making a cup of tea. Memory difficulties and other types of cognitive difficulties can impact on people's ability to undertake many routine activities that we would take for granted on a day to day basis.

Ellen's story

We met Ellen in the *Informed about Dementia DVD*

Ellen is 80 and lives at home. Her husband died 6 years ago and she has 3 children and 4 grandchildren. Her sons both live at a distance and her daughter Carolyn lives nearby and visits every evening. While raising her own children, Ellen worked by keeping accounts for her husband John's car repair business and was a treasurer of the local WRVS. She has always been busy and enjoyed using her skills to support the family business and organise their home life and she particularly enjoys cooking.

You are working with Ellen to support her to remain at home. Two days a week when she does not attend the lunch club, you call in to support her with preparing lunch. Ellen has always been a keen cook and usually you just support her to get everything ready for lunch. However, on the last few occasions you have noticed that Ellen has been turning on the gas on the cooker but forgetting to ignite it. On several occasions you have come to the flat and found that Ellen had made herself a cup of tea with cold water.

Carolyn has been round for lunch recently and has told you she has found tins of soup in the oven and burnt toast under the grill at different times, and she is thinking about getting the cooker disconnected because she is worried about her mum.

Reflection

1. How did reading about Ellen and Carolyn's difficulties make you feel?
2. How would you feel if you were experiencing these difficulties?
3. How do you think Ellen would feel about having the gas cut off from the cooker?
4. What do you conclude about the experience for people with dementia who are struggling with everyday tasks?
5. When a person with dementia has difficulty carrying out an everyday task, how do you think you could help?

Record your answers here:

Module 1 - Understanding Dementia

The story we have told about Ellen demonstrates the experiences of a person with dementia who has problems sequencing actions and remembering what they have just done. This can often leave people feeling like a failure and really frustrated.

You may remember from the DVD that Leanne had put up signs for Ellen to try to help her to remember things. This can be useful in some circumstance though it is important not to add to the confusion people might experience with too many signs. Other services and agencies such as occupational therapy can become involved and there are also telehealth-care solutions that can support people to remain independent for longer. We will explore telehealth-care in more detail later in this resource.



Remember

“People with dementia should feel safe and secure and are able to be as independent as possible”

Quality of Life Indicators.
Promoting Excellence (2011)

Difficulties with disorientation and confusion

Gradually, over a period of years, as people progress through the stages of the dementia journey they will experience problems meaning that they become disorientated to the time of day, the place they are in, and the people who are around them. People who have dementia may find they can become lost in environments which were previously very familiar, such as the street where they live. They may forget how they got to a certain place and therefore, how to get back home.

Millie's story

Millie is 85 and has lived in the same small Scottish town all her life, as have her daughters. Millie is part of a close and sociable family. Millie hardly spent any time on her own until the death of her husband 8 years earlier. Millie was very active in the local church and at various stages she led the Sunday school, Guides and Brownies and latterly, the Women's Guild. Participating in the life and work of the Church is very important to Millie.

Millie was diagnosed with Dementia a year ago. She lives alone but receives a lot of support from her two daughters who take it in turns to have her over to their houses on different days during the week, bringing her home in the evenings. Millie's short term memory has been gradually deteriorating and she has become more confused and disoriented. One night last winter she went out late in the pouring rain and was knocking on neighbours doors in a distressed state. Worried neighbours called the police who took her home. After this incident Millie went to stay with one of her daughters for a while but felt frightened to go back home again.

Adapted from a case study provided by Durham local authority
http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=152



Reflection

1. How did reading about Millie's difficulties make you feel?
2. How would you feel if you were experiencing these difficulties?
3. How do you think Millie's family were feeling?
4. What other problems could be caused by experiencing confusion or disorientation?
5. What practical help or support could be given to support someone experiencing these difficulties?

Record your answers here:

As the dementia journey progresses people with dementia may become confused about the time of day. For example this could cause people to get up in the middle of the night wanting to go out. They may fail to recognise people they know well and become distressed or suspicious when apparent strangers try to assist them with tasks. Their ability to think, to reason and to calculate can all become impaired. This can lead to them making decisions which do not appear to make sense, or to experience difficulty in solving problems. Handling money may become problematic if the person finds it difficult to recognise currency, work out their change or they become uncertain about the value of money. Eventually, people with dementia will probably need help with even simple daily activities such as washing, dressing, eating or going to the toilet.

Language and communication difficulties

Communication is a very complex process for us all and many communication skills can pose difficulties for people with dementia. They can experience difficulty in expressing their feelings and opinions. Similarly, people can find it more difficult to understand the communication of others. Some skills people have in expressing themselves can be well preserved, while other aspects of expression can cause them a lot of difficulty. People who have dementia will differ in how their language and communication skills are affected, but there are often similarities in the types of day-to-day communication problems people can experience.

Donald's story

Donald is a 68 year old retired joiner who is married to Sheila. They have 3 children and 4 grandchildren. He has been very active and involved in his local golf club and 20 years ago he was captain of the golf team and was secretary to the club committee for 10 years. Acting as secretary to the committee was a significant part of his life. Donald is very physically fit and has continued to attend the club regularly to play a round of golf. Donald is also a keen reader and is extremely interested in Scottish history. Donald was recently diagnosed with dementia.

Donald has stopped going to the golf club and he and Sheila discuss why this has happened. Donald explains that he does not enjoy it there any more because sometimes when he has been talking to people he has forgotten their names and then halfway through a sentence he has forgotten what he was talking about. He is also having difficulty in marking his score card and when his friends remind him what the score is he sometimes does not seem to be able to follow what they are saying. Donald says he feels stupid and he thinks people are getting annoyed with him.

Reflection

1. How did reading about Donald's difficulties make you feel?
2. How would you feel if you were experiencing these kinds of difficulties?
3. What other problems could be caused by experiencing difficulties in communication?
4. What practical help or support could you give to people experiencing communication difficulties?

Record your answers here:

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As the dementia journey progresses, people's ability to process information becomes slower and more difficult for them and their responses to communication from others can become delayed.

Communication can become frustrating, as the person with dementia struggles to find the right word or uses the wrong word with increasing frequency. They may begin to experience difficulty in holding conversations as they struggle to find the right words to express their thoughts and feelings.

We need to make sure we don't respond unhelpfully to such difficulties, for example:

- Assuming that we know what the person is trying to communicate
- Wrongly completing sentences on their behalf rather than allowing them sufficient time to express themselves.

Negative experiences in communication may result in people with dementia withdrawing from conversations and social interaction, becoming isolated and feeling depressed.

In later modules we will look at person centred ways to ways to support communication with people with dementia.

It is always helpful to consider whether particular difficulties people may be experiencing can, be made worse by unhelpful care or support approaches or a confusing environment.



Remember

We can do a lot to support people to overcome the difficulties they are experiencing by understanding their experiences making simple adaptations to the way we communicate with them and offer support.

Later in this module we will look at the impact of the environment on people with dementia.

Dementia, depression and delirium – you need to know the difference

It is sometimes difficult to distinguish between dementia, delirium and depression. Most people tend to confuse the three conditions, especially delirium and dementia, because they all have symptoms in common. However, older people and people with dementia are more at risk of delirium.



Remember

Older people and people with dementia are more at risk of delirium.

Although it can sometimes come on fairly quickly as a result of a stroke or other brain injury, dementia symptoms are usually progresses slowly. Most common types of dementia begin with subtle symptoms and difficulties which grow more obvious with the passage of time.

Delirium and Dementia

- Delirium develops quickly. There is usually a sudden and significant change in a delirious person, often in a matter of hours. There is a sudden onset of agitation, hallucinations, and rapid changes in a person's level of consciousness. Because delirium is usually a sign that something important and potentially very damaging is occurring, people with delirium need immediate medical attention.
- Delirium can result from an infection, or other physical problems. Unlike dementia, once the physical problem is treated the delirium usually passes.
- People with dementia are more at risk of delirium.

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Remember

Remember people with delirium need **immediate** medical attention.

Depression and Dementia

Because the symptoms of depression and dementia can be similar and can co-exist, an older person with dementia may sometimes be wrongly thought to have depression, and vice versa. But it is important to note that depression is common among people at all stages of their dementia journey.

- In depression, other impairments typical of dementia such as in language, visual perception and ability to orientate themselves in time and space are unusual.
- A depressed person will occasionally complain of an inability to remember things but is more likely to recall information when prompted. In contrast, depending on their diagnosis and severity of symptoms, a person with dementia is less likely to benefit from such cues to aid recall, will tend to experience more significant memory problems and/or lack of insight into these.
- In severe depression, the powers of reasoning and memory may be very badly impacted, and it is this state that is most easily confused with dementia. However, in a person with depression, this impairment is mainly due to poor concentration and the condition is reversible with appropriate treatment or if depression improves spontaneously. This is not the case with dementia.

Self assessment quick quiz

Check whether you have understood the main points so far

Answer true or false to the following questions

1. Alzheimer's disease affects only affects older people.
2. Dementia can cause problems with visual perception.
3. All types of dementia have the same symptoms.
4. Dementia is a progressive condition which has different stages.
5. It is only brain damage that is responsible for the problems experienced by people with dementia.
6. There is nothing that can be done to improve the quality of life of people with dementia.
7. Everyone with dementia will experience it in the same way.
8. Delirium can take years to develop.
9. People cannot have dementia and depression at the same time.



Activity

Design a poster for your work area which can help the staff quickly identify the main distinguishing features of dementia, delirium and depression.

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Below is a summary of the main points so far:

- There are many diseases and disorders which can cause dementia.
- Alzheimer's disease and vascular dementia are by far the most common.
- Alzheimer's disease affects approximately 5,000 people under the age of 65 in the UK.
- Every type of dementia involves a process of progressive damage to the brain which affects people differently at different stages.
- Each lobe of the brain has many different functions and specific difficulties will result from damage to each lobe.
- There are many similarities in the symptoms that occur in different types of dementia, but also some key differences.
- Although there are many common symptoms, each person's experience of these will vary.
- Unhelpful care approaches or a confusing environment can cause problems for people with dementia as well as the damage to the brain.
- Depression and delirium can sometimes be confused with dementia.

What are the protective and risk factors relating to dementia?

Dementia can affect anyone, from bakers to bankers, from politicians to pop stars. There is nothing we can do that will provide total protection against dementia, but there are some things that might decrease the risk of developing it. These are known as protective factors. There are also certain things that could increase our chances of developing dementia. These are known as risk factors.



Activity

How much do you know about the risk factors related to dementia? Take a look at the list of various aspects of life and lifestyle below. Make a note of whether you believe each of them to increase the risk of dementia or whether you think it may help lessen the risk of dementia.

1. Growing old.
2. Occasionally drinking moderate amounts of wine.
3. Taking regular exercise.
4. Having a close relative with dementia.
5. Having high blood pressure.
6. Having Down's syndrome.
7. High blood cholesterol levels.
8. Suffering severe or repeated head injuries.
9. Drinking large amounts of alcohol regularly.
10. Smoking.
11. Eating large amounts of saturated fat.
12. Eating polyunsaturated fatty acids (for example, oily fish).
13. Being obese.
14. Eating fresh fruit and vegetables.

Risk factors are characteristics that appear to have some relationship to the development of a disease. If these risk factors are present, there is an increased likelihood that the disease will develop, though this is by no means a certainty. There are some risk factors that can be modified, for example lowering blood pressure which reduces the risk of a stroke. Other risk factors cannot be modified - for example a person's age or family history.

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Age

Age is the most significant known risk factor for dementia. It is possible to develop dementia early in life, but the chances of developing it increase dramatically as we get older. One in 50 people between the ages of 65 and 70 years have some form of dementia, compared to one in five people over the age of 80 years.

Genetics

There is evidence that the genes we inherit from our parents may contribute to the likelihood of us developing certain diseases. The relationship between our genes and the development of dementia is still not fully understood, but there are some families in which it appears that an increased risk of developing dementia is inherited from one generation to the next. This most often occurs in families where dementia appears relatively early in life. There are specific genes that can affect a person's risk of developing Alzheimer's disease. Nonetheless, having a parent or other close relative with later onset Alzheimer's disease only slightly increases the risk of developing the disease, compared with if there were no cases of dementia in the family at all.

Learning disabilities

Improvements in medical and social care have led to a significant increase in the life expectancy of people with learning disabilities. As with the general population, the effect of ageing on people with learning disabilities (which includes the increased risk of developing dementia) is becoming an increasingly important issue.

People with learning disabilities can be affected by dementia in very similar ways as other people. However, for people with learning disabilities, the early stages of dementia are more likely to be missed or misinterpreted. This can be because the person may find it hard to express their experiences, and communication issues may make it more difficult for others to assess change.

People with Down's syndrome are at particular risk of developing dementia and the prevalence of dementia in people with other forms of learning disability is about four times higher than in the general population.

Physical health conditions

Conditions that affect the heart, arteries or blood circulation can specifically increase a person's chances of developing Vascular Dementia. These conditions include:

- mid-life high blood pressure
- high blood cholesterol levels
- stroke
- diabetes
- heart problems such as a heart attack or irregular heart rhythms
- Mid-life obesity can also increase a person's risk of developing dementia in later life.
- severe or repeated head injuries

Diet

The risk of developing many types of illness, including dementia can be affected by our diet. A healthy and balanced diet that enables a person to maintain a normal body weight is likely to reduce the likelihood of developing high blood pressure or heart disease which, as we saw above, can put a person at greater risk of developing dementia. Too much saturated fat has a negative impact on our vascular system whereas the polyunsaturated fatty acids found in oily fish might also help to protect the heart and blood vessels and lower the risk of developing dementia. Fresh fruit and vegetables contain many vitamins and antioxidants, which may prevent heart disease and protect the brain.

Smoking

Smoking has an extremely harmful effect on the heart, lungs and vascular system, including the blood vessels in the brain. Smoking increases the risk of developing Vascular Dementia.

Alcohol

Prolonged periods of excessive alcohol intake or regular consumption beyond recommended safe limits, can increase our risk of developing some types of dementia.

Physical exercise

Regular physical exercise helps to keep the heart and vascular system healthy, which can help to reduce our risk of developing Vascular Dementia.



Activity

Design a leaflet for your work area which can help to promote healthy lifestyle behaviour that can reduce the likelihood of developing some types of dementia.



Remember

The same health behaviour that can protect against peoples' likelihood of developing dementia can also positively influence people to be able to live well with dementia.

In later modules we will explore approaches to promoting health and well-being for people with dementia.

The impact of a diagnosis of dementia

There is considerable evidence to show that receiving a diagnosis of dementia can be very helpful for a number of reasons. These include:

- More time for the person with the dementia diagnosis and their families to come to terms with and adjust to the diagnosis.
- More time to consider and provide care and treatment options to improve functioning and quality of life.
- More time for the person with the diagnosis and their carers to make future plans and arrangements (especially regarding financial and legal matters) before the condition becomes more severe.
- Enabling better use of specialist services such as dementia services, geriatric medicine, and neurology
- Preventing or delaying transition into institutional care.

Out of the shadows
Alzheimer's Society (2008)

In later modules we will discuss early interventions which can promote the best possible health and well-being and quality of life following a diagnosis of dementia.

It is important that we remember that the impact of a diagnosis of dementia on the person and their families and carers may be difficult to predict and there are a range of factors that can have an effect. These appear to relate to the individual's own personality, background and circumstances, as well as the way in which the diagnosis is provided. For some people, a diagnosis of dementia comes as a shock, whereas for others it can confirm their suspicions and provide relief in receiving confirmation regarding what is happening. People can experience a range of emotions including feeling numb, frightened, angry, worried, sad, guilty or frustrated. However, some people may also feel relieved to find there is a medical reason for their memory problems.

People with dementia may sometimes find it difficult to recognise or explain their emotions, particularly if they are already experiencing difficulty finding words. If you are working with someone who has recently been diagnosed with dementia it is important to:

- Be sensitive to what the person may be feeling.
- Pay attention to verbal and non-verbal signs of emotion.
- Support the person, acknowledging that this is a difficult time for them.
- Reassure the person where possible and/or appropriate.

Sometimes it is natural for us to want to make the person feel better but unfortunately, at times, well-intentioned comments or actions may not be helpful. For example, telling a person with a diagnosis of dementia that they should try not to feel sad or that they have nothing to worry about is unlikely to be helpful and has the potential to make their distress worse. Imagine how you would feel in a similar situation. It is quite possible that the person will simply think that you do not understand how they feel or what they might be experiencing.

Always be aware that a diagnosis of dementia is also likely to affect the person's family and carers. They may quite often have been the first to notice that something is wrong. For some people, it is a long-awaited explanation after weeks, months or years of

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worry, consultations and tests. For others, this news may come as a complete shock.



Remember

When people receive a diagnosis of dementia it can affect them in different ways. It is important to respond sensitively – and this applies to families and carers as well.

The impact of dementia on communication

Communicating positively with people with dementia is important in supporting the best quality of life for them and their families and carers. It is important to identify a person's communication strengths and weaknesses, and how to minimise any potential barriers to effective communication. We need to consider which factors are due to dementia, including language difficulties, and consider how these might affect quality of life for individuals.

The effects of dementia on language can include:

- choosing incorrect words to name items or express thoughts or feelings.
- the use of single words rather than more detailed phrases or complete sentences.
- difficulties in pronunciation.
- replacing words with others that are similar in meaning or sound, but which do not effectively convey the meaning the person had intended.
- difficulty in following a conversation, particularly where there are a number of individuals involved.
- difficulty understanding the meaning of words and phrases spoken by other people.
- reduced concentration leading to the person with dementia being more easily distracted.
- where English is a person's second language, this can increase the likelihood that they may forget the meaning of words in this second language.

Additionally, we should distinguish which other factors can be barriers to communication.

The other factors can include:

- inappropriate environment – physical, social or care.
- boredom.
- effects of medication.
- inappropriate communication from others.
- abuse.
- apathy.
- fear.
- pain.
- aggression from others.
- mental health issues.
- other medical issues e.g. results of strokes, Parkinson's disease.
- inappropriate dentures.
- sight or hearing difficulties.

Communication skills are progressively affected as dementia develops in the person. In the early stages, there may be difficulty in finding words and the person may try to talk around the word they are looking for, to convey meaning. They may be less fluent and communicating may require more thought and effort from them. The loss of language skills for the person with dementia starts with those words we use least and those we learned last.

As dementia progresses, the person may develop a range of more specific language problems. Some people experience expressive dysphasia, this means they may understand what is said to them but experience difficulty in expressing this understanding or conveying their response. They may also develop receptive dysphasia, where they find it difficult to understand what is being said to them.

It may be the case that as the dementia journey progresses and the person's ability to communicate diminishes, their ability to process information deteriorates and their responses can be delayed. People may become less likely to initiate conversation under these circumstances.

Sometimes we may wrongly think that if the person with dementia does not understand it will not matter if we talk about them while they are there. We may believe that even if the person does comprehend something of what is being said, that they will forget about it in five minutes. However, our body language and gestures are likely to be understood and the person with dementia could be aware that they are being talked about, even if they do not fully grasp the meaning of what is said. This can be upsetting and it is possible that they will continue to feel upset long after they have forgotten why.

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Each person will experience the dementia journey in their own way. These unique experiences will therefore impact on their ability to communicate and this will change over the different stages of their journey.

For people to live well with dementia and experience the best quality of life possible, person centred approaches which support positive communication and involve the person, their families and carers should be used.

In Module 2 we will explore person centred approaches to communication and in Module 4 we look at communicating with people with dementia when they are distressed.

The impact of the environment on people with dementia

The environments where we support and care for people with dementia are complex and can have a profound affect on the quality of life people experience. They involve many inter-related aspects which initially might not appear relevant until explored and fully understood. It is important however to understand that it is not only the physical environment that merits our attention, but that other aspects also impact on our lives and particularly for people with dementia.



Activity

In what ways do you think the environment where you work could impact on the person with dementia? Think of both positive and negative impacts.

Now ask someone with dementia (and their carer if appropriate) who uses your service, what they think about the environment and assess your thoughts in light of their responses.

Is there anything you should change as a result?

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The physical environment

Living well with dementia can pose significant challenges. Something that might seem simple to the person without cognitive impairment can feel difficult, frustrating, confusing and even frightening for someone with dementia. This is why the environment should be assessed and modified, sometimes in very simple ways, to promote independence and quality of life for people with dementia. A well designed environment can make a big difference to how a person with dementia can manage their daily activities and therefore their quality of life.



Remember

“I have the right to be as independent as possible and be included in my community”.

The Standards of Care for Dementia in Scotland (2011)

It is crucial that the environment is enabling and is not a barrier for the person with dementia. Neither should it isolate them, in fact, the physical environment can play an important part in improving the lives of people with dementia by complementing treatments, supporting people to maintain the use of their abilities and helping them to cope with difficulties such as impaired memory and loss of reasoning and learning skills. A few simple changes can have a significant, positive impact.

In creating a safe, relaxing and calm area designed to reduce stress levels and maximise independence for as long as possible, some of the areas you will want to consider are:

- Décor – use of colours, furnishings.
- Signage.
- Lighting.
- Noise levels and the use of noise absorbing materials.
- Stimulation, exercise and activity.
- Private and communal space uses.
- Use of assistive technology.

A useful website to visit to help you explore this

area is: www.scie.org.uk/publications/dementia/environment/index.asp

Where it is important to create environments which are safe and secure, it is also important to adopt positive approaches to risk for people with dementia and environmental changes can minimise risks while, at the same time, maximising independence.

The social and cultural environment

Social and cultural environmental factors can also have a profound effect on well-being, morale and self confidence and, when well considered, can support people to flourish.

What do you need to consider when trying to create a social and cultural environment which is physically, psychologically and emotionally beneficial for people with dementia?

Such an environment would have opportunities for:

- Independence and participation in carrying out activities and self care.
- Personalised care and attention and providing for unique needs.
- Stimulation, exercise and activities meaningful to the individual.
- Social interaction and continuing links with the community.

Some of the wider aspects which also impact on the social and cultural environment are the attitudes of staff.

There is more information about the social and physical environment, and about risk enablement in later modules.

Promoting equality and respecting diversity when working with people with dementia

Dementia can affect anyone from any background, socioeconomic group, culture, religion and as we saw in the previous section, at a range of ages. Dementia can also affect people alongside other conditions including physical and mental health conditions and learning or physical disabilities.

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Equality and diversity is about the whole person, it is an integral part of a person's well-being and is key to ensuring that we provide person centred care and support.

Equality is about ensuring that people are treated fairly according to their needs and making this normal practice and behaviour. Diversity is about respecting differences.

Respecting diversity includes respecting a person's spiritual, cultural and religious beliefs. Spirituality could be described as the need for meaning and value. Recognising specific needs of people from different religions/beliefs as well as from the same religion/belief helps in developing a person centred service.

Recent research suggests that an individual's experience of dementia is informed by their cultural background, core values and beliefs. This calls for a culturally sensitive approach to dementia support and care (Downs, 2000 (1) Hashmi 2009 (2), Laurence et al 2011(3)). It is critical therefore that staff consider the experience of the person with dementia within its cultural context and provide culturally appropriate care and support.

However it is always important to identify individual needs and preferences and not assume that all people who speak the same language practice the same religion, or that all people following the same religion practice the same rituals or share the same beliefs.



Activity

What do you think you might need to do to ensure that you promote equality and respect the diversity of people with dementia you work with?

Record your answers here:

Age

Age can be a barrier to appropriate support and care. Younger people with dementia can often feel that they are made to fit into a service, rather than the service being appropriate to their needs. Sometimes no specialist services exist, and younger people with dementia can find themselves lost in an inflexible system that does not accept responsibility for their support and care.

Younger people with dementia that you work with are more likely to:

- have a job at the time of diagnosis.
- have a family, including children.
- be more physically fit and active.
- have financial commitments such as a mortgage or supporting children through university.

It is important to remember that younger people with dementia are likely to have different priorities and interests to older people. Person centred support should take account of the individual priorities, interest and needs at whatever age. We will explore person centred care in Module 2.

For children and young people in families where someone is living with dementia it can be particularly difficult. This can also be a cause of concern for the person with dementia and their carer. It is important that the whole family is supported and you can find some useful guidance at Alzheimer's Society at the following link http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=108.

People with a learning disability and dementia

People with a learning disability who are also living with dementia may not fully understand what is happening to them. Careful thought and planning by support staff should ensure that familiar language is used to explain changes. The person may be living with other residents or a partner with a learning disability when they receive their diagnosis. It is important to consider the impact of dementia on these people, as well as on the person receiving the diagnosis. It is important for staff and families and carers to gain access to specialist help, support and services.

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Top ten tips to support equality and diversity

- Identify and support the cultural, language and spiritual needs of people with dementia in all care plans and reviews.
- Consider the different cultural understandings of dementia when discussing the subject with people with dementia and their families and carers.
- Make sure that our communication reflects appropriate cultural, spiritual and religious values and beliefs
- Provide people with dementia and their families with information in their preferred language or format.
- Make sure that cultural diversity is reflected in all services, including health and personal care and food services.
- Identify and support the spiritual needs of your care recipients, including current and desired religious practices and beliefs,
- Make sure that people with dementia have access to culturally appropriate emotional and spiritual support.
- Support people with dementia to engage with activities and therapies to support cultural, spiritual and religious values and beliefs.
- Make sure that the living environment is appropriate to support cultural, spiritual and religious values and beliefs.
- Use professional interpreting services familiar with the care setting for dementia assessments.

To support inclusion, equality and diversity, the availability of accessible information is key to providing people with choice and control and ensuring people who use services know their rights. To ensure information is equally accessible to all people, it is important that we provide information in a range of ways and formats. This includes face to face, by telephone, online, written information in a variety of languages and formats, and services which meet the needs of people with a hearing and/or sight impairment.

We do not like the terms “dementia sufferer” or “suffering from dementia”, or “dementia victim”. These are demeaning and portray us in a negative light.

You would not want your loved ones spoken about in such disparaging terms. Sadly the media love these terms, despite my protests, and I cannot blame people for being misled into using derogatory language also.

I did likewise at one time, and could kick myself for my insensitivity. Use “person with dementia”, or “people with dementia”, or “affected by dementia” please. Thank you.

Mr. James McKillop
A person with dementia



Remember

“I have the right to be regarded as a unique individual and to be treated with dignity and respect.”

The Standards of Care for Dementia in Scotland (2011)

Module 1 - Understanding Dementia

Module summary

In this module, we have built a foundation of knowledge about dementia on which the following 4 modules will be built. We have examined some of the more common types of dementia, their prevalence, how they affect the brain, and what signs, symptoms and difficulties people are likely to experience as a result.

We have also looked at the range of factors that can increase or decrease the risk of developing dementia. We have considered the impact of a diagnosis of dementia. We have explored the impact of dementia on people's communication skills and the impact of the environment on people with dementia. Finally, we have considered the importance of equality and diversity in dementia care and support.

Action into practice

From your learning in this module

- Make a note of three new things you have learned about dementia and about people with dementia and their families and carers
- Make a note of three areas of dementia practice you would like to learn more about as you continue through this learning resource
- Make a note of three changes you could make that you feel could enhance your practice.

When you have completed your journey through this learning resource, return to your notes and check whether you have achieved the second and third points.

Module 1 - Understanding Dementia

References

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**Module 2:
Promoting Person and Family Centred
Care and Community Connections**

Module 2 - Promoting Person and Family Centred Care and Community Connections

Introduction

The term 'person centred' is widely used by those who work in health and social care settings. The approach places an emphasis on seeing the person as an individual with unique qualities and strengths, personal history and personality. Most important of all is how the approach ensures the person with dementia is the focus of our attention and not the dementia itself.

In this module we will explore elements of person centred care in more detail. We consider how we can support people with dementia to remain connected with valued lives and communities. We explore strengths and assets based approaches and the different ways, including self directed support and telehealthcare, that can be used to support people with dementia continue to live independent lives for as long as possible and to improve their quality of life throughout their dementia journey.

Learning outcomes

By the end of this module you should be able to:

1. Describe what is meant by a person centred approach
2. Identify the role of Life Story Work in supporting the quality of life for people with dementia their families and carers.
3. Identify and explain the relationship between person centred care and support and personalised services.
4. Describe approaches to supporting people with dementia to maintain their social networks and community connections

What is person centred care?

In the introduction to this resource we mentioned the *Promoting Excellence* framework and the *Standards of Care for Dementia in Scotland*.

The Standards of Care for Dementia in Scotland were developed to help people with dementia and their carers understand their rights and how they can help to make sure that they are supported and are listened to. These will be explored further in Module 5. The *Promoting Excellence* Framework is designed to ensure that staff have the knowledge and skills to work in a human rights based way that improves peoples quality of life. The Framework identifies key outcome indicators of quality of life (QoL) for people with dementia and their families and carers.

Module 2 - Promoting Person and Family Centred Care and Community Connections

Consider the Standards of Care and QoL Indicators below:

Standards of care for dementia domains	QoL outcome indicators
<ul style="list-style-type: none">• I have the right to a diagnosis• I have the right to be regarded as a unique individual and to be treated with dignity and respect• I have the right to access a range of treatment and supports• I have the right to end-of-life care that respects my wishes• I have the right to be as independent as possible and to be included in my community• I have the right to have carers who are well supported and educated about dementia	<ul style="list-style-type: none">• People with dementia have access to a timely and accurate diagnosis of dementia• People with dementia feel empowered and enabled to exercise rights and choice, maintain their identity and to be treated with dignity and equity• People with dementia maintain their best level of physical, mental, social and emotional well-being• People with dementia have access to individuals, groups and organisations that can support their spiritual or personal beliefs and reflect their cultural wishes• People with dementia have access to quality services and can continue to participate in community life and valued activities• People with dementia feel safe and secure and are able to be as independent as possible• People with dementia are able to maintain valued relationships and networks and have the opportunity to develop new ones, both personal and professional• People with dementia and their family, friends and carers have access to information, education and support that enhances the well-being of the person with dementia and those that support them



Activity

Imagine you have just received a diagnosis of dementia. Which of the standards or QoL indicators would you consider to be of particular importance to you, and why?

Think about a person you know with dementia. To what extent are the standards and QoL indicators like those outlined above being applied to shape his or her care and support?

Record your answers here:

Module 2 - Promoting Person and Family Centred Care and Community Connections

To enable workers to ensure the Standards and Quality of Life Indicators are implemented in practice, and to promote the best quality of life possible for people with dementia and their families and carers it is important that the care and support we deliver is person and family centred and based on the outcomes that are important to people



Activity

What is your understanding of person centred care?

How would you recognise person centred care in practice?

Record your answers here:

The philosophy of person centred care originally comes from the work of Carl Rogers and has since been further developed by others including the psychologist Professor Tom Kitwood. He was the first to write about person centred care in relation to dementia and his work remains a major influence today. He first introduced the concept of 'personhood' (which is the essence of who we are) in the 1990s stressing that the pace at which the person's dementia progressed was greatly influenced by how

they were treated by people and society. He saw 'person centred' approaches as ways of working with the lived experience of the person with dementia that emphasised communication and relationships. This approach has been further developed and become the cornerstone of many policy and practice initiatives. If we are to practice in a truly person centred way then we need to have a deeper understanding of what it means.

Reflection

Think about you own role

1. Do you think that you have a person centred approach?
2. What do you think are the main elements that make your approach person centred?

Record your answers here:

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There are many different approaches to person centred care and this can be confusing. For this module we will be using a model based on a review carried out by Brooker (2004) (1). She concluded that most approaches are essentially made up of four key elements which are:

Key elements of person centred care

Valuing people with dementia and those who care for them and promoting their rights and entitlements regardless of age or cognitive ability.

Treating the person with dementia as an individual; appreciate that the person has a unique history, personality and life experience that will affect their response to dementia.

Taking the perspective of the person with dementia; recognise that it is this perspective and experience that will influence how the person acts.

Supporting the person's social environment; recognising the importance of relationships and a positive social environment to support psychological well-being.

We will now look at each element in turn and explore how they can guide our practice.

Valuing people with dementia

Valuing people is at the heart of person centred care and underpins how the other three elements are put into practice. It is about recognising that people with dementia and their families and carers have the same rights as everyone else in our society.



Remember

“I have the right to be regarded as a unique individual and to be treated with dignity and respect.”

The Standards of Care for Dementia in Scotland (2011)

Until recently people with dementia have been portrayed in the media very negatively, and services and resources were not set up to meet their needs. This has often led to people with dementia, their families and carers feeling stigmatised and excluded from their communities. These feelings increase as social contact, meaningful activities and experiences diminish and can lead to feelings of isolation, loneliness and a sense of being worthless. Some people with dementia may have stopped doing things in their community because they were wary of the attitude and reaction of others.

Changes in the policy focus in health and social care over the last few years has meant that people with dementia, families and carers, staff, and services are moving towards 'strengths and asset based' approaches which utilise their own personal and community resources. This enables people with dementia to be much more involved in decisions about their own care, treatment and support than was the case in the past.

This is reflected in the **personalisation agenda** which is defined as a way of working with people that “... enables the individual alone, or in groups, to find the right solutions for them and to participate in the delivery of a service. From being a recipient of services, citizens can become actively involved in selecting and shaping the services they receive.”(Scottish Government 2009)(2).

We can support strengths based approaches by focusing on what the person is able to do rather than what they cannot do. This means moving away from a focus on people with “problems” towards working with the person, their family and carers to identify their strengths and abilities. We need to see them as the same person who is able to contribute within their

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existing role within their family, social networks and communities.

People with dementia may need to make a range of adjustments to their life because of dementia throughout their journey but it is important that we support them to continue to engage in as many of their previous activities as independently as possible for as long as possible.

For people with dementia their life history and experience can be used to support this when they are no longer able to communicate with us verbally. Taking strengths based approaches a step further is recognising the value of networks, social connections and community based supports and this is referred to as an **assets based approach**. Supporting and enabling the person with dementia to contribute and remain included in their community rather than as someone who only receives services can not only help them to feel valued but it can also contribute to maintaining and promoting their identity and self esteem.

The reflection section is contained within a light blue rectangular area. At the top, the word 'Reflection' is written in a bold, dark blue font inside a white, cloud-like thought bubble. Below this, three smaller white thought bubbles are arranged in a descending line from right to left. The main text of the reflection section consists of three numbered questions and a prompt to record answers, all in a dark blue font.

Reflection

1. Think about some community based activities that you engage in.
2. How would you feel if you were unable to do these activities anymore?
3. Do you think this would impact on your own view of yourself as a valued person?

Record your answers here:

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We need to recognise that the person with dementia has the same right to access opportunities and relationships as we all do and we should find creative ways to support and assist them to remain included. We may not intentionally exclude someone and it can happen very slowly, and it can sometimes be difficult to realise its full impact.

Donald's story

You may remember in Module 1 we met Donald and heard that he had stopped going to the golf club because of his embarrassment about his memory and communication difficulties.

Imagine the following future for Donald:

Sheila had persuaded Donald to return to the golf club where he had continued to attend for a few weeks but recently he had taken a wrong turning on the way and been late for a game. Well-meaning friends and relatives were concerned about him walking alone to the club, so slowly he stopped attending as frequently. As his difficulties become a bit more challenging for others to understand or deal with they stopped inviting him to social events or to play in competitions.

If you were to carry on with this story you can see how, over time, this way of limiting Donald's involvement and lowering of expectations could lead to him being excluded from both his former social connections and an important activity in his life. Imagine the impact this could have on his life and well-being.

Later in this module we will explore a range of ways that people with dementia can be supported to be involved in their communities.

In our day to day contact with people with dementia we must show that we value people by treating them with dignity and respect and ensuring that we support them to meet their needs, and respect their wishes and aspirations.

Ellen's story

You may remember Ellen who we met in the *Informed about Dementia DVD*.

You might like to revisit Ellen in the DVD to remind you of her story.

Ellen is getting ready to attend the lunch club, her support worker has helped her get organised and Leanne from the lunch club arrives and both begin to engage in a conversation across Ellen. Leanne asks how Ellen has been and the support worker replies "She's not too bad, no screeching or being a nuisance today".

Reflection

Imagine you are Ellen: How would these comments make you feel?

Would this make you feel valued?

What would you do differently that showed that you valued Ellen?

Record your answers here:

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It is easy to see how disrespectful this behaviour was in this scenario and how it shows a disregard for Ellen as a person which would not have made her feel valued. Unfortunately this is sometimes how people with dementia are treated particularly as their dementia progresses.

Leanne should have addressed Ellen directly and asked how she was and allowed her time to reply. If the support worker felt she needed to comment she should have again included Ellen in this by way of recalling how their morning has been in a supportive and sensitive manner.

Valuing the person with dementia as an individual

Taking an individualised approach to working with a person with dementia and their families and carers is the most important element of a person centred approach; this involves valuing the unique person and seeing their dementia as only one part of this picture.

We do this by considering their;

- Personal history,
- Personal experience
- Personality
- Aspirations
- Strengths
- Fears
- Priorities and preferences

Knowing the person with dementia



Activity

Does knowing the person has dementia affect our view of them as a person?

Read the introduction to the 3 people below and decide who you think has dementia

“Hello, I am Ryan, I am 62 years old and have recently retired from working as a Pharmacist in my local town. I enjoy golf but do not get to play as often as I would like to.”

“Hello I am Anne, I am 52 years old and have recently taken early retirement from my job in the bank. I am moving to London to live with my daughter. I enjoy playing bridge and hope I will be able to continue when I move”.

“Hello, I am Marie, I am 74 years old, and married with 2 grown up children. I have enjoyed motor sport all my life both as a job and as a hobby. I particularly enjoyed off road trials and lead my team in many recovery competitions and continue to participate in club training events”.

Were you able to decide who had dementia?

What assumptions did you make?

Record your answers here:

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There is no right answer as it could be the case that any of these people or none of them have dementia. Often we make assumptions about a person's life when they have dementia. For example we may think that they cannot experience quality of life or participate in activities they have always enjoyed.

If we know the stories from a person's life it becomes much easier for us to see the person behind their dementia. When you hear about someone's life history it can become clear that they have had many valued roles. We are often defined by our roles: wife, father, support worker, musician and so on and we may have several roles at any time. We need to be aware of people's roles, both past and present and provide opportunities for them to use skills and past experience.

Finding out about the person can take many different forms but life story books with different sections and photographs as well as memory boxes with objects that are special to the person are frequently used. The benefit of recording someone's life story is that it can later be used to communicate the person's wishes, hopes and aspirations when they are no longer able to communicate them.

The main advantages of life story work

- It helps us to have a better understanding of the causes of someone's behaviour or their distress.
- It enables us to give the person what they want and need rather than guessing.
- It allows us to support the person to engage in activities that are of interest and are meaningful to them. A person may have advanced dementia but they are still able to engage to some extent in something that has held a great interest to them. Dementia changes a person's ability to interact with their environment but the person is still there.
- It enables us to form relationships based upon understanding and empathy.
- It can provide the basis of assessment of risk and risk enablement across a range of situations and knowing what is important to the person.

Supporting the person to write their story can also be a very therapeutic in developing a trusting relationship with them. It should encourage a relationship centred approach which recognises the relationships that the person has with others. Writing a life story should involve the person with dementia, their family, carers and service providers. This can then lead to them identifying a **circle of support** which could include family, friends, professionals and others who person with dementia consider to be important to them. This circle of support should also include all those assets identified within the person's community.



Remember

“People with dementia feel empowered and enabled to exercise rights and choice, maintain their identity and to be treated with dignity and equity”

Quality of Life Indicators.
Promoting Excellence (2011)

Someone's life story is best started as soon as practical after the person is diagnosed with dementia, but this must be **when the person is ready** and wants to consider it and it must be developed at a **pace that suits them** as this is a continuous process that is developed over time.

A timely diagnosis of dementia can allow the person to begin to plan for the future and they should be supported to undertake '**advanced planning**'. This means that the person can think about, discuss and record their wishes and decisions for future care and their life story can be developed at the same time.

Some people with dementia and their families and carers may be unaware of advance plans and it is important that we inform them about them and their benefits. It is important to remember that only decisions made by the person can be included in the advanced care plan. It is also important that palliative and end of life care planning is discussed as early as the person with dementia wants and is included in any plans. The plans can include advance statements, personal statements and appointing others to take decisions on their behalf when they no longer have capacity to do so which we explore further in Module 5

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The template below has been adapted and is a shorter version of one created by Alzheimer Europe:

Statement of values

Preferences

The things I like to wear, eat, drink, my friends, music, hobbies or pastimes, special interests, what items I have around me.

My spiritual and philosophical beliefs

What helps give your life purpose meaning and direction

What makes life worth living

What makes me the sort of person I am and the things that have special meaning in my life.

Dislikes

Things that I do not like to do, do not like others around me doing, or do not like about my environment.

What I fear most

What might take away the pleasure from my life, or cause it to lose its meaning or quality, making me fearful, anxious or distressed.

Attitudes to making decisions

How I like to make decisions – independent-minded or tend to depend on the advice of others.

People who matter

How and who I would like to be involved if I am not capable of making certain decision and the people I do not want involved.

My attitudes to professionals who are treating me and caring for me

My relationships with doctors, nurses or others in the other caring professions, especially the degree to which I tend to rely on their judgements.

Attitudes to illness and disability

How I might cope with illness, disability, pain and discomfort.

Attitudes to death and dying

My view on giving and withholding treatment that may hasten or delay my death. Where I would like to be and whom I would like to have around me.

After my death

My wishes for example, about who to inform about my funeral.

Other values

My values, not mentioned before, but which are important to me.

Reflection

Take some time to consider what is important to you and write your own statement of values using this template.

If you were going to share it with someone you felt should know- how would you feel about sharing this information?

Record your thoughts here:

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Activity

How would you encourage and support a person you work with to complete their Statement of Values?

Record your answers here:

We would encourage you to view the full version of the Statement of Values available on Alzheimer Scotland website:

<http://www.alzscot.org/pages/info/makingdecisions.htm#values>

When we consider what it means to treat the person with dementia as an individual we are looking at assessing and reviewing their strengths and needs so that we can support their plan of care throughout their journey. However it is important to realise that the person's dementia journey begins before their diagnosis. Receiving a diagnosis of dementia needs to be supported by specialist dementia workers.

If you are working with someone who has recently been diagnosed with dementia you could offer the person with dementia and their family written information and signpost them to resources such as Living Well with Dementia and Coping with Dementia which are available from NHS Health Scotland. Other information

sources would include libraries and voluntary organisations such as Alzheimer's Scotland.

You should be aware that this is a sensitive time for the person with dementia and their families and carers so it is important to ensure that this is the appropriate time and circumstance. If you have any concerns you should seek advice from your manager or if you do not have a manager your local Alzheimer's organisation may be able to offer support and advice.

People also should be supported for an extended period after their diagnosis to enable and empower the person with dementia, their family and carers to plan and take control of the services they need.

Alzheimer Scotland have described **5 pillars of support** which everyone must be offered in the time after a diagnosis.

Five pillars of post diagnostic support

Help to understand dementia and manage their symptoms – by providing accessible information for the person their families and carers to help them to come to terms with dementia and learn to self manage (explored further in Module 3).

Support people to stay connected to their community – this includes all of the elements of supporting relationships and inclusion, strengths and assets based approaches, mentioned earlier.

Peer support from other people with dementia and their families and carers – this is highly effective in helping people come to terms with their dementia, find coping strategies, and maintain their well-being. An example of peer support is the Scottish Dementia Working Group. You can find out more about them at their website <http://www.sdwg.org.uk/>

Help to plan for their future decision-making – this includes all the advanced planning described earlier.

Support to plan the shape of their future care from their own perspective - together with those around them, developing a personal plan with their choices, hopes and aspirations. This can help the person with dementia to think creatively about the support they might require and about how the people

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around them can offer support. This approach uses techniques to place these hopes and personal outcomes at the centre of practice. It goes beyond person centred approaches and converts the person's hopes into a live plan, with a series of goals, steps and outcomes that all those involved in that person's life will help to support.

As the person progresses to the later stages of the dementia journey it is important that we find out if they have developed advanced plans and life stories. Even if they have not got plans in place we can still get to know the person and identify their needs wishes and aspirations. Gradually through communicating with the person more information can be discovered about their life experience. We can take opportunities, particularly through songs, music, films and key events from history that are from the person's childhood and teenage years to bring to mind memories from that time.



Remember

It is not possible to work in a way that is person centred without taking an individualised approach but it is possible to do individualised care that is not person centred (Brooker 2007).

Often a person who is in the later stages of the dementia journey can recall childhood and teenage memories but not recent memories.

They may be confused and respond to something that is happening now because they are linking it to the past. It may be related to many things such as, their work, family or home. For this reason we also need to be aware of past traumatic or negative experiences as they can be relived as dementia progresses, in the same way positive ones are, but are more likely to lead to distress.

When a person does not have a care plan May et al (2009) (3) have suggested a useful template to help us to gather information to support person centred planning:

Elements required for developing a person centred care plan

Biography or life history	Where did the person grow up? What jobs did the person have? Who is in the person's family?
Personality	What they are like as a person? What motivates the person? What influences the person's mood?
How the person is responding to their current situation	Does the person appear distressed, anxious, withdrawn? Is the person happy and calm?
Capacity for doing	What are the person's strengths What are the person's abilities
Health and Cognitive support needs	How the person behaves How the person thinks How the person communicates How the person relates to the world and everything around them

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Below are some examples of the ways in which understanding the person's life story can help us to understand a person's behaviour: Cover up the right hand side of the table and read the behaviours first. Imagine how you would react caring for this person, then read the snapshot life history.

Behaviour	Snapshot life story
Fred went around the unit at night switching all the lights off and would scold the night staff for being up.	Fred was a night security worker at a coal mine all his life and was just doing his job.
Mary would search the unit for her children constantly and would gain great joy when a visitor brought a new born baby to the unit.	Mary had a large family, totalling 12 children, some of whom died as babies.
Joanne would get up at 4am and try to leave the unit stating she needed to go to work.	Again, Joanne was going to start milking the cows, something she had done all her married life.
Lewis hit out at staff whenever he required assistance to go to the toilet. He became upset, angry, swore and tried to use his fists against staff.	Lewis was an adult survivor of repeated and prolonged childhood sexual abuse.

Reflection

How do you feel about your initial thoughts about the people described above now?

Would you approach their care differently with this snapshot?

Record your answers here:

These examples emphasise the need to ensure the person's life story and advance plans are not just developed, but that they should be used all the time to help to develop positive partnership relationships with the person, their family and carers to ensure that the person is engaged in activities that are meaningful to them.

Taking the perspective of the person with dementia

When we are working with people with dementia in a person centred way we need to be able to see the world from their point of view. We can do this through effective communication, empathy and relating directly to them to understand their individual needs. This will give focus to all our interactions with them and support the person's social and spiritual engagement to live their life to the fullest throughout their journey. When the person engages in experiences that are meaningful to them it allows them to express themselves, to connect with others and contributes to a good quality of life as well as improving their health and well-being.

In the earlier stages of dementia the person is able to tell us what activities they wish to engage in and they should be supported to continue to engage in them for as long as possible. This can enable people to continue to live well with their dementia for longer. As their dementia journey progresses the person may find it more difficult to initiate and sustain activities, and may need assistance in getting started or choosing an activity. They may also need step by step instruction and prompting. Having a life story can help us to support people to engage in activities that are truly meaningful activities rather than set activities that everyone is

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expected to participate in. Engaging in physical and social activity has been found to improve physical, mental, emotional and social well-being

Why are activities so important?

Participating in activities can help to maintain physical fitness, prevent frustration, boredom and distressed behaviours.

Activities can:

- help the person maintain their independence
- help maintain skills
- improve self esteem
- improve the quality of life for the person with dementia
- often compensate for lost abilities
- allow the person to express their feelings, through art, music, singing and dance
- provide social contact through social activities and outings,
- help to maintain social and family contacts and networks



Activity

What kind of activities do you engage with people you work with?

How do you think you could improve them?

Record your answers here:

Reflection

Think of a song, piece of music or singer you do not like listening to.

Sit in a room for at least 30 minutes listening to it. Imagine being subjected to it day in, day out over years.

How would you respond if you were unable to leave the room without assistance and you could not ask?

Record your answers here:

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As we saw with Jim in the **Informed about Dementia DVD** it is important to find imaginative and creative approaches to enable the person to engage in something they like and they will be able to engage in even if their capacity to understand language is severely limited.

We should always ask the person's permission before any intervention or activity, even when someone has advanced dementia. This lets them know that we respect them as individuals and supports them to maintain their identity. The person may not be able to make major decisions but they can be supported to make day to day choices such as, what they want to eat and drink, what they want to wear and what they need to feel comfortable. As verbal communication becomes more difficult we need to look for clues in how the person behaves and responds as well as understanding what they are trying to verbally communicate.



Remember

“People with dementia maintain their best level of physical, mental, social and emotional well-being”

Quality of Life Indicators.
Promoting Excellence (2011)

The more that we know a person's life the better we become at understanding and interpreting what the person is trying to tell us. Sometimes if we think we cannot make sense of someone's response, we can try to understand the context from the point of view of the person with dementia. We can think what the person has just been experiencing or what we know about the person's life and history and see if we can make a connection. For example, what was on TV just before someone seemed keen to tell you about something? Might there be something their personal history which makes them more interested in discussing this topic?

Communicating with a person at the advanced stages of the dementia journey

Communicating positively is crucial throughout the person's journey including when supporting the person in dying well at the end of their life.

Top communication tips

Gain the person's attention

It is important to gain the person's attention first, before you begin to speak. Approach them from the front so they can see you coming towards them. Try and make eye contact, make sure you are close enough and in the correct position for them to see your face and body movements. You may find it helpful to touch their arm gently but be mindful of their feelings on being touched and that it does not frighten them.

Use the person's name

Importantly, use the person's name when you address them. Using the person's name may help them understand that you know them and are not a stranger and this can be very reassuring.

Remind the person who you are

It is very helpful to remind the person who you are each time you return to them and at frequent intervals while you are supporting and caring for them. This ensures they do not become alarmed at this strange person trying to engage with them. Repeating who you are frequently may feel rather artificial but it will remind the person that they are with someone who is caring for them.

Keep the noise down

Reduce distractions such as activity and noise wherever you can. Try and find a quiet area where the person with dementia can concentrate on what you are trying to communicate.

Do not rush

Take your time with the person. It is tempting to hurry when you are busy but this will inevitably mean that you will take longer in the long run, as the person with dementia may not cooperate with you. Simply slowing down your

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rate of speech can help. Try to increase your communication time both in speaking and listening. It may help if you silently count to seven between short sentences and then give the person the same time to answer.

Listen to the person

Taking time to really listen is important as the person with dementia may be struggling with their words and any pressure from you may increase their anxiety; making it much more difficult to communicate their needs.

Keep calm

Use a calm tone and manner to reduce distress and make the person feel more comfortable with you. It is important to remember that no matter what stage of the journey they are at the person with dementia will respond to your non verbal signals, even very subtle movements of your face and body. If you need to repeat information try not to look or sound impatient, even if you are in a hurry.

Make things simple and straightforward

Try and use words the person with dementia will understand, free from jargon. Sentences should be short and contain only one idea at a time. In the same way, when giving guidance to the person, break down complex instructions into simple stages, delivering these one at a time. Open questions can be very challenging for the person with dementia partly because of their memory difficulties. It can be helpful to present them with simple choices, rather than complex questions. It is vital that you are specific in your language; using full names rather than pronouns. Give clear instructions, for example rather than saying "sit there" you could try saying "sit in this blue chair".

Use prompts and cues where possible

Written or photographic prompts can help a good deal as it provides another cue for the person who may not understand what is being asked of them.

Use humour when appropriate

Humour can be a very useful way both of communicating and defusing tense situations, however it must be used very carefully as it can misfire where the person with dementia

has been unable to process any subtle or complex message involved in what you say. A smile and pleasant manner is almost always as effective in smoothing the communication pathway.

Use the person's preferred methods of communication

It is important to establish a person's preferred methods of communication using information from them and from others e.g. families and carers, friends, support workers, or health/ social care professionals involved with their care – in fact anyone who knows the person well. For example using the person's first spoken language, Makaton or communication aids such as pictures or speech mats.

Talking mats is a communication tool which uses a mat with picture symbols attached as the basis for communication. It is designed to help people with communication difficulties to think about issues discussed with them and to provide them with a way to effectively express their opinions.

It enables the person with dementia to express their views and remain involved in planning their lives. It can also support families, friends and carers to communicate with the person. If you access the following website www.talkingmats.com you can watch a video clip of a person with dementia using a talking mat.



Remember

Never assume that the person with dementia cannot understand you.

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In addition to routines, preferences and meaningful activities we need to be actively aware of the person's comfort needs. When the person is no longer able to let us know their opinion we need to be able to think things through from their point of view. This includes their environment which needs to have design features to support independence, social connections and safety. If the person has difficulties in making sense of the world around them the physical, social and cultural environment becomes extremely important for them.

As well as the wider design features we also need to consider what is referred to as the 'micro' elements of the environment. This includes the temperature of the room, the atmosphere i.e. noise, smells, clothing, seating, opportunity to move around, pace of communication as well as physical health issues.

Jim's story

You may remember Jim who we met in the *Informed about Dementia DVD*.

Jim is 84 and a retired art teacher. He was passionate about art and it provided a focus for his working life and his spare time. He enjoyed teaching at the local college and taught a small art class in the local village. Fond of many styles of art, he would travel across the country to exhibitions and would often spend weekends in the west of Scotland painting landscapes and seascapes. He had never married and had few close friends. Jim is now living in a care home but the following scenario could apply equally in an acute hospital ward, community hospital setting or his own home.

You may wish to remind yourself about Jim's story by revisiting the DVD.

Jim is in the advanced stages of his dementia journey and is no longer able to communicate verbally. He manages to eat and drink independently and can walk with the support of one person. He requires assistance with all personal care but is able to wash and dress his upper body.

Jim is assisted to get up and taken to the dining room for breakfast. Because the care home is short staffed his support worker takes

Jim in the wheelchair and leaves him in it to have his breakfast. He eats his porridge and toast but cannot reach his mug of tea. He tries to get the attention of staff but they are busy and each person tells him they'll be with him shortly. The table is cleared and the worker moves Jim from the table in the wheelchair while talking to her colleague about extra cover for the afternoon shift. She does not notice Jim trying to signal that he needs a drink. Jim is taken to one of the quiet lounges as he does not like the noise in the bigger lounge. He is placed next to the window where he can see the garden. It is a lovely warm day.

At lunch time another worker comes in to take Jim to the dining room and finds him very distressed, flushed in the face and trying to reach towards his shoe.



Activity

What might be causing Jim's distress?

What are the risks for Jim when the staff are busy and preoccupied?

How can a person centred approach be adopted even when there is a shortage of staff?

Record your answers here:

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What could be causing Jim's distress?

You may have considered the fact that Jim had not had a drink and he is sitting in a potentially very warm position near the window. Staff did consider his preference about where he would like to sit, but did not consider that Jim is unable to communicate verbally or move away from the window. He appears to be trying to reach his shoe which could for example indicate that his sock or shoe is uncomfortable.

What are the risks for Jim when the staff are busy and preoccupied?

If Jim is regularly taken in a wheel chair rather than being supported to walk he could quickly become more dependent. This could happen without anyone noticing unless there is a constant focus on Jim's strengths and abilities.

Jim could also become dehydrated if attention is not given to supporting him to access enough to drink. This could result in deterioration in Jim's health which could lead to pressure sores. Another reason why we need to take the perspective of the person is that sometimes when someone can not communicate verbally in a busy environment it is easy to overlook their needs.

How can a person centred approach be adopted even when there is a shortage of staff?

If we look at the risks to Jim and the potential for increasing the level of care and support he may need as a result we would realise that –a little time spend can mean a lot of time saved.

When care settings are very busy there is a tendency to adopt a task focused approach to complete routines that suit the organisation and our practice rather than the person. For example it might be that Jim could have had his breakfast a little later allowing staff to take their time and ensure he was comfortable and his independence is maintained. Or perhaps there are others who could have breakfast later. There are usually person centred solutions where the only barriers are our organisational systems and processes.

Supporting the person's social environment

When we are working with people with dementia we need to recognise their need to have social and loving relationships and enriched social environments where they can feel included throughout their journey.

In the early stages of dementia and following a

diagnosis the person is at risk of withdrawing from their family and social network because of their fears and how other people respond to them. We have looked at how we can support the person after a diagnosis to continue to engage and maintain their social networks earlier in this module.

As the person's dementia journey progresses there is a stronger reliance on non verbal communication and while their cognitive abilities decline their depth of feeling remains and their emotions may even appear stronger.

A quote from a person with dementia emphasises this for us.

“As we become more emotional and less cognitive, it's the way you talk to us, not what you say, that we will remember. We know the feeling, but don't know the plot. Your smile, your laugh and your touch are what we will connect with. Empathy heals. Just love us as we are. We're still here, in emotion and spirit, if only you could find us.”

(Bryden 2005, p138)

In order to support the person's social environment, we need to have a valuing, respectful and enhancing culture of care. Brooker (2007) suggests that our culture of care and how we respond to people with dementia is learned in the same way as new staff learn to fold sheets, i.e. we learn from others how to respond to the person.



Remember

If we understand how to enhance the person's social environment we can continually challenge the culture of care by reinforcing person centred interactions.

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We can support the person through emotional comfort, physical touch, and comforting words or gestures as well as the use of a respectful manner which maintains the person's identity. We should avoid infantile communication such as 'baby talk' or a patronising manner.

Sometimes because we are busy and in a hurry we can tend to take over personal tasks rather than allowing the person to do things for themselves. Instead of doing this: we should enable the person by focusing on their strengths: allowing them to do as much as they can for themselves in personal routines, such as washing and dressing; including them in discussions and actively encouraging them to engage with their social network.

The table below outlines practice examples of a socially supportive environment compared to a socially alienating environment.

Supportive Social Environment	Alienating Social Environment
Workers are courteous, welcoming and show genuine affection, care and concern for the person	Workers ignore the person and speak over the person
A person's request for support or help is responded to	The person's requests for help are ignored and workers intentionally avoid any contact with the person
Workers recognise when a person's dignity may be at risk and support and protect the person	Workers mock and joke about the person and allow them to be humiliated.
The worker maintains a relaxed pace	The worker is hurried and the atmosphere is noisy and busy
The worker speaks to the person and talks them through every proposed activity or action	Activities and actions are carried out without stating intent or speaking to the person
The person is treated as an equal partner and respected	The person is frightened and fearful of workers

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Activity

From your experience of working with people with dementia think of an example of a socially supportive environment and an example of an alienating social environment to add to this list.

Record your answers here:

We would encourage you to read Brooker (2007) *Chapter 5 Social Environment*, where this is further developed and can support your thinking about application in practice.

Personalised approaches to maintaining networks and community connections

Earlier in this module we described strengths and assets based approaches and how they relate to person centred care and personalisation. There is a range of ways to support the person with dementia to access and use personalised services that enable people with dementia to remain connected with their networks and communities.

Self directed support

Self-directed support enables people to arrange some or all of their support, instead of receiving services arranged by their local authority social work or housing department. It applies to people who would like more flexibility, choice and control over their care so that they can live at home more independently.

If people choose to organise their own community care support package, they are in charge of the arrangements. This should allow them to organise their lives the way they wish. They receive a sum of money to spend on the support they need instead of receiving council services. If they want, they can choose to organise some of their own support to complement or replace the support received from public services. Families and carers of people with dementia can be involved in arranging or supporting the person to manage this under the legal processes described in module 5.

Most people who use social work services can get self-directed support, sometimes called direct payments. The term 'self-directed support' is used because it emphasises that people are in control of their own support arrangements. As we discussed earlier this is part of the government initiative of personalisation which is about addressing the needs of whole communities, ensuring everyone including people with dementia have access to the right information, advice and advocacy to make decisions about support they need.

People often use SDS to get support with:

- Personal care like having a bath, washing or getting dressed
- Living in their own house through help with managing money, cooking and cleaning
- Getting out and about to see friends, joining in activities with other people, or going on a short break (respite)

To find out much more about SDS, visit the Self Directed Support Scotland website [<http://www.selfdirectedsupportscotland.org.uk/>].

So far, we have explored how SDS can provide creative approaches to building on people's assets. Earlier in the module we examined the quality of life outcome indicators for people with dementia and the Standards of Care for Dementia in Scotland. We can now examine how we can identify priorities and preferred outcomes for people with dementia and how SDS can be used in meaningful ways to support quality of life for people with dementia.

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Donald's story

It has now been over a year since Donald was diagnosed with Alzheimer's type dementia. He and his wife Sheila have been coping reasonably well. Recently, however, things have been more difficult. Donald's forgetfulness is becoming more problematic. He has gone out for a walk on a couple of occasions and wasn't able to find his way home. He has also left the house with the doors unlocked and the windows open. Sheila is finding it hard to cope and feels on edge all the time. They have begun to argue a lot with each other. Sheila's GP feels that she is no longer able to cope and feels that Donald should start to attend the day unit at the local community hospital. Donald is not keen on the idea.

If you return to the Quality of Life indicators in the table at the start of this module you may identify that the indicators that might be particularly important for Donald at this point may include:

- Feeling empowered and enabled to exercise his rights and choice, maintain his identity and be treated with dignity and equity
- Maintaining his best level of physical, mental, social and emotional well-being
- Having access to individuals, groups and organisations that can support his and Sheila's spiritual or personal beliefs and reflect their cultural wishes
- Having access to quality services and being able to continue to participate in community life and valued activities
- Feeling safe and secure and able to be as independent as possible
- Maintaining valued relationships and networks
- Having the opportunity to develop new relationships, both personal and professional



Activity

How could SDS be used to support Donald to enable him to achieve the Quality of Life Outcomes he has identified?

Record your answers here

You may have identified a number of opportunities for Donald to use SDS and personal funding, including costs for transport or employing a personal assistant to remain engaged in activities he values, such as:

- Attending the golf club
- Keeping in contact with their children and grandchildren
- Attending support groups
- Having time apart to engage in personal interest and activities the couple both value

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Remember

“People with dementia are able to maintain valued relationships and networks and have the opportunity to develop new ones, both personal and professional”

Quality of Life Indicators.
Promoting Excellence (2011)

Telehealthcare

Self directed support and people having their own budgets means, amongst other things, that innovative use of telehealthcare can assist people to be more independent which can contribute to improving their quality of life. It can reduce the risk of accidents and the resulting need for hospital admission. It provides a safety net and a response system to support families and carers and can be personalised to meet each person's differing needs.

However, it is not for everyone and requires careful assessment to ensure it does not result in increased confusion and distress because of the difficulty in learning to use new equipment. It is best introduced to the person as early as possible to ensure the person is familiar with it.

Examples of the range of telehealthcare supports

- Support knowing the day, date and time - there are many clocks and clock calendars with large displays and pictures, or that speak the day, date and time.
- Finding things - there are gadgets that can help you to find things such as keys or wallets. They flash or make a sound to guide you to them.
- Remembering to do things- such as signs in words or picture notice boards and sticky notes. Other more high tech gadgets such as voice recorders can sometimes link these to a motion detector to trigger a particular message being played, for example by the front door. Or you can use voice recorders to remind you to get off a train or bus at a particular stop.
- Taking medication-such as -Flip lid boxes labelled with the day of the week and time of day. Automatic pill dispensers that make a sound or flash when it's time to take a tablet.
- Keeping safe - there are many gadgets to make people feel safe in their home, such as: night lights or lights that turn on when they are needed. Sensors that detect smoke, carbon monoxide, high or low temperatures or gas Gadgets that indicate when someone might have fallen. Sensors that detect if the front door has been left open and sensors that detect if someone has got out of bed at night and not returned, or if someone hasn't moved out of their chair.
- Individual alarms worn on the person- to alert people in a specialist response centre as they will know how to react. This might be: calling the house, contacting a carer or someone in the family, contacting another professional who can go to help or contacting the emergency services.
- Tracking devices- can be used within the person's own home or while they are out and about to be able to find them if they get lost. These can give the person freedom and the ability to stay at home longer.

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We will examine ethical issues and telehealthcare in Module 5.

Millie's story

You will remember in Module 1 we met Millie who has a diagnosis of dementia and whose short term memory has been gradually deteriorating. One night last winter she went out late in the pouring rain and was knocking on neighbours doors in a distressed state. Worried neighbours called the police who took her home. After this incident Millie went to stay with one of her daughters for a while but felt frightened to go back home again. This was obviously a huge concern for her family who were becoming increasingly worried and anxious about her safety, especially at night. A meeting was set up with the social worker to try to come up with a solution. The family were thinking that residential care was the only option even though Millie was physically in good health.

Here is what happened:

Millie's social worker was keen for them to try other methods of support before they resorted to seeking a residential care placement. The options put forward to the family were increased home care support through the day, a sitting service or respite care to give the family a break, overnight stays, or connection to the community alarm service and the installation of a telecare device which would let the Warden Services know if Millie had left her house at night after a preset time.

A Warden Services supervisor visited the family to decide upon the most appropriate response for their circumstances, which in their case was for the mobile wardens to go out if the alarm went off as they could get there a lot quicker than any of the family.

Millie still likes to go to the local shop for her paper every morning and the family were very keen for her to retain this element of independence, so they asked for any alarm that went off after 8am to be ignored until they arrived to disarm the device.

This solution has worked very well for Millie and her family. Millie feels safer and the family have peace of mind in the reassurance that the telehealthcare device provides. She now attends Day Care twice a week for social stimulation and this, along with the excellent support she gets from her family, and the use of telehealthcare, means that Millie is now able to stay in her own home.

[Adapted from a case study provided by Durham local authority:
http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=152]

Telehealthcare can make a significant contribution to personalised care and support but we need to take account of the following issues:

- The person with dementia, their families and carer's **needs, choices and beliefs** must be considered in the decision making process.
- Each product should be evaluated to make sure that it is suitable for a particular individual. **Knowing the person**, their background and life



Activity

Do you think there were any other options for Millie?

Record your answers here:

Module 2 - Promoting Person and Family Centred Care and Community Connections

story will help inform the evaluation process.

- Consideration must be given to **capacity and consent**.
- **Risk assessment** which includes the assessment of risks in the home as well as outside form a crucial component of a good needs assessment.
- **Families and carers also need appropriate training** and support in the use of telehealthcare.

You can find out more about telehealthcare at the Joint Improvement Team website <http://www.jitscotland.org.uk/action-areas/telecare-in-scotland/>.

Self assessment quick quiz

Check whether you have understood the main points of this module

1. What are the 4 elements of person centred care?
2. What is a strengths based approach?
3. What is an assets based approach?
4. How can you communicate with a person with dementia to show the person that you value them?
5. Identify 3 ways that telehealthcare could be used to support a person with dementia

Module 2 - Promoting Person and Family Centred Care and Community Connections

Module summary

In this module we have explored what a person centred approach to care means. We also looked at a range of ways that people with dementia can continue to maintain valued roles and relationships and be supported to remain independent for as long as possible within communities. We considered the possible services, approaches and technologies that people can access and chose with an individual budget.

Action into practice

From your learning in this module

- Make a note of three new things you have learned about person centred care
- How might you implement these in practice?
- Using the knowledge you have gained from working through this module, find out about the resources and services in your local area that could support people with dementia to maintain community connections and design a leaflet or poster to promote the resources that you identify

Record your answers here

References

(1) Brooker, D. (2004) *What is person centred care for people with dementia? Reviews in clinical gerontology*. 13, (3) 215-22

(2) Changing Lives: Personalisation: A Shared Understanding: Commissioning for Personalisation: A Personalised Commissioning Approach to Support and Care Services
<http://www.scotland.gov.uk/Publications/2009/04/07112629/0>

(3) May, H. Edwards, P. and Brooker, D (2009) *Enriched care planning for people with dementia. A good practice guide for delivering*

**Module 3:
Promoting Health and Well-being for
People with Dementia**

Module 3 - Promoting Health and Well-being for People with Dementia

Introduction

Health and well-being is important to us all and no less for people with dementia. The *Promoting Excellence framework* identifies that people with dementia should be entitled to maintain their best level of physical, mental, social and emotional well-being. In this module we examine approaches to supporting people with to keep as well as possible throughout their dementia journey.

Learning outcomes

By the end of this module you should be able to:

1. Recognise the importance of self management of health and well-being for people with dementia
2. Understand the factors that can impact on the health and well-being of people with dementia
3. Describe the common physical health and well-being issues that may be experienced by people with dementia.
4. Describe the common mental health and well-being issues that may be experienced by people with dementia.
5. Understand the importance of memory support methods and approaches for people with dementia

Self management of health and well-being for people with dementia

Self Management is a concept that is underpinned by a belief that well-being and living well is about much more than the absence of symptoms. Supporting people to self manage enables them to “be all they can be” and to maximise their quality of life. Self management approaches recognises that people, families and carers, and the community they live in have strengths, assets and resources that can be drawn upon to enable people to be active partners in managing and addressing any difficulties they may be experiencing. We explored some of these issues already in Module 2. Promoting self management sometimes requires staff and services to “think outside the box” and look for solutions that have not previously been used in more traditional models of health and social care.

Key components of promoting self management of health and well-being for people with dementia include: agreeing goals and identifying peoples priorities and preferred **outcomes**.

- creating **person centred** care plans that focus on what people at the centre of care and treatment

want, to guide their care at home or in another setting.

- providing **personalised** services that are tailored to the persons choice and control and not expecting people to “fit” with existing services
- **using strengths** based approaches which support people to build on the things they can do, or could be supported to do, to look after their own health and maintain their sense of well-being.
- assets based approaches to working in **partnership** with the person with dementia and the key people, organisations and agencies involved in supporting them and, importantly their wider social networks and community.

A well-being focused approach and supporting self-management for people with dementia is not about professionals leaving people to ‘get on with it’ or handing over responsibility to individuals, families and carers. It is about supporting people to remain living independently in their own communities for as long as possible, and when this is no longer possible ensuring that the same approach is adopted in any care setting.

Promoting self management is about helping people to gain more control in their lives by sharing information, signposting to services and by giving people the tools and support to remain active participants in their own care.



Remember

Carers also have a right to an assessment of their own physical and emotional needs and to get the right information to enable them to access services and provide the best possible care and support.

<http://www.careinfoscotland.co.uk/can-i-get-help-with-caring/carers-assessment.aspx>

Later in this module we will explore common physical and mental health and well-being issues but we should always be aware that as we support people with dementia we should adopt a person centred and strengths based approach which promotes involvement and self management of mental and physical health conditions at all times.

Module 3 - Promoting Health and Well-being for People with Dementia

What are the factors that can impact on the health and well-being of people with dementia?

Many factors can combine together to influence the health and well-being of everyone and these are no different for a person with dementia. These include our personal circumstances and environment.

Factors that influence everyone's health and well-being include:

- where we live
- our environment (social, cultural, physical and economic)
- our access and use of health and social care services

Additionally individual characteristics can influence our health and well-being

- genetics
- education
- health behaviours
- relationships with friends and family.

There is more information about the impact of the social, cultural and physical environment on the person with dementia in Modules 1 and 2.

In Module 1 also we looked at genetics and health behaviours in relation to dementia



Remember

the same health behaviour that can decrease our likelihood of developing dementia can also positively affect our chances of living well with dementia

Physical health and well-being and dementia – exploring the issues

The importance of people with dementia keeping physically well

It is important that everyone involved in the life of the person with dementia are alert to the person's physical health. In the earlier stages of the dementia journey, following a diagnosis it can be very helpful if the person with dementia has regular check-ups with their GP, including sight, hearing and dental checks. At this stage in the journey many people are still able to give information about themselves, and will be able to adjust more easily to any necessary supports such as hearing aids or glasses. As someone's dementia journey progresses they may become less able to identify health problems or to tell others about them, so it is important to look out for signs that the person might be experiencing physical health problems.

Exercise and physical activity for people with dementia

Leading a healthy lifestyle includes physical activity which can be beneficial for physical and mental health and can improve the quality of life for people in all stages of their dementia journey. It can also provide opportunities for people to engage with and socialise with other people, reduce any feelings of isolation they might be experiencing, and help to support them to improve or maintain their independence.

Physical exercise can promote and support people's mobility which can in turn:

- improve circulation and improve cardiovascular health.
- reduce the risk of high blood pressure and heart disease.
- reduce the risk of some types of cancer e.g. colon or breast cancer
- reduce the risk of stroke and type 2 diabetes.

Additionally it can:

- prevent stiffness, muscle wasting and joint strength
- improve bone density and reduce the risk of osteoporosis
- improve balance - this can reduce the risk of falls, the negative outcomes related to falls, and importantly the fear of falls.

Physical exercise can also promote mental well-being by:

- promoting relaxation and a sense of calm, and can also help to ensure a good night's sleep
- reduce the likelihood of anxiety, stress and depression developing.

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In the earlier stages of dementia people should be encouraged and supported to maintain any physical activities they have usually been engaged in. For people who may not have previously engaged in such activity it may be an opportunity to take up new or different activities. Local community or sports centres often provide a range of organised exercise and physical activity sessions and exercise classes, music and dance, indoor bowls or swimming.

Some of these activities can be modified and carried out at home. In addition, walking, golf, gardening and housework are also good forms of exercise. Regular physical activity is beneficial and for us all. Around 30 minutes five times a week is recommended, though this can be broken up into shorter sessions. A range of different physical activity can help to maintain interest by introducing variety.



Remember

think about the things the person *can* still do for themselves: promote independence whenever you can.

As people progress along the dementia journey regular physical exercise can help to reduce the need for more supported care and adaptations required to the person's living environment. Exercises can range from changing position from sitting to standing, walking a short distance into another room or moving to sit in a different chair at each mealtime throughout the day. A daily routine involving moving around the home can help to maintain muscle strength and joint flexibility.

Dancing can help improve physical, psychological and emotional well-being and can easily be incorporated into everyday activity for example dancing from one room to another. Gardening can be an enjoyable activity for people at all stages of the dementia journey. If the person does not have access to a garden, looking after pot plants or flowers can be enjoyable as well. Physical activity is not all about

organised exercise or joining a gym. Small amounts included into daily life can make all the difference.

It is always important to be aware of potential health issues that may prevent someone from doing exercise, and seek further advice when unsure. A physiotherapist or a suitably trained fitness professional can help to devise exercise regimes for individual or group exercise programmes.

It is not unusual for people who have dementia in care settings to have less access to outside space, particularly in the later stages of the dementia journey and as they become less mobile. Getting out and about provides fresh air, variety in the day and can enhance psychological well-being.



Activity

Think about the people with dementia that you work with. Think of three ways that you could support them to incorporate more physical exercise or activity into their daily routine.

Record your answers here:

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Relationships and sexuality

Dementia causes many changes in a person's life as time passes. One area in which there are often changes, which are seldom discussed, is that of intimate relationships. For many couples coping with dementia, physical intimacy continues to be a rich source of mutual comfort, support and pleasure for many years. We need to ensure that the person is supported to maintain companionship and physical intimacy in a respectful and dignified manner.

Sometimes a person with dementia may appear to lose their inhibitions and make sexual advances to others or undress or touch themselves in public. They might make sexual advances to someone who they mistake for their partner. It's possible that what appears to be sexual is actually an indication of something quite different, such as needing to use the toilet, discomfort caused by itchy or tight clothes or feeling too hot, expressing a need to be touched, or for affection, misunderstanding other people's needs or behaviour.

We need to be aware of this and respond appropriately, by remaining calm, gently discouraging inappropriate behaviour, and if persistent seeking specialist advice. As we have already seen, knowing the person and engaging them in activities meaningful to them will help you to understand why the person is acting in this way as well as how to prevent, support and respond.

The relationship may be with their partner or if they no longer have a partner it may be that they form a new relationship particularly in care settings and we should not interfere as long as there is no risk to the person or others. One of the difficulties is that as the person's dementia progresses, it is often unclear whether they have 'mental capacity' to consent to sexual relations and if you suspect they are at risk or are being abused, you need to follow the process for reporting abuse described in Module 5.

Problems with vision experienced by people with dementia

Dementia often causes problems with visual perception. Although the person may still have good eyesight, they may experience problems in recognising what they see. Understanding possible difficulties and providing support and intervention can help people with dementia to feel safe. It is common, for instance, for people with dementia to experience a decreased ability to perceive colour contrasts and

depth. This can make it hard for people to recognise the edges of objects or to interpret patterns or shadows. Because of these difficulties an apparently normal environment can become extremely challenging to a person with dementia.

Vision difficulties can sometimes result in a variety of 'visual mistakes' that can cause a person with dementia to misinterpret their environment and what is in it. The outcome of these difficulties can be severe for people with dementia as they may not know or remember that they are making mistakes and they may also have difficulty explaining what they have seen.

Some people with dementia can also have age related deterioration in their vision. A number of visual disorders are commonly associated with ageing including cataracts, glaucoma, macular degeneration and retinal complications from diabetes. Illness, medication and the type of dementia the person has can all impact on their vision in a range of ways. There are a number of categories of visual "mistakes" that people with dementia can experience.

You can find out more about visuoperceptual difficulties at the Alzheimer's Society website http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1408

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Tips to support people with dementia who have visuoperceptual problems

The environment can sometimes cause stress for people with dementia if perceptual issues are not considered. If a person with dementia seems to be experiencing problems navigating their environment it can be helpful to make adaptations to eliminate confusing features.

- Provide good lighting
- Try to eliminate shadows.
- Avoid busy patterns on walls and flooring where possible.
- A matt, light-coloured floor will reflect light upwards and enhance overall lighting levels.
- Remove or replace mirrors and shiny surfaces if they are causing difficulties.
- Highlight important object and visual cues
- Camouflage objects that you do not want people to see.
- Avoid 'visual obstacles' such as changes in floor surfaces or patterns.

People with dementia can also be affected by physical health issues that we can all experience for example hearing difficulties, dental issues and other more serious health conditions like cancer or heart disease.



Remember

“People with dementia maintain their best level of physical, mental, social and emotional wellbeing.”

Quality of Life Indicators.
Promoting Excellence (2011)

Ellen's Story

Remember Ellen.

In the *Informed about Dementia* DVD she was very distressed about her tablets and Leanne (a worker) suspected there was something other than dementia that was contributing to her distress. Leanne's manager visited Ellen and Carolyn (Ellen's daughter) and suspected that Ellen may be having hearing difficulties.

Carolyn went with Ellen to her G.P who referred them to a specialist for a hearing assessment. As it turned out Ellen was found to have a hearing impairment and was provided with a hearing aid which made communication between Ellen and Carolyn considerably easier.



Remember

we should not assume that the difficulties that people with dementia face are always related to their dementia. It is important that if we notice any unusual or out of character changes in the way the person is behaving and responding that any physical health issues are checked out. Knowing the person well can help us to notice when this is happening.



Remember

if you are at all concerned about the well-being of a person with dementia or their carer you should speak with your manager. If you do not have a manager you could contact a health or social care professional.

Module 3 - Promoting Health and Well-being for People with Dementia

Supporting good nutrition for people with dementia

Eating well is vital to maintain the health, independence and well-being of people with dementia. The impact of good nutrition on our health cannot be underestimated. Malnutrition and dehydration can affect our physical and mental well-being. Eating a nutrient-rich diet, with plenty of fruit and vegetables, omega 3 oils, and low amounts of salt and saturated fats, can help to maintain the health of both our heart and brain.

For many people with dementia, eating and maintaining a healthy weight can become more difficult as their dementia journey progresses. For some people with dementia, the changes that are experienced can have an impact on their ability to eat and drink which can result in weight loss, malnutrition and dehydration, or even weight gain. As with any one of us, the appetite of a person with dementia may vary from day to day. It is helpful to be aware of some of the changes that can occur as dementia progresses.

Potential nutritional difficulties people with dementia may experience include:

- Difficulties using cutlery - for example food may fall off cutlery which can be frustrating for the person.
- Communication difficulties may make it difficult for a person to explain what they want or what they dislike.
- Difficulties with their sight and visual perception can mean that the person is unable to see or to recognise cutlery, crockery or the food.
- Inability to associate the names of food with the actual food itself.
- Inability to remember all the options given to them.
- A noisy environment can be confusing and can make it difficult for the person to concentrate.
- A person with dementia may be uncomfortable eating with other people or in an unfamiliar environment.
- The person may be experiencing pain or are be afraid that they may choke on the food.
- Dentures or dental plates may no longer fit correctly, making it difficult and painful to chew.
- A person may experience difficulties chewing and swallowing as their dementia progresses.

Signs that someone is experiencing swallowing difficulties include:

- repeated coughing, throat clearing or choking after swallowing food or drinks
- a wet sounding voice after swallowing
- reluctance to eat and drink or simply not swallowing food and drinks.



Activity

Which specialist services do you think you or the person with dementia or their carer could ask for help in relation to eating and nutrition difficulties?

Record your answers here:

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How can we help people with dementia have good nutrition?

- We should not assume that if a person is not eating that they do not want to.
- It is up to us to try to identify what the difficulties are.
- Regular monitoring of their weight can help to alert us to changes.
- The more we know about a person with dementia, the easier it is to meet their nutritional needs.
- Use the person's life history to encourage conversation about food if a person is struggling with a poor appetite.
- Ask people with dementia about their mealtime preferences. Families and carers can be a valuable source of information if the person with dementia is struggling to communicate their eating habits and preferences for food and drinks.
- The environment where people are having their meals needs to be calm and relaxed - for example switch off the television or turn down loud music to avoid distractions
- Ensure that food and drink is visible and available throughout the day so that people can eat and drink whenever they feel hungry or thirsty.
- Showing the person with dementia the food you are offering, and naming it, can help the person connect the words with their memory.
- Finger foods can help a person who has difficulty with cutlery to eat independently.
- Providing soft textured foods for people who cannot chew can help. But do not assume that a pureed diet is the answer when a person with dementia declines food or if they appear to show difficulties chewing and swallowing food and drinks. This can, if given inappropriately, make things worse if people are reluctant to eat it.

Seek specialist help if there are any concerns about a person with dementia chewing and swallowing food or drinks, a speech and language therapist can provide advice and strategies to help the person at mealtimes. It is also vital that a person with dementia has access to a dentist to ensure that any dental health problems or difficulties with poorly fitting dentures can be addressed as soon as possible.

If a person needs adapted eating equipment, an occupational therapist can provide assessment and advice. A dietician will complete a comprehensive nutritional assessment and can offer advice and support for people with dementia who are experiencing weight loss or excessive weight gain.

Supporting people with dementia with their personal hygiene and continence

If the person with dementia is not able to understand the care that is offered, or how you are trying to help them they may become distressed during physical care activities. Activities like washing, dressing, bathing, or helping people move or reposition may cause the person to feel they are being harmed. This can be very challenging for staff trying to provide good care to the person.

People with dementia can be very sensitive to non verbal behaviour and reactions of others. So it is likely that the person will sense if carers are anxious, rushed or annoyed. It is very important to be calm and relaxed in your approach and use the communication approaches we outline in Module 2.



Remember

Where there are particular personal care activities that seem to cause distress it is essential that these are examined to try and find out why this may be the case and resolve the problems.

Module 3 - Promoting Health and Well-being for People with Dementia

Things you should consider:

- Is it essential that this care activity is done?
- If so is it essential that it is done at this point in time?
- Is there a time that better suits the person?
- Is this activity causing any pain?
- How many staff are there when it is carried out?
- Where is it being carried out?
- Would it be appropriate for family or other carers to be present during the care activity?
- What activity was the person with dementia doing before this care activity?

You can find out more about understanding and supporting people with distressed behaviour in Module 4.

How to help a person with dementia wash and bathe

For most of us, washing and bathing are personal and private activities. Therefore, when assisting someone with dementia to wash or bathe, it is important to be sensitive and respectful of their dignity. Helping a person with dementia to maximise their independence and manage their own care as far they are able is desirable. However, washing and bathing can become a source of great distress for the person with dementia. It can also be physically and emotionally challenging. There are a number of reasons for this including some of the following:

- Pain as a result of illness and musculoskeletal conditions.
- Weakness caused by frailty and ill health.
- Anxiety and misunderstanding because of memory impairment, loss of understanding or recognition of the bathroom or previous negative bathing experiences.
- Fear of falling, especially when being moved around in lifting equipment and hoists.
- Noisy, cold or unfamiliar environments.
- Being naked in front of a stranger. The person with dementia may not understand that you are there to care for them.

It is not always necessary to provide an immersion bath for the person with dementia. It may be better to seek alternatives to an immersion bath as a way of maintaining personal hygiene. A shower, if the person can manage this, might be preferred however they are also subject to many of the same challenges noted above.

Today, many people bathe or shower daily, but 30 years ago it was normal to have a bath only twice a week. However, washing is not just about smelling fresh and looking well-kept. It also helps prevent ill health. Not washing enough can lead to infections and skin complaints. If the person you are caring for doesn't choose to wash as often as you would wash yourself, that's not necessarily something to worry about.



Remember

Washing is a matter of personal choice.

Margaret's story

Remember Margaret who we met in the *Informed about Dementia* DVD. Margaret had been admitted to hospital with chest and urinary tract infections. Margaret had dementia and delirium and it was some weeks before she was able to return home. After her return her support worker tried to get her to have a bath, something she had enjoyed before her admission to hospital. Margaret had cried and pulled away, refusing to go near the bath. While she was in hospital, she had been bathed by two nurses using a hoist. The nurses were very kind and reassuring but she had never needed lifting equipment before and the whole experience had been very distressing for her.

The person with dementia may forget incidents as Margaret forgot the bath in the hospital. However, the emotions those incidents generate may remain with them for a long time.

Margaret saw the bath and felt afraid. For Margaret the pleasure of bathing was lost and she could not explain why.



Reflection

1. How did reading about Margaret's experience make you feel?
2. How would you feel if you were experiencing these difficulties?
3. Can you think of ways that you could make the experience of bathing easier for people experiencing these difficulties?

Record your answers here:

The long term impact of a negative bathing experience can have serious implications for the person with dementia and their carers. When the person is in an advanced stage of dementia, care tasks such as washing, bathing or changing their clothes can be very difficult to manage. The person may continually grasp at people and objects in the environment. This hand grasp is often a reflex action and the person cannot help themselves. If you try to prise their hand off they will simply try to grip harder, often causing pain and injury.

How to help a person with dementia remain continent

Incontinence is not an inevitable symptom of dementia, but there are a number of reasons why someone with dementia could become incontinent. The person with dementia may have often profound difficulties doing tasks in a sequence or pattern. This loss of ability can also affect the person finding their way around. For example, in order to find the toilet you need to:

- Know where you are now
- Know that you are looking for the toilet
- Know how to get to the toilet
- Recognise it when you get there
- Know how to remove the appropriate clothing etc.

Of course there may be people who manage very well and other people who may benefit greatly from a referral to occupational therapy for further assessment to maximise their abilities, while others may require more intensive help and support.

The person with dementia can experience difficulty in recognising what an object is for or telling objects apart. For example they may not recognise the difference between a toilet and a bin and may use the bin to urinate in. If they have age related changes in vision or an eye disorder this can make this lack of recognition worse for them.

Leaving doors open so the toilet is clearly visible is the most successful way to direct the person with dementia. Toilet signs should be realistic and placed at a height that can be seen even by a person in a wheelchair. Signs on the floor can also help as many people may be looking down to the floor to prevent falling in the unfamiliar environment. Taking steps to increase colour contrast and stronger colours can help not only the person with dementia but those with other visual impairments such as cataract or glaucoma. It is more important to have a strong contrast than any particular colour.



Activity

Have a look around your place of work or the home of the person you support. Can you see any way that you could improve the physical environment to make it easier for people to remain continent?

Record your answers here

There are also various medical conditions, which are amenable to treatment, which can contribute to a person becoming incontinent. Medical causes include:

- Urinary tract infections - these usually respond to treatment with medication.
- Prostate gland trouble - this affects men and may be resolved with an operation.
- Side-effects of medication - the GP can address this by changing the person's prescription or altering the dose.
- Severe constipation - constipation can put pressure on the bladder, and can also lead to faecal incontinence. Eating foods that are high in fibre, drinking plenty of fluids and keeping physically active can help prevent this.

Helping with mobility

There are a number of important factors to consider when supporting a person with dementia to remain mobile and to mobilise. There are a range of information sheets which list strategies with which to approach specific situations at the following website http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1631

If someone with dementia has difficulty walking, or has any other movement difficulties, it is important to take particular care that they don't develop pressure sores - especially if they are older. Pressure sores can be easy to treat early on, but if they are left untreated they do get worse, and can be very painful. Someone with dementia may not be able to let you know if they are uncomfortable and in pain.

It is crucial that if we are concerned that we seek professional advice. Earlier in this module we covered skin care, food, fluids and continence support, as paying attention to these important areas also maintains healthy skin and prevents the development of pressure sores.

Preventing slips, trips and falls

People with cognitive difficulties can be an increased risk of falls. Numerous difficulties including confusion, disorientation, memory loss, restlessness and agitation can contribute to their risk of falls. The physical environment including the quality of lighting, the nature of floor coverings, uneven surfaces and undefined steps - can be challenging for people with dementia especially those with visual difficulties. Perceptual problems can also result in difficulties relating to seeing objects of a similar colour, spatial awareness, shadows, darkness, textures or shiny surfaces.

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Memory loss can contribute to falls when a person with dementia forgets the layout of a building. People with dementia can also forget when they are no longer able to walk. Some medications can also have adverse effects on movement and walking.

Slips trips and falls can be very serious for people with dementia and can result in loss of mobility and independence, or hospitalisation.



Activity

Make a note here of the main hazards in your place of work and/or in the home of the person that you support that could increase the likelihood of slips trips or falls.

Suggest some options for change that could prevent this.

Record your answers here:



Remember

When a person with dementia falls it can have serious consequences including a loss of independence and decline in quality of life.

Supporting people to sleep well

Dementia can sometimes cause people difficulties in getting to sleep. In more advanced stages of dementia people can become confused about night and day, and may get up in the middle of the night, thinking that it is morning. Sleep disturbance – in particular, persistent wakefulness and night-time restlessness – can be distressing for the person with dementia and difficult for the people around them. Things that can help include:

- avoiding excess sedation
- ensuring a range of stimulating activities - someone is more likely to nap during the day off if they are bored
- reducing fluid intake in the evening, and avoid stimulating drinks such as tea and coffee
- taking some form of exercise during the day

Supporting people with dementia experiencing pain

There are as many causes of pain and discomfort in people with dementia, as there are for those who do not have dementia, yet pain is one of the most common symptoms that people with dementia experience. However, it is often not recognised and can be poorly treated or go untreated altogether, even though it is not difficult to treat. The main reason for this is that, as dementia progresses, the person's ability to communicate their needs becomes more difficult and family, carers and staff need to work hard to observe and understand the signs that the person with dementia may be displaying.

The person with dementia's response to the distress the pain is causing can result in verbal outbursts,

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non verbal signs or/and distressed behaviours which can be perceived as 'being difficult'. In these circumstances, attempts must always be made to explore and understand what the underlying cause is. There are now a range of resources available to assist staff to establish whether a person with dementia is in pain, especially if the person cannot tell you in words. One example is the Abbey Pain Tool (you will find a copy of the Abbey Pain Tool at the following website: www.dementiacareaustralia.com). The tool suggests there are other ways in which the person may be letting us know they are in pain, perhaps through screwing up their face or rocking back and forth for example.

Once the existence of pain and its causes are established, there are a wide range of medications which can be used to alleviate it. In addition, or as an alternative, there are other ways to tackle discomfort and pain. There are simple interventions such as distraction, relieving boredom, a calm and comfortable environment, and social contact which can all help to alleviate pain.

What if the person with dementia is admitted to hospital?

Someone with dementia may be admitted to a general or specialist hospital ward either as part of a planned procedure, such as a cataract operation, or following an accident, such as a fall. Another reason why a person with dementia may be admitted to hospital is because of delirium which is a sudden change from the way they usually are and we explored this in Module 1. For example a person who is usually quiet and withdrawn may become extremely distressed and agitated or someone who is usually very engaged suddenly becomes very tired and withdrawn.

Hospital environments can be disorientating for a person with dementia, and may make them appear more confused than usual. We can enhance their care and support by providing information about them as an individual as well as their medical needs. The Alzheimer's Society has produced a useful booklet '*This is me*' to support person centred approaches which can be completed before the person goes into hospital:

http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=399.

The risks of hospital admission to people with dementia can include one or more of the following:

- Increase in mortality.
- Increase in time in hospital.
- Increase in unwanted drug reactions.
- Earlier admission to residential care.
- Incontinence.
- Reduced cognitive function.
- Increase levels of dependence if they return home

Because of these risks it is important to support people with dementia, their families and carers to avoid illness and infection that can compromise their well-being. It is imperative that all of us working in a care environment have a sound knowledge of prevention and control of infection.

For more information on infection control visit this the following link:

<http://www.nes.scot.nhs.uk/education-and-training/by-theme-initiative/healthcare-associated-infections/training-resources/preventing-infection-in-care.aspx#nav>.



Remember

Delirium is a serious condition and a medical emergency.

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Activity

What might you be able to do for the person you are working with in order to make their stay in hospital more comfortable?

Record your answers here:

If you are working with in an acute general hospital you can access the NHS Education for Scotland, Dementia in Acute General Hospital Settings Learning Resource:

http://www.nes.scot.nhs.uk/media/350872/acute_dementia_interactive_2011.pdf.

Palliative and end of life care for people with dementia

Providing palliative care is not only about the care a person might receive at the end of their life. It is more about an overall approach to the provision of care and support appropriate for that person, at a given point in time.

A palliative care approach should be available to a person with dementia throughout their dementia journey. It is also important to ensure that the care and support you are providing at this stage, as with any other, is culturally and spiritually acceptable for that person.

The specific palliative care issues that may be relevant for people with dementia are advanced decision making, pain management, nutrition and dehydration and treatment of fever and the end stage of dementia. For further information about assessment tools to support the person's palliative care needs throughout their journey the following websites may be useful.

- http://www.gmc-uk.org/static/documents/content/End_of_life.pdf
- <http://www.mcpcil.org.uk/liverpool-care-pathway/>

Mental health and well-being and dementia

Dementia can affect different people in different ways. However there are some common issues that can affect a lot of people living with the condition. These issues are not in themselves symptoms of dementia, but they can be difficult to cope with and can sometimes trigger anxiety, depression and other psychological problems.

Many people with dementia can also experience a lack of understanding from other people which can lead to feelings of isolation and loneliness. People can become socially excluded if their condition leads them to lose contact with their social networks or they have to give up work. People with dementia can also experience problems accessing appropriate treatment, support and information to manage their symptoms and this can sometimes be exacerbated by lack of coordination between services.

Depression and dementia

Depression and dementia share many of the same symptoms. This can make it difficult to identify depression in people with dementia. In Module 1 we looked at the distinguishing features. Depression is a common condition and around one in five of the population of Scotland will experience depression at some point in their lives.

Depression is more than feeling a bit low. It is a persistent condition in which a number of feelings, such as sadness, hopelessness or lack of energy, dominate a person's life and make it difficult for them to cope. In the early stage of the dementia journey they may be a reaction to the person's awareness of their diagnosis. We outlined the features of depression in Module1 and you may want to look back on this for reference.

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The main treatments for depression include psychological therapies, antidepressants, and social support or attention to the person's environment.

Mild depression may respond to increased social support, exercise, activity and attention to the person's environment. This can be achieved by, for example:

- pleasant activities that the person can still enjoy, such as short walks or outings.
- making sure there is a reassuring daily routine.
- protecting the person from unwanted stimuli, such as bright lights, loud noises and too much hustle and bustle.
- supporting people if they appear isolated and bewildered in a large group.
- one-to-one interaction, such as talking, hand holding, or gentle massage, if appropriate.
- The use of pets can also be helpful for people with dementia.



Remember

“I have the right to access a range of treatment and supports.”

Standards of Care for Dementia in Scotland (2011)

Psychological therapies for people with dementia who are depressed

For people in the earlier stages of dementia, talking about feelings may be a helpful way of treating depression using approaches that include:

- counselling
- cognitive behavioural therapy
- support groups

Talking therapies give people with dementia and/or their families and carers the chance to speak in confidence to a trained professional about the problems or issues that are causing them concern.

Drug treatments for depressions

Anti depressants can work well for a lot of people with dementia and depression. They may be helpful not only in improving persistently low mood but also in controlling the irritability and rapid mood swings that can sometimes occur in dementia.

BUT some anti depressants can have a number of side effects so it is important that if you are working with a person with dementia who is also taking anti depressant medication, that you are aware of this.



Remember

Knowing the person well or speaking to families and carers should help you recognise whether someone is affected by side effects and medical support is recommended in such instances.

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Perceptual problems that people with dementia can experience

Hallucinations

Hallucinations are sensory experiences that cannot be observed by anyone other than the person experiencing them. These experiences may include any of the senses, but the most common are visual (seeing things) and auditory (hearing things) this can be strange and frightening for the person with dementia.

Delusions

Delusions are ideas that seem to us to not be based on reality but are real to the person experiencing them and are often very distressing. The person might believe, for example, that people are stealing their money or possessions, or they may have ideas about people intending to harm them.

Misidentification

People with dementia can misidentify other people. For example, sometimes they do not recognise their partner as being the person they have known. At other times, they may think their reflection in the mirror is another person and become frightened, or think that voices on the radio or television are from people in the room with them.

You will appreciate that having these experiences can be very distressing and some factors that may make these experiences worse for the person with dementia include:

- Sensory defects, such as poor eyesight or poor hearing.
- Side effects of some medications.
- An unfamiliar environment.
- Inadequate lighting, making visual cues less clear
- Physical conditions – such as infections, fever, pain, constipation, anaemia, respiratory disease, malnutrition or dehydration.
- Unfamiliar staff.
- Disruption of familiar routines.
- Misinterpretation of environmental cues because of such things as forgetting to use a hearing aid or glasses.
- Sensory overload because of too many things going on at once.

What can you do to help people with dementia experiencing perceptual difficulties?

- Do not argue or tell the person off – it is better to acknowledge that the person may be frightened by their experiences.
- Make sure medical checks take place to eliminate physical health problems.
- Ensure that the person has access to any necessary sensory aids.
- Do not assume that suspicions are delusions. In some circumstances they may be true. (Module 5 explores harm and abuse further).
- Attempt to distract the person if possible. Distractions that may help include music, exercise, activities, conversation with friends and looking at old photos.
- Try to respond and validate the underlying feelings that the person with dementia is experiencing, for example fear.
- Physical contact may be reassuring as long as the person is comfortable with this.
- Try to maintain a familiar environment and staff and a consistent routine.

Supporting people with dementia and memory problems

In the early stages of the dementia journey there are a range of ways to support people's health and well-being by addressing the memory issues associated with dementia.

Medication that can help with memory problems

Following a diagnosis of dementia there are a range of pharmacological treatments that have been developed that can improve symptoms, or temporarily slow down their progression, in some people.

Generally, memory enhancing medication can be taken without too many side-effects **but** people's experiences will vary. For those who experience side effects the most frequent can be loss of appetite, nausea, vomiting and diarrhea. Other side-effects include stomach cramps, headaches, dizziness, fatigue and insomnia, increased blood pressure and constipation.

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Remember

If someone with dementia you are working with experiences these symptoms whether or not they are taking medication it is important to support them to seek professional medical advice or speak with your manager.

Other approaches to help with memory problems

Cognitive stimulation is a recommended evidence based intervention for people with dementia. People with mild-to-moderate dementia should be offered the opportunity to participate in cognitive stimulation activities.

Cognitive stimulation takes many forms including informal stimulation through recreational activities and/or more formally via structured programmes which aim to provide stimulating activities based on psychological theories of cognition. Cognitive stimulation can be carried out by health professionals, carers or relatives in a variety of settings.

There are a variety of formal programmes that train people in specific cognitive stimulation therapies, one such programme is Cognitive Stimulation Therapy.

Practical steps to help people with memory difficulties

There are also some basic strategies which we can use when we communicate with people with dementia that can help them with their memory difficulties such as:

- Providing information in small chunks, using short sentences.
- Allowing the person time to take in the information before giving more information - or expecting a response to a question.
- Minimising distractions such as background noise.
- Provide information and answers where necessary rather than pressuring the person to guess.
- Sometimes repeatedly correcting the person's mistakes can be very demoralising for the person - in these situations it may be much more helpful to acknowledge the person's feelings rather than repeatedly correct their answer.

Memory aids may also be useful such as:

- Wall charts for checking medication intakes.
- Calendars to remind people of events or appointments can help to minimise worry and uncertainty.
- Writing down lists such as shopping lists or instructions such as steps to complete when preparing a meal.

Module 3 - Promoting Health and Well-being for People with Dementia

Self assessment quick quiz

Check whether you have understood the main points

Answer True or False to the following questions

1. Physical exercise and activity is good for people with dementia
2. The only reason someone with dementia might fall is because they have forgotten how to walk
3. Carers of people with dementia are entitled to an assessment of their own support needs
4. People with dementia do not mind if they experience an uncomfortable personal care experience because they soon forget all about it
5. When people with dementia do not eat it is not always because they are not hungry
6. When you get a diagnosis of dementia there is nothing you can do that will help the symptoms
7. People with dementia can continue to enjoy intimate relationships

Module 3 - Promoting health and well-being for people with dementia

Module summary

In this module we have looked at a range of health and well-being issues that affect people with dementia and explored the ways that we can help and support them to keep well throughout their dementia journey.

Action into practice

From your learning in this module:

- Make a note of three new things you have learned about how you could support people with dementia to maintain their health and well-being.
- Reflect on your practice in relation to supporting people with dementia with their personal care needs.
- Identify three changes you could make that you feel would enhance your approach to supporting personal care for people with dementia.

Record your answers here:

**Module 4:
Meeting the Needs of the Person with
Dementia who is Distressed**

Module 4 - Meeting the Needs of the Person With Dementia who is Distressed

Introduction

In this module we will consider how to support people with dementia who are experiencing stress and distress. We will look at what this term means and what stress and distress might look like. We will examine how you might understand it and through case example we will explore how you could prevent people becoming stressed or distressed and if required, respond to this in a positive and person centred way.

Learning outcomes

By the end of this module you will be able to:

1. Understand that when a person is expressing stress and distress they can be communicating unmet needs.
2. Identify the common types, causes and triggers for distressed behaviour.
3. Contribute to recording and understanding distressed behaviours using an antecedent, behaviour and consequences approach.
4. Describe how to respond when a person with dementia is expressing stress and distress.
5. Recognise the importance of gaining access to professional support and interventions to alleviate stress and distress.

What do we mean by stressed and distressed behaviour in a person with dementia?

If someone appears distressed, agitated, angry, or anxious, it can be difficult to know how to respond when attempting to help the person.

Think about how you like to be supported by others when you feel angry or frustrated:

- Is it best to leave you alone?
- Can you think of someone you know who needs to talk it out, or even seeks out other people to make them feel better about something that is bothering them?
- Every person is different in how they respond to experiencing strong emotions.

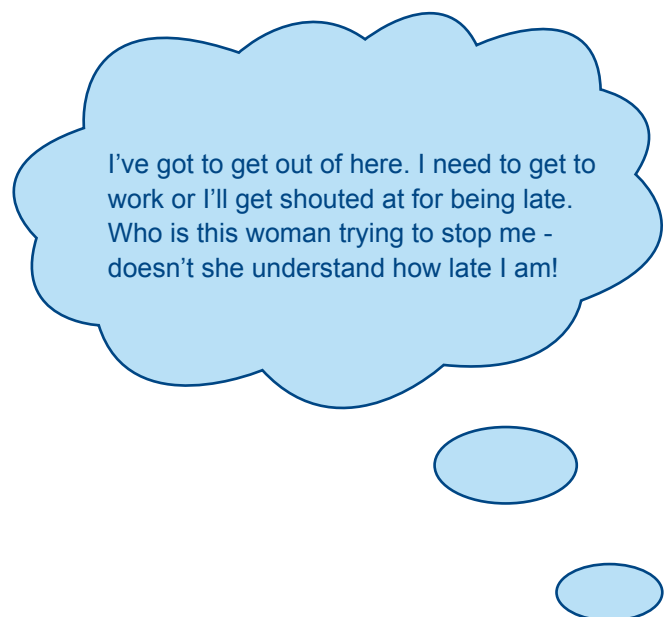
Now consider someone who has dementia who feels distressed, agitated, angry, or anxious. In Module 1 we explored the difficulties that people with dementia have in communicating and we developed this more in Module 2. People with dementia can

have difficulties in communicating what has caused their emotions. The way they may act when feeling distressed may be viewed as 'challenging' by other people, carers and loved ones. It is important for us to understand the causes, triggers, and ways of responding to stress and distress in a person with dementia, as dealing with this poorly can cause further emotional distress for the person and/or cause significant distress for carers.

Our perceptions of something that is difficult to manage can differ between people and therefore it can be helpful to **ask yourself the following questions first:**

- Is it really a problem?
- Who is it that finds the distressed behaviour problematic?
- Are there external factors that are challenging to the person with dementia?
- Is the behaviour compromising the safety of the person or others?

Distressed behaviour can be seen as an attempt to communicate an unmet need (Cohen-Mansfield, 2000) (1). Distressed behaviour may be the only way the person with dementia can still communicate with us. Hopefully we can identify the person's needs and meet these to prevent them from feeling distressed in the first place. For example, identifying and treating a hearing impairment early through fitting a hearing aid can reduce social isolation, improve mood and prevent distress.

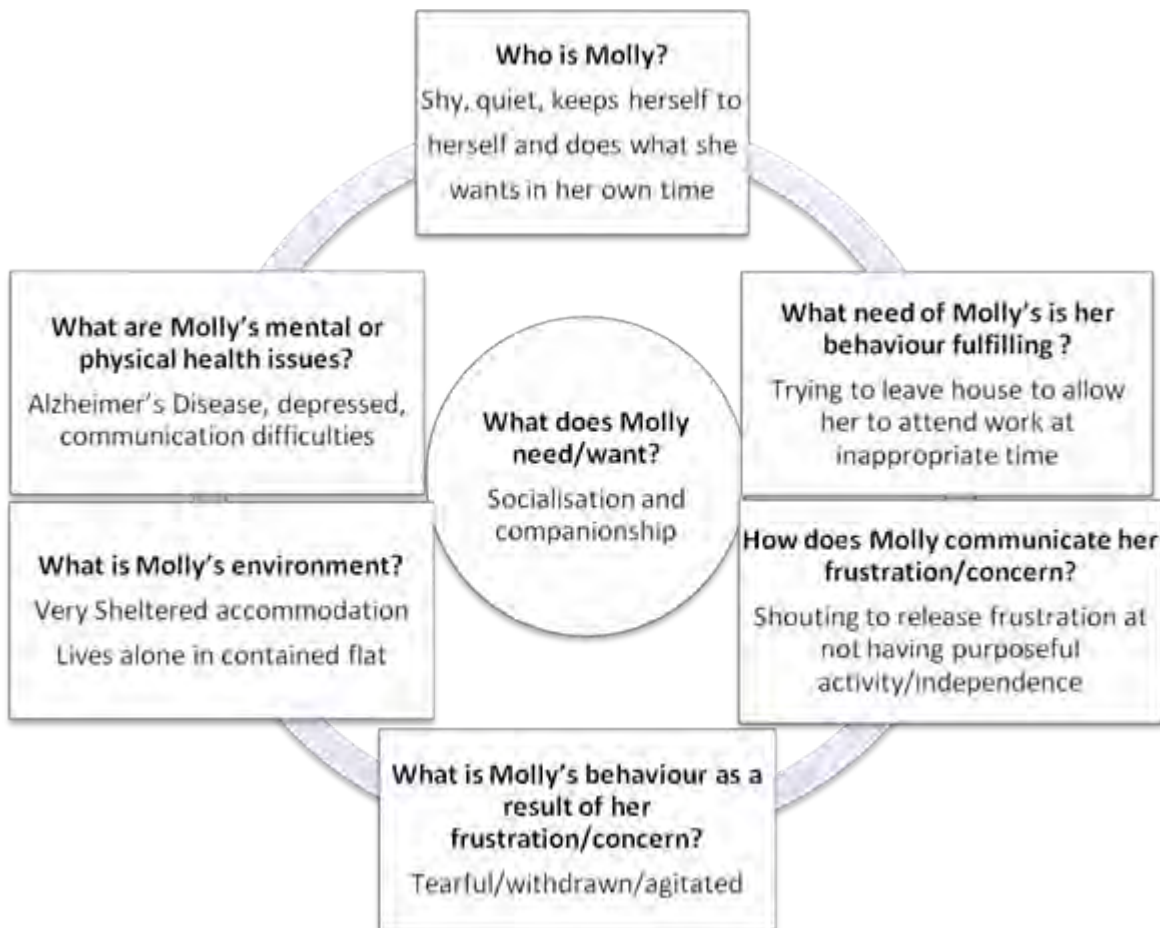


Module 4 - Meeting the Needs of the Person with Dementia who is Distressed

This thought is an example of the need a woman called Molly had – to get out to go to work. However a carer was trying to stop her from leaving her house in the middle of the night. When the carer stood in front of the door and repeatedly said “No you can’t leave” Molly shouted at the carer and became agitated since she believed she wasn’t being allowed to leave to attend to her duties.

Let’s use this model to see if we can understand Molly’s behaviour:

Using Unmet Need Model (Cohen-Mansfield 2000) (1)



Module 4 - Meeting the Needs of the Person With Dementia who is Distressed



Activity

Think of a person with dementia whom you support.

Do you think the person may be communicating that they have needs that are not being addressed?

Are they making constant requests for help, making strange noises, hoarding items or doing something different?

Using the model above as a guide, answer the questions in bold in relation to the person with dementia who you thought of.

Please ensure that you anonymise any information

Record your answers here:

When thinking about distressed behaviour, considering whether the behaviour is a way of communicating an unmet need is essential. However, it is also important to consider that the behaviour may be an expression of an emotional state.

What are the common types, causes and triggers for distressed behaviour?

People can express stress and distress in dementia in many ways and this can vary between people. For one person it may be simply shouting at other people, while for another it may be that they become withdrawn and unresponsive to those around them. For example, Alec who recently moved into a nursing home frequently paces the floor, follows staff around the care home and appears generally agitated. This can be viewed as Alec experiencing stress or distress, as he only started behaving in this way a few weeks ago. When he first moved into the home he was someone who would happily talk to other residents

Some people perceive distressed behaviours as aggressive, and can be frightened of the person displaying these. Most aggressive acts are due to anxiety or indicate the person feels threatened. Pushing people away or hitting, can actually be a way of communicating 'Stop. I do not like this'.

Module 4 - Meeting the Needs of the Person with Dementia who is Distressed



Activity

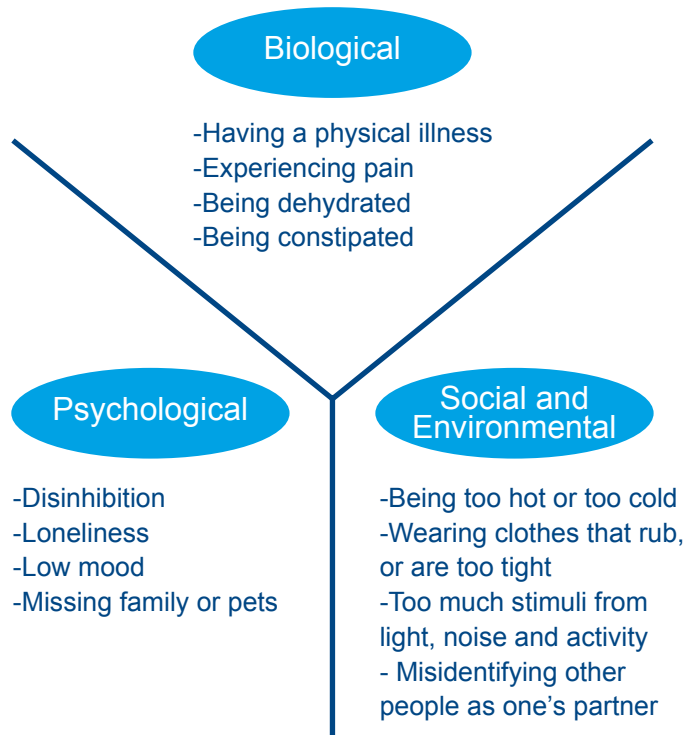
Think of a person with dementia you work with who has exhibited signs of distress and note down the range of behaviours that you noticed.

Please ensure that you anonymise any information

Record your answers here:

Triggers & causes of distressed behaviour

Here are some examples of some of the common causes of distressed behaviour



Note: Most distressed behaviour occurs some, rather than all of the time and the person may behave in a number of different ways.

Often there can be more than one behaviour present at any one time.

James (2011) (2) also suggests it can be useful to differentiate between:

1. Non-Active forms of behaviour (related to apathy & depression)
2. Active forms of behaviour:
 - a) reactions to stressful situations
 - b) walking and interfering activities
 - c) failures to inhibit actions
 - d) thoughts and emotion
 - e) a mismatch between the person and the environment



Remember

If people with dementia are expressing distress it is critical that the situation is assessed accurately.

Module 4 - Meeting the Needs of the Person With Dementia who is Distressed

Ellen's story

Remember Ellen, whom we met in the *Informed About Dementia* DVD and in earlier modules:

Ellen is 80 years old and lives at home with support from her daughter Carolyn and Homecare staff. In the DVD Ellen appears distressed, shouting at her daughter and pushing her away when she is due to attend the lunch club. She states that she needs to find her tablets. Ellen cannot find her tablets and Carolyn is finding it difficult to know how to respond to her.

If we look back at Ellen's life, we find that she was always a very busy and organised person. While raising her three children, she worked by keeping the accounts for her husband John's car repair garage. She has always valued feeling needed, enjoyed contributing to the family business and organising the family's home life.



Activity

What do you think might have been causing Ellen's distressed behaviour?

Record your answers here:

Module 4 - Meeting the Needs of the Person with Dementia who is Distressed

Possible causes of distressed behaviour

It can be useful to think of the distressed behaviour as the 'tip of the iceberg'. You see the behaviour but there are many factors that interact and cause the person to experience distress.

Distressed Behaviour

Physical Environment

Lack of space, privacy and routine
Under or over stimulated by others

Personality

Someone who has always been very shy is now spending long periods in a busy day room. Or, someone who has always been a worrier may be fearful of new situations

Cognitive and neurological difficulties

Not being able to stop unsociable behaviours e.g. touching strangers.
Remembering that they no longer have to go to work due to changes in the brain

Mental health

Anxiety, depression, psychosis

Care and Cultural Environment:

Structure and carer interactions

Perceptual deficits

Not being able to see, hear or touch objects effectively, leading to confusion

Physical health problems

Arthritis which is causing pain. Hand tremor leading to frequent dropping of objects

Biological Changes

Increasing appetite, reduced or increased energy levels, increased irritability

Medication

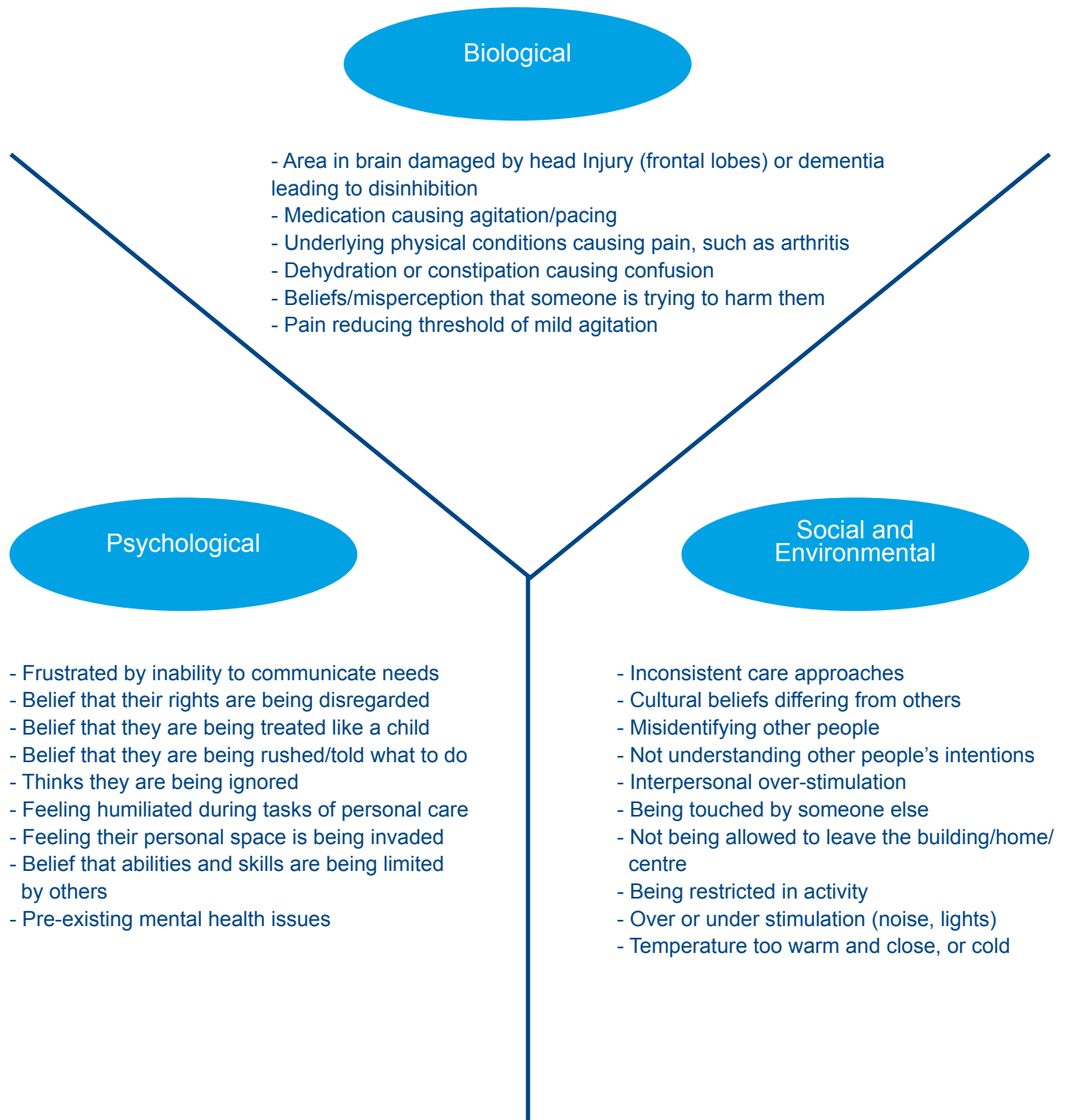
Interactions of multiple medications, side-effects

Beliefs

I'm 32 years old and I need to collect the kids from school

Module 4 - Meeting the Needs of the Person With Dementia who is Distressed

Here are common causes for behaviour perceived as aggressive. You may notice the similarities between some of the factors below and those already identified as causing distressed behaviour.



Module 4 - Meeting the Needs of the Person with Dementia who is Distressed



Activity

Now that you have looked at the table above answer these questions

Do you think any of these factors could be related to Ellen's situation?

Which factors do you think they could be?

Can you think of anything that could help Ellen's situation?

Record your answers here:

Reflection

Have you ever had an experience where you felt that someone was "being difficult"?

What are your thoughts about this, having read the information above?

What impact will this have on your practice?

Please ensure that you anonymise any information

Module 4 - Meeting the Needs of the Person With Dementia who is Distressed

Approaches to understanding distressed behaviour

As part of providing person-centered care for people with dementia who are experiencing stress or distress, it is important to conduct an assessment to identify or understand what need is not being met. You may be asked to contribute to the assessment in a number of ways. If you work closely with the individual on a frequent basis or know them well, you may be asked to complete ABC charts.

What are ABC charts?

ABC charts help us to assess the situation surrounding the distressed behaviour. They give us time to reflect and consider what was happening before, during and after, an episode of stress or distress. The examination of completed ABC charts can provide some answers, or at least some theories, about the causes of the behaviour or in other words, the unmet need that is being communicated.

The ABC chart:

- aims to shed light on the emotion that the person may be experiencing at the time (e.g. fear, anger, sadness, anxiety, frustration).
- helps us to understand what they might be thinking and what they are trying to communicate to others.
- is a method for analysing what just happened and to consider all possible clues in the environment that may be triggering or maintaining someone's distress. It also helps us record and monitor how often the person is experiencing distress and monitor any improvements over time.

The first rule of ABC charts is to be specific about what it is you want to assess and understand. For example, stating that you are assessing 'agitation' is not specific enough. Ask yourself how you know the person is agitated. It should be as specific as 'pushing' or 'stripping off clothes'.

The second rule is that you should complete ABC charts consistently – if you start the process, you should complete them every time the distressed behaviour is displayed.

On the following page is an adapted ABC chart, originally developed by professionals in Newcastle (James, 2011) (2).

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ABC Chart

1. Distressed Behaviour.....

2. Date and Time	3. Where was the distress observed?	4. Who was there at the time?
-------------------------	--	--------------------------------------

5. What was going on for the person prior to the incident (A – antecedent)

6. What did you observe the person do? (B – actual behaviour)

7. Record what the person said during the incident?

8. What made the situation better? (C - consequences)

9. What emotion were they expressing before the incident?

- | | | |
|------------|--|--------------------------|
| Angry | <input type="checkbox"/> Frustrated | <input type="checkbox"/> |
| Anxious | <input type="checkbox"/> Happy | <input type="checkbox"/> |
| Bored | <input type="checkbox"/> Irritable | <input type="checkbox"/> |
| Content | <input type="checkbox"/> Physically Unwell | <input type="checkbox"/> |
| Depressed | <input type="checkbox"/> Restless | <input type="checkbox"/> |
| Despairing | <input type="checkbox"/> Sad | <input type="checkbox"/> |
| Frightened | <input type="checkbox"/> Worried | <input type="checkbox"/> |

10. What emotion were they expressing during the incident?

- | | | |
|------------|--|--------------------------|
| Angry | <input type="checkbox"/> Frustrated | <input type="checkbox"/> |
| Anxious | <input type="checkbox"/> Happy | <input type="checkbox"/> |
| Bored | <input type="checkbox"/> Irritable | <input type="checkbox"/> |
| Content | <input type="checkbox"/> Physically Unwell | <input type="checkbox"/> |
| Depressed | <input type="checkbox"/> Restless | <input type="checkbox"/> |
| Despairing | <input type="checkbox"/> Sad | <input type="checkbox"/> |
| Frightened | <input type="checkbox"/> Worried | <input type="checkbox"/> |

Reference: Newcastle Challenging Behaviour Team - see James (2011)

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ABC stands for:

A – Antecedents: This means what was happening just prior to the person becoming distressed. Antecedents can trigger or reinforce distress. Identifying antecedents helps to identify causes of distress so that preventative action can be taken in the future.

B – Behaviours: This is simply a description of the behaviour(s) witnessed by you/staff/carers. You should not interpret the behaviour – just provide factual details as to where the person was, what they said or did, to whom etc.

C – Consequences: These are the responses or outcomes to the distressed behaviour, either from others or the person in distress. This helps to determine what might be achieved by communicating their distress. For example, in many instances ABC charting can highlight the things that have been successful in dealing with distress and these can be incorporated into a person centred care plan.

How to complete ABC charts

ABC Charts should only include your **observations - NOT personal opinion or impressions**. They are a factual and objective tool. Think of it like presenting evidence in a court of law - report what you saw and heard only. Do not begin to try to guess **'why'** the person acted in a certain way. This comes later!

Record all sections of the ABC chart. If any are missed then the chart is not going to be as helpful. For example, the date and time are important to record. This can provide a clue as to whether the person tends to become distressed at a particular time of day. Sometimes patterns can emerge e.g. when sedative or painkilling medication is wearing off or has just been given. If behaviour occurs before lunchtime, this could indicate hunger. Or does this occur on a Sunday when four family members visit and perhaps over stimulate the person?

Consider these questions when completing ABC Charts:

1. What is the specific behaviour you are analysing?

Example answer: Repetitive shouting 'Help me! Help me!'

2. What is the date and time?

Example answer: Monday at 8pm

3. Where was the person?
For example, the kitchen/ at the back door/ in the toilet/ in the day room or travelling from somewhere to another place?

Example answer: Sitting in the day room in the corner

4. Who was present in the environment? Remember to include yourself!

- Were there other people before this who had just left?
- Was the person alone prior to your arrival?

Example answer: Penny, Iain, and myself (nursing assistant)

5. Completing the A's: How noisy was the environment? Was the temperature hot or cold? Lighting? Who else was there? Was someone else agitated? What just happened?

Example answer: 'Penny was sitting in the day room watching the television. Iain walked behind her and touched her head. It was warm and quiet in the day room'

6. Completing the B's: What happened? How did the person behave? How often did it occur and how long did it last?

Example answer: 'Penny screamed after Iain touched her head and shouted "Help me! Help me!" for approximately 30 minutes'

7. What did the person say at the time of the incident?

Example answer: "Help me! Help me!"

8. Completing the C's:

- How was the situation resolved?
- What did you do to try and reduce the distress?
- What did you say?
- How did you try to comfort the person?
- Did they respond to your touch?
- What tone of voice did you use?
- Did people leave or arrive to assist?

Example answer: Two other staff came to assist, but Penny increased her shouting. Staff left the day room and redirected Iain away. I tried to reassure Penny by stating "Its okay Penny, you are safe now" in a soft tone and stroked her hand. I began talking about the dogs she had when younger.

9. How did the person look before the incident in terms of the emotions being experienced? (there are tick boxes in the chart for you to use)

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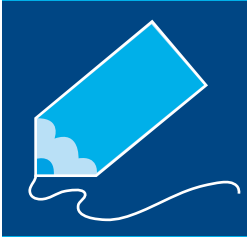
Example answer: Penny looked frightened, worried, and anxious.

10. How did the person look during the incident in terms of the emotions being experienced? (there are tick boxes in the chart for you to use)

Example answer: Penny looked frightened, worried and anxious

Why do we have to fill in ABC charts?

By completing ABC charts, we are learning about the individual rather than using a 'one-size-fits-all' approach. All people are different and something that can cause distress for one person will not necessarily cause distress in another. Rather than using methods or ways of interacting simply on 'hunches', 'trial and error', or 'what seemed to work for someone else', the ABC assessment process should guide the development of a person-centered and individually tailored support plan. It is everyone's responsibility to contribute to the assessment and recording of the needs of people with dementia who are expressing distressed behaviour.



Activity

Using the DVD *Informed About Dementia* watch Ellen's scenario in Chapter 3 and using a blank copy of the ABC chart, try to review what the ABCs were during the situation where she pushes her daughter.

We have provided a completed chart at the end of this module for you to compare (Appendix 1).

Record your answers here

What happens after the ABC charts are completed?

After ABC charts are completed over a period of 1-2 weeks, a member of staff who has been trained in ABC analysis can analyse all of these and help the team develop a shared understanding of the individual's distress, its causes and some of the thoughts and emotions which may have triggered the person's distress. Once we understand this, we can then develop an understanding of what we can do to reduce their distress and meet the needs which are currently unmet. This will form part of the person-centered care plan.

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Remember

Continued monitoring of distress communicated by people with dementia can tell us if their person-centered care plan is working.

Using person centred approaches to support people with dementia who are communicating distress.



Remember

Preventing people with dementia becoming distressed in the first place should be our primary aim.

Preventing distress

Prevention of distress should always be our priority in person-centered care. If you follow these guidelines then the likelihood of having to respond to distress and stress should reduce.

Some key issues you should consider are outlined as follows:

Always use helpful communication approaches

Maximising people's opportunities for helpful communication can reduce the likelihood of people with dementia becoming frustrated or distressed when they have difficulty understanding or responding to what is being communicated to them.

Remember these simple rules for communicating with people with dementia to reduce the potential that they may experience confusion resulting in distress:

- Avoid jargon.
- Speak calmly using gentle tones
- Keep sentences short.
- Allow people time to understand and respond to your questions – rushing people can make them more confused, muddled, and anxious.
- Use the person's name to let them know you have met them before and are not a stranger.
- Remind the person who you are
- Use everyday words.
- Smile and nod to show you are listening and trying to understand.
- Try to address sensory deficits e.g. does the person have suitable glasses and a working hearing aid, if required?

Encourage people's choice and independence

Support the person to be as independent as possible. For example, encourage people if they are having difficulties completing some tasks. Don't take over because they are slower at completing some activities. It is okay if people take longer to get dressed in the morning. It is better for them to complete tasks for themselves with support and encouragement, than for these tasks to be done for them, as this can make people feel frustrated and angry.

Make sure the person is not in pain

You can prevent distressed behaviour by checking factors such as pain levels and by providing pain relief on a regular basis before this leads to distressed behaviour.

Make sure the person's fundamental care needs are being met:

For example ensure the person has regular toilet breaks and is not hungry or thirsty.

Make sure the person has opportunities to engage in meaningful activity

Providing appropriate stimulation can be both a

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preventative measure and a response to distressed behaviour. If someone appears withdrawn, depressed, bored or lonely, why not ask if you can provide personalised activity such as listening to a genre of music they have liked in the past or looking at old photographs they have (stopping if they appear at all distressed).

Always show respect for the person

Take the time to explain what you are trying to do before beginning a care task. You wouldn't assume you can walk into your friend's house and start moving things about. Treat people with dementia as you would anyone else. Ask them if you can come in, or ask 'is it ok if I help you with that?'

Ask permission to carry out tasks or to enter their personal space such as a bedroom and give an explanation of what you would like to do. Be prepared to repeat instructions, calmly and clearly. It is also important to make sure they have had time to fully waken up before beginning with tasks such as personal care or medication regimes. Startling someone can lead to a frightened or defensive response.



Remember

"I have the right to be regarded as a unique individual and to be treated with dignity and respect"

Standards of Care for Dementia in Scotland (2011)

Responding positively to people with dementia who are communicating distress

In this module we will explore in more detail some examples of people with dementia communicating distress and how you can respond positively to support them.

An example – A person communicating distress by shouting and searching

Let us return to Ellen's story. Last time we saw her she appeared distressed (shouting at her daughter Carolyn) about trying to find her tablets and was pushing Carolyn away.

Points to consider:

Ellen is looking for her tablets, but what else might she be communicating?

- Could Ellen be in pain?
- Is she having difficulty recalling where she has put things?
- Is she frustrated with her memory lapse or worried about not being able to find her tablets?
- Is she trying to communicate that she doesn't like the lunch club?

How could you best respond?

- Use the **verbal communication techniques** we have described (calm voice, gentle tone, short sentences)
- Also **use non-verbal communication** - making eye contact demonstrates that the person has and is worthy of your attention. Show you are listening and demonstrate empathy/understanding by using facial expressions and non-verbal cues such as nodding, tilting your head to the side.
- Let the person know you can see they are upset/angry/scared e.g. "You look upset Ellen".
- Ask the person what they are trying to communicate eg. "What is upsetting you Ellen?".
- When Ellen responded with "I'm looking for my tablets", you should not try to get her to 'remember' where they are – this will only frustrate her more. If she could remember she would!
- Ask "Are you sore?" or "Are you in pain?" and wait for her response. If this is "No", then consider asking "Why don't I help you look for your tablets?" helping Ellen to find her tablets in a calm way, to reduce her alarm and distress at not being able to find them herself.
- Ellen may also be communicating that she does not wish to attend the lunch club today. Ask Ellen if she wishes to attend. It is Ellen's choice and decision to whether to attend.
- If Ellen states that she is in pain, ask her "Where are you sore?". If Ellen indicates that she is

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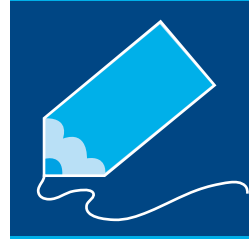
in pain you could speak with Carolyn or your manager about Ellen consulting with her GP or nurse, to seek advice on whether an assessment is required or if pain medication can be given.

In this scenario, if it is a regular occurrence for Ellen to be worried that she may have missed her tablets (as Ellen may have always been a person who did not like to miss her tablets throughout her life), a preventative measure such as ticking the calendar or a white board when medication has been taken may help to reassure Ellen that she has taken her medication for that day/time.

An example – A person communicating distress by verbal aggression

Penny has lived in her house for twenty years. She is receiving homecare support but when various carers try to assist her in getting out of bed or by prompting her to take medication, she can become verbally aggressive and will scream and shout repeatedly. The carers do not know how to react and no matter how much they try to explain to her, she just keeps shouting.

Penny's thoughts: 'I have lived in this house all my life and I can't believe all these people that I don't know are in my bedroom. Who are they? I have shouted and shouted "HELP! HELP!" at them but they won't leave'.



Activity

Put yourself in a similar situation to Penny. How would you feel if you found someone you hadn't met before in your kitchen cooking a meal when you got home tonight?

Write down the emotions you may feel:

What would you think?

What would you do if the stranger approached you in this way?

How would you want the person to behave towards you in this situation?

What could you say to be helpful or reassuring?

Record your answers here:

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How could you best respond?

Verbal communication

- Use good verbal communication: Tell the person who you are eg. "I am Angela, Penny. I come in the mornings to see if you need any help with anything. How are you today?"
- Communicate that you actually know the person and you are not a complete stranger.

Use their preferred name. Talk to them about their personal interests or experiences, for example Penny may feel more orientated if you said "I saw a painting you might have liked yesterday" or "Tell me about your dogs?", if she is known to have had dogs throughout her life or enjoyed art. If you do not know about the person's interests make this your task! Talking about familiar things to the person works by providing a pleasurable distraction and reducing their anxiety by allowing them to relate to something familiar.

Nonverbal communication:

- Direct the person to a photograph with you both in it – by showing a photograph of you both together, this will be a memory prompt or reminder that the person has spent time with you before.

An example – A person communicating distress by physical aggression

Consider Jeannie's thoughts. A carer is trying to support her with her personal hygiene care.

Jeannie's thoughts:

'That woman is trying to take off my clothes! Who is she? I only came in here to get my wee brother and take him home. The police should know about this place. Well she won't be stripping me! I think she must be mad. I'll give her a good slap; that will stop her'.

Meeting the personal care needs of people with dementia can sometimes be very difficult.

Points to consider:

Washing and bathing can become a source of great distress for the person with dementia and can also be physically and emotionally challenging. Remember we explored this in module 3. There are a number of reasons for this.

- Being naked in front of a stranger can be difficult. The person with dementia may feel embarrassed and not understand that you are there to care for them.
- Pain as a result of illness and musculoskeletal conditions can make the person wish to avoid certain tasks.
- Physical weakness caused by frailty and ill health.
- Anxiety and misunderstanding because of memory impairment.
- Loss of understanding, or inability to recognise the bathroom and its purpose.
- Previous negative bathing experiences.

How could you best respond if someone has been physically aggressive?

When someone is stressed or distressed their levels of physiological arousal can increase. It can take 45-90 minutes for these levels of to return to normal after an aggressive outburst such as a physical assault, so make sure that once the aggressive act is over, the person is given time to calm down in a quiet area where the likelihood of provocation is minimal.

Try not to show criticism or irritation and do not confront them. Watch for warning signs that they are becoming more anxious or agitated. Get help if the situation does not begin to calm down quickly. Do not make sudden movements or use a sharp tone - remain calm and keep your voice low. Give the person plenty of space.

An example – A person communicating distress by behaviour that could compromise their safety or the safety of others

Alec lives in very sheltered housing and has recently started to stand at exit doors for long periods of time.

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Activity

Is Alec trying to leave because he does not recognise this as his home?

If so, could you place more familiar objects around for him such as pictures of himself with staff and other residents?

Does this behaviour occur at certain times such as meal times?

Is the environment too noisy or overwhelming for him at these times?

Would he benefit from time in a quiet room for his meals?

Record your answers here:

How could you best respond?

If the person is engaging in an action which is compromising their safety you could explain to them the reason why they should not do this and then try to redirect them to another activity.

You could, for example explain to Alec – “I’m sorry Alec but this door is a fire exit. If we had a fire we couldn’t get out so it’s not safe for you to stand here”. Try distraction eg. saying “Anne has just made some cakes in the kitchen. I’m going to have one. Would you like to come and get one with me?”

An example – A person communicating distress by touching or inappropriate sexual behavior

Iain lives in sheltered housing and tends to touch staff and other residents. He has also been touching his genitals in public areas.

Points to consider:

- Why do you think Iain tends to grab hold of staff and other residents?
- Does he seek comfort from others?
- Are there particular people he touches regularly e.g. females?
- Do they remind him of his wife? Is he missing intimacy with her?

How could you best respond?

- You could consider approaches such as Simulated Presence Therapy – this can provide comfort. This is the technique of playing a personalised audio or video tape of the main carer to the person with dementia. This recording might be of the carer recalling a positive shared memory such as a family trip.
- Provide appropriate physical contact – hold or stroke the person’s hand whilst talking to them in a calm manner. Make the person feel acknowledged and included by using their name e.g. “That’s a lovely red jumper you have on today Iain”

Further points to consider in this situation that could inform your response:

- Are the female residents wearing similar clothes to Iain’s wife?

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- Do they have similar glasses or hairstyles?
- Can these be modified with the ladies consent, in order to reduce the likelihood of him misidentifying them as his wife?
- Would this behaviour reduce if his most frequent contact is with a male staff member?
- If this is an unmet sexual need, can he be directed to a quiet private area where he can fulfil this without upsetting other residents?

Other ways that people may communicate distress

Repetitive Questioning

The person may ask the same question over and over again. This is usually related to memory loss and they simply cannot remember the answer you gave them. If they are also feeling anxious or unwell this can make the situation worse. Try not to be insensitive when you respond. Do not say things like, "I've already told you that", as this can increase the person's feelings of anxiety. **It is best to provide the answer for them each time, since asking them to guess by giving them clues often leads to errors and more confusion!**

Once you have given the person the answer, try to distract them or encourage others to do so.

Distraction can be a very effective way of supporting people with dementia who are experiencing distress. The general idea is to talk about something that is not related to what is distressing the person. It is important to use short and simple sentences and to stay calm. This is particularly effective if you know something of the person's life history such as their hobbies or previous occupation.

The main aim of distraction is to try and re-focus the person onto something that is less distressing or anxiety-provoking. If you find yourself becoming irritated by their repetition, it can help to leave them with someone else for a short time until you feel more responsive. The person can also become stressed by planned future events such as hospital trips. In this case, it is often better to tell them about this just before it happens, so they don't become more anxious and worried over time.

Repetitive phrases or movements

Some people repeat the same phrase or movement time after time. This is called perseveration. This can be caused by physical discomfort and is made worse when the person is in pain or unwell. It can also be exacerbated by the demands of noisy, busy

environments.

Treating the person's physical condition and reducing the demands of the environment may help. Repetitive behaviour such as moving the chairs around or trying to empty bins can be caused both by anxiety or boredom. Having something safe for the person to occupy themselves with may help in this situation.

Suspicion

Sometimes the person with dementia may accuse people of stealing from them or talking about them. This can be due to the memory problems they have or difficulties in making sense of the world around them. This is often worse when they find themselves in a strange environment and are unwell or injured. It is important to appreciate that the person cannot control their beliefs and that these are real to them. It is therefore useless to argue with these beliefs. By showing that you understand why they are distressed they may become calmer. Distracting them, rather than discussing their beliefs and reassuring the person that you are there to help, may ease the situation.

Of course it is also important to check the truth of any assertions the person may make, but if these are clearly untrue, then it is equally important to support the person with dementia who is likely to be very distressed by these beliefs. Focusing on the feeling the person is expressing is a more appropriate intervention than challenging the belief.

To avoid persistent suspicion ask yourself: Can I prevent the suspicion from happening? For example, if someone is suspicious that someone is stealing their wallet, or repeatedly asks where it is (because they cannot find it); could you or their carer get them a brightly coloured & extra large sized wallet? Each night this could be put in a basket by their bedroom door and as a visual aid, a tick could be placed on the wall chart next to it to confirm it has been put in the correct place.

Pharmacological approaches to distressed behaviour

Medications

A number of medications are prescribed to try to manage distressed behaviours expressed by people with dementia. This is because health professionals are trying to treat what they believe to be the cause of the person's distress. For example, if a person is shouting or screaming at others that only they

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can see and they are very distressed by this, it is reasonable to think that they are experiencing hallucinations. Therefore, treating the psychosis or hallucination would be desirable, to reduce the distress. Sometimes other behaviours such as aggression, agitation, or mood problems such as anxiety and depression are also treated with prescribed medications, with the aim of reducing the distress associated with these.

However, many experts have highlighted the fact that some medications are prescribed with the intention of using a sedative or tranquillising effect to reduce behaviours perceived as 'difficult'. In fact, some of these medications do not have a high success rate in reducing actual distress, and can come with serious significant unwanted effects and carry additional risks.

Medical professionals are all too aware of this, and are reducing the prescription of medications that have little benefit to the person and may also cause serious risk. Health professionals would prefer non-pharmacological options where possible, with regular reviews of prescribed medications for individuals.

There are a range of unwanted effects and negative outcomes associated with many of these medications used to treat the problems people with dementia might face including psychosis, sleep disturbances anxiety, agitation and distress.

Possible unwanted effects of medication

- Increased mortality rate
- Risk of falls and therefore, fractures
- Drowsiness
- Movement problems
- An increase in the rate of difficulties with memory or language
- Increase in agitation and confusion
- Constipation
- Stroke
- Incontinence
- Dry mouth
- Weight gain
- Diabetes
- Walking about (sometimes called "wandering")
- Liver toxicity
- Sexual dysfunction
- Stomach upset
- Blurred vision and dizziness.

Anti-depressants are sometimes given to people with distressed behaviours due to their sedative effects.

It is recommended that people who are prescribed these medications have these regularly reviewed by their doctor or nurse.



Remember

If you have concerns that the person you care for has not had a recent medication review, or is affected by any of these side effects you should raise this with the person's family or carer and/ or your manager or the person's medical practitioner.

For more detailed information on medications used for treating symptoms of distress, please read 'Dementia: Drugs used to relieve depression and behavioural symptoms' published by the Alzheimer's Society by clicking here:

http://alzheimers.org.uk/site/scripts/document_pdf.php?documentID=110.

Memory problems are common even in the early stages of dementia and therefore some people can be forgetful in taking their medication. Some people with dementia may need essential medications for other physical health conditions such as heart problems or pain and it is vital that these are taken as prescribed. If you suspect this is the case for the person you care for, requesting medication in blister packs (or a dosette box) may help the person manage their own medication or assist carers to monitor medication intake. A chart can also be helpful for some people to record when they have taken their medication.

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Accessing professional support and interventions to alleviate stress and distress



Remember

Prevention is best!

There will be times when the person with dementia when you support may become stressed or distressed and you feel unable to help. If you think back to the potential causes of distressed behaviours, you will remember that there are a number of factors that can cause these. These include medications, the physical, environmental, psychological and emotional factors to name a few. It is therefore important that we are able to assist the person to access the right support and in a timely fashion.

For example, if your communication style has not helped to alleviate someone's agitated behaviour because actually it is pain that is the main trigger for their distress, what they really require is medical support to assist them with this. Therefore, when you have tried to prevent distress, have used the strategies documented here and have found that they have not helped it is important that you support the person to access professional assessment and review. You should always ensure that families and carers are involved in their decisions.

However, if you find that you are at all unsure you should communicate your concerns to your manager or, if you do not have one, approach a relevant professional. The person with dementia may already have a Community Psychiatric Nurse (CPN), Psychiatrist or other mental health professional who can assess and intervene, but will be unable to help if they do not know there is a problem. Otherwise the person's GP should be able to help. We all have a responsibility to contribute the prevention of distress in people with dementia.



Remember

"I have the right to access a range of treatment and supports."

Standards of Care for Dementia in Scotland (2011)

Often, the first port of call is the person's GP who can screen for infections or refer to specialist services such as community treatment teams that include nurses, social workers, medical staff, psychologists, occupational therapists and a range of other professionals. These multi-disciplinary teams can assess and intervene appropriately to attempt to meet the person's individual needs.



Remember

No two people are the same. Distressed behaviour may appear similar, but have different causes. Different causes need different approaches and interventions.

It is important to prevent distress in people with dementia not just for the person in distress, but for their families and carers. Observing someone in distress can result in the carer experiencing stress or distress too. It is important to discuss difficulties managing or coping with stress and distress in people with dementia, for all parties involved. Carers can be signposted to Alzheimer Scotland and health and social care services for information help and support.

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Self assessment quick quiz

Check whether you have understood the main points of this module by completing the set of multiple choice questions below:

1. Stress & distress in dementia reflects the fact that:

- A) The person's needs have not been met and this is their way of communicating this.
- B) The person is confused and doesn't know what they are doing.
- C) The person is seeking attention.

2. Identify the possible causes of Stress & Distress:

- A) Stress and distress almost always has a biological cause.
- B) Stress and distress can be caused by individual biological, psychological or social/environmental factors.
- C) Stress and distress can be caused by a combination of factors.

3) True Or False - depression and withdrawal are not examples of stress and distress in dementia

4) The A, B and C in an ABC chart stands for:

- A) Assessment, Background, Consequences.
- B) Antecedents, Behaviour, Consequences.
- C) Antecedents, Behaviour, Causes.

5) ABC charts should:

- A) Be completed consistently every time the behaviour occurs.
- B) Be completed once per week to give a snapshot of the behaviour.
- C) Be completed for the most significant behavioural episode of each day.

6) Prevention of stress and distress is always best. Which of the following are effective ways to prevent stress and distress? (tick all that apply):

- A) Show respect to the person with dementia.
- B) Maximise communication.
- C) Prevent pain.
- D) Engage in meaningful personalised activity.
- E) Encourage choice & independence.
- F) Ensure the person's fundamental needs are met.

7) If someone with dementia appears distressed and is shouting and hitting out at others you should follow the following steps:

- A) Change medications to include a sedative to reduce obvious distress.
- B) Try to redirect them each time they are distressed by engaging them in an existing group.
- C) Use ABC charts to establish any patterns to the problems. Review medication/side effects. Review the person's life history & background. Develop theories about the cause of the distress, develop interventions based on your theories of what may be causing the behaviour, test these out and monitor the results.

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8) Pharmacological interventions may be used alongside non-pharmacological interventions – it is important to consider the following factors:

- A) The side effects of medications are monitored and regular reviews of medication regimes are carried out
- B) The medications are easy to access & administer
- C) The medications are consistently kept at the highest possible dose

Answers:

- 1) A
- 2) C
- 3) False
- 4) B
- 5) A
- 6) ALL
- 7) C
- 8) A

Module 4 - Meeting the Needs of the Person With Dementia who is Distressed

Module Summary

In this module we have we have considered the experiences of people with dementia and we have learned that it is important to try to prevent stressful situations arising to therefore avoid the person with dementia becoming distressed. However, given the complex interplay between the effects of the condition, the needs of the individual, and the physical and social environment surrounding them, this can often be challenging.

We learned about using ABC charts as a way of analysing, monitoring and understanding the behaviour being displayed as well as the distress caused to the individual and explored a range of possible responses designed to alleviate the stress and distress.

We, once again, heard about the need to be person centred in our approaches to helping the person with dementia, their family and their carers in responding to difficult situations which can be traumatic and challenging for everyone.

Action into Practice

From your learning in this module

- make a note of three new things you have learned about supporting people with dementia who are experiencing stress and distress.
- have a look around your place of work and see if there are any environmental or social issues that could cause people with dementia to experience distress.
- make a note of three changes you could make that you feel could enhance your practice.

Record your answers here:

References

- (1) Cohen-Mansfield, J (2000) Use of Patient Characteristics to Determine Nonpharmacologic Interventions for Behavioural and Psychological Symptoms of Dementia. *International Psychogeriatrics*, Vol 12, Suppl. 1, 373-380.
- (2) James, I.A. (2011) Understanding behaviour in dementia that challenges; A guide to assessment and treatment. London. *Jessica Kingsley Publishers*.

Module 4 - Meeting the Needs of the Person with Dementia who is Distressed

Adapted from James, I A (2011) (2)

1. Distressed Behaviour..... Pushing/General Agitation

2. Date and Time Friday 11:30am	3. Where was the distress observed? Ellen's lounge	4. Who was there at the time? Daughter Carolyn and Lunch Club support worker Leanne
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5. What was going on for the person prior to the incident (A – antecedent)

Ellen was searching the lounge, at the mantle piece behind framed pictures, whilst Carolyn was trying to communicate that she had to go to the lunch club. Leanne was standing in the lounge also. Carolyn touched her on the back and showed her jacket. Ellen continued to search in her handbag.

6. What did you observe the person do? (B – actual behaviour)

When Carolyn attempted to reassure she had taken them already and tried to put her coat on she pushed her away.

7. Record what the person said during the incident?

Ellen shouted “I need to take my tablets”

8. What made the situation better? (C - consequences)

Ellen left the lounge to search for tablets and no-one followed her. Gave her space.

9. What emotion were they expressing before the incident?	10. What emotion were they expressing during the incident?
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**Module 5:
Supporting and Protecting People's
Rights**

Module 5 - Supporting and Protecting People's Rights

Introduction

People with dementia their families and carers have the same rights as everyone else in society and we need to empower, enable and support them to exercise their rights throughout their dementia journey. In this Module we will explore what rights are and our duty to ensure the dignity, civil and legal rights of people with dementia are respected and they are given the level of assistance they want and need to participate in decisions that affect their lives. We will look at how their rights and legal protections have been strengthened by recent legislation and safeguards.

Learning outcomes

By the end of this module you should be able to:

1. Understand and apply the Charter of Rights for People with Dementia in Scotland to inform and develop your practice.
2. Understand the principles and provisions of legislation in place to protect people with dementia, and their families/carers rights and choices and how this should inform your practice.
3. Understand the principles and provisions of policy and legislation that are in place to provide people with dementia and their families/carers with safeguards and protection, and how this should inform your practice.
4. Understand the principles of capacity and consent and how this applies to your role to inform and develop your practice.
5. Contribute to the assessment and support of people with dementia who may be experiencing neglect, harm or abuse.
6. Examine the concepts of risk and risk enablement in relation to your role in supporting people with dementia.

What are rights?

Rights can mean different things to different people, and in different cultures and countries. In Scotland and the UK rights are something people expect to have to live an acceptable quality of life. They are not about privileges or being allowed to do something – they are a 'given' and are generally thought of as protected. We would expect that people with dementia, their families and carers would experience these same rights. Unfortunately people with dementia can experience stigma, abuse,

discrimination, mistreatment and a lack of access to appropriate services to meet their needs. The rights of their families and carers are also sometimes ignored and they are not supported or treated as partners in supporting and caring for the person with dementia. However because of the excellent legislation we have in Scotland, all workers have a role in ensuring people's rights can be better protected to maximise their potential for a good quality of life.



Activity

What is your own view of rights?

Do you know what your rights are?

Record your answers here

The Charter of rights for people with dementia and their carers in Scotland

In 2009 the Cross Party Group in the Scottish Parliament on Alzheimer's published *The Charter of Rights for people with dementia and their carers in Scotland* (1). The Charter reflects protection laws that already exist in Scotland and uses these to focus on the rights specific to people with dementia. It describes how people with dementia, their families and carers can be empowered and supported to exercise these rights at every stage of their journey and wherever they live in Scotland.

Module 5 - Supporting and Protecting People's Rights

The table below outlines a summary of the Charter of Rights.

Summary of Charter of Rights

Participation

The person with dementia and their family and carers have the right to:

- Information in a format which is accessible to them and the support they need to exercise their right to participate in decisions affecting them.
- Live as independently as possible with access to recreational, leisure and cultural life in their community
- Full participation in all elements of care assessment, planning, support and treatment decisions including advance planning.
- Participate in creation and implementation of policies affecting their well being and the exercise of their human rights.

Accountability

The person with dementia and their family and carers have the right to:

- Enjoy human rights and fundamental freedoms in every part of their lives, including full respect for their dignity, beliefs, individual circumstances and privacy.
- All organisations and individuals responsible for the care and treatment of people with dementia should be held accountable for the respect, protection and fulfilment of the person's human rights and adequate steps should be taken to ensure this happens.

Legality

The person with dementia and their family and carers have the right to have their human rights respected, protected and fulfilled. In addition they have the right to:

- Live in dignity and security, free from exploitation, violence and physical, mental or sexual abuse.
- Economical, social and cultural rights including an adequate standard of living, social protection and the highest attainable standard of physical and mental health.
- Information to participate in decision making and where rights are not observed, the right to seek remedy through effective complaint and appeal procedures.
- The same civil and legal rights as everyone else and where someone lacks capacity anyone acting for them must have regard for the principles and provisions of the Adults with Incapacity (Scotland) Act 2000.

Non-discrimination and equality

The person with dementia and their family and carers have the right to:

- Be free from discrimination based on any grounds such as age, disability, gender, race sexual orientation, and religious beliefs, social or other status.

Empowerment

The person with dementia has the right to:

- Access appropriate levels of care providing protection, rehabilitation and encouragement.
- Help to attain and maintain maximum independence, physical, mental, social and vocational ability and full inclusion and participation in all aspects of life.
- Access social and legal services to enhance their autonomy, protection and care.
- Services provided by professionals and staff with appropriate training on dementia and human rights.
- The person with dementia, their family and carers have the right to access opportunities for community education and lifelong learning.



Activity

Are any of these rights similar to your list?

If there are differences why do you think this might be?

Record your answers here

- Adult Support and Protection (Scotland) Act (2007).
- Equality Act (2010).

These laws on their own do not protect people but they do create a framework in which organisations and individual workers are legally required to provide services to a certain standard.

Each Act can be used on its own to protect a person or they can be used together when this is needed. One of the key elements of these laws is that they all are based on 'principles' that must be followed when used to protect people.



Activity

Take a few minutes to consider what 'principles' means to you and make a list below

Record your answers here

How the law in Scotland helps to protect people's rights

Legislation aimed at protecting rights tends to be developed as a result of concerns that individuals and particular groups of people are at greater risk of having their rights denied such as people with mental health problems, older people and people with dementia. However we cannot assume that because a person has a particular need, health issue or disability that they cannot exercise their rights and choices. The law in Scotland assumes that every adult has a right and is capable of making all decisions affecting their lives. Deciding someone is not able to make decisions or protect their own interest can be extremely complex.

In Scotland legislation that may be used to protect the rights of people with dementia include:

- The Human Rights Act (1998).
- Adults with Incapacity (Scotland) Act (2000).
- Mental Health (Care and Treatment) (Scotland) Act (2003).

Principles are basic moral rules that we use as the basis for all our judgements and actions. They can help us to think about our own attitudes and prejudices. In adult protection laws, principles are general rules that guide the way we work with people and make decision when we use each Act. It is important that you know the principles of each Act and can use them to influence your practice.

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The following table describes the shared principles of the 3 pieces of Adult Protection legislation in Scotland which we need to take account of before we consider any intervention, action, or treatment.

Adults with Incapacity Act 2000	Mental Health Act 2003	Adult Support and Protection Act 2007
Benefit -The intervention must enable the person to do something which they could be reasonably expected to do if their capacity was not impaired.	Benefit - Any intervention under the Act should be likely to produce for the service user a benefit which cannot reasonably be achieved other than by the intervention	Benefit - The intervention must enable the person in some way.
Least Restrictive Option - The intervention must balance risk versus protection and be the least restrictive on the freedom of the person	Least restrictive alternative - Service users should be provided with any necessary care, treatment and support, both in the least invasive manner and in the least restrictive manner and environment compatible with the delivery of safe and effective care, taking account of, where appropriate, the safety of others.	Least Restrictive Option - The intervention must balance risk versus protection and be the least restrictive on the freedom of the person.
Past and Present wishes of the Adult - This needs to take into account if it is something the person would have chosen to do in the past or in their present circumstances.	Participation Service users should be fully involved, to the extent permitted by their individual capacity, in all aspects of their assessment, care, treatment and support. Account should be taken of their past and present wishes, so far as they can be ascertained.	Respect for Adult's Past and Present wishes - Needs to take into account if it is something the person would have chosen to do in the past or in their present circumstances
Views of relevant others - Must be taken account of including family carers and others appointed to make decision on person's behalf	Respect for carers Those who provide care to service users on an informal basis should receive respect for their role and experience, receive appropriate information and advice, and have their views and needs taken into account.	Consider views of others - There must be taken account of including family carers and others appointed to make decision on person's behalf.
Encourage the Adult to Act - Use existing skills and develop new skills	Informal care - Wherever possible care, treatment and support should be provided to people with mental disorder without recourse to compulsion.	Encourage the Adult to Participate - Providing information and support to enable to do so.
	Non discrimination - People with mental illness should, whenever possible, retain the same rights and entitlements as those with other health needs.	Non discrimination - The adult should not be treated less favourably than another adult.
	Respect for diversity - Service users should receive care, treatment and support in a manner that accords respect for their individual qualities, abilities and diverse backgrounds and properly takes into account their age, gender, sexual orientation, ethnic group and social, cultural and religious background.	Respect for Diversity - The adult's abilities, background and characteristics must be taken into consideration in any intervention.

Module 5 - Supporting and Protecting People's Rights

We can see that many of the principles are the same across all 3 Acts, particularly the need to take account of benefit, least restrictive option, past and present wishes, views of others and encouraging the person to participate. These are also in line with the Charter of Rights and the Human Rights Act (1998) which you will read about a little later in this module.

There is no absolute right answer but if Peter had always bought birthday presents for their grandchild and it is known that he did this as part of a loving and sharing relationship then it would be acceptable. Although, the amount spent would also need to be in keeping with previous exchange of gifts.

Now read the next scenario.



Activity

Consider the principle of 'benefit'.

Read Peter's scenario and consider if David and Nicola are considering the benefit to him of their actions.

A brother and sister, David and Nicola, who both care for their Dad, Peter, who has advanced dementia, have been arguing about how much of Peter's money either of them spends. The tension is coming to a head, and David accuses Nicola of 'abusing' Dad's finances by purchasing a television as a birthday present from Dad to her daughter.

What 'benefit' is there for Peter in buying a birthday present for his grandchild?

Record your answers here:



Activity

David lives in the South of England and has decided he wants to buy a car so that he can increase his visits to Peter from twice a year to four times a year.

Would this be of benefit to Peter?

Record your answers here:

It would be very difficult to justify this expenditure when the benefit would be more to the relative than the person with dementia.

Module 5 - Supporting and Protecting People's Rights

The Human Rights Act (1998)

The Human Rights Act supports and strengthens the other Acts. It came into force in October 2000 and has made rights from the European Convention on Human Rights enforceable in British Courts.

Human rights are rights and freedoms that everyone is entitled to. The Human Rights Act originated from concerns for people being denied their basic rights during World War II and set out to provide a common understanding of what everyone's rights are.

There are 16 basic rights that apply in Scottish law, all of which have been taken from the European Convention on Human Rights. The 16 basic rights cover things like freedom from inhuman treatment to everyday things like respect for your privacy and family life. The convention recognises that while rights cannot be taken away except in extreme circumstances, most are balanced against the rights of other people such the right to respect for private life and family, while others are considered absolute such as the right to life.

The principles which underpin the Human Rights Act are:

- Equality
- Respect
- Dignity
- Fairness
- Autonomy

Rather than detailing all 16 Rights here are some practice examples adapted from the Alzheimer Scotland website which relate directly to people with dementia and will help you to recognise these in your practice and workplace.

Examples of human rights that may be disregarded in practice

The right not to be treated in an inhuman or degrading way.

- Leaving a person in soiled or unchanged clothing or bedding.
- Leaving food for the person when they are unable to feed themselves.

The right to respect for private and family life, home and correspondence.

- Separation of families and other relationships due to hospital or care home admissions.
- Not receiving support to participate in activities meaningful to the person.
- Staff in care homes, supported accommodation or hospital etc controlling mail, phone calls etc without authority.

The right to freedom or liberty.

- Detaining a person in hospital who lacks capacity to consent to admission and without using legal process.
- Delays in discharging people detained under mental health legislation.
- Excessive, and inappropriate use of restraint in all care settings including the person's home.

The right to a fair trial.

This does not just apply to criminal proceedings but to a broad range of areas where a person's civil rights or responsibilities are decided upon.

- The person's complaint is not investigated by an organisation.
- The person is not made aware of the right to complain and given information on the procedure in any care setting or service provided to them.

The right not to be discriminated against.

Discrimination can be direct or indirect. This right does not apply on its own. A person can only use the human rights act to argue discrimination if another human right is breached.

- A person is not given access to medical treatment or community care services, based on age, disability, gender or ethnic origin or because they have dementia.
- For example a person with dementia not offered physiotherapy treatment in the belief that they will not be able to follow exercise instructions
- Information or options are given in a way that is inaccessible to the person.
- Not offering food to take account of a person's cultural differences such as kosher or halal foods.

Reflection

Reflect on your own work environment and practices and how you contribute to protecting the rights of a person with dementia.

Read Bill's scenario to help get you started

Bill lives at home and receives informal support and care from a neighbour, out of goodwill and community spirit. The neighbour has observed that Bill has become upset at times when he receives letters from friends telling him of news, and these can include recent deaths. The neighbour decides that to protect Bill, they will censor his mail and remove handwritten letters from his mailbox before Bill can see them.



Activity

Imagine you support Bill in his home and discover this is happening. What would you do?

Record your answers here:

Adults with Incapacity (Scotland) Act (2000)

The Adults with Incapacity (Scotland) Act (2000); (AWI), created a legal framework for making decisions on behalf of a person who does not have the capacity to make decisions. It covers the person's welfare, property, financial affairs and medical treatment. It enables them to make their own arrangements for how their affairs should be managed if they lose the capacity to make decisions in the future. It recognises that, as far as possible, people should have autonomy and be able to control their own lives and another person can only make decisions on their behalf when it is justified and necessary.



Remember

People should not be making decisions for someone else if that person has capacity to make decisions.

What is capacity and incapacity?

All adults are presumed to be legally capable of making personal decisions and of managing their own affairs unless it is established that they lack capacity to do so. This applies even when the decisions are unwise. Capacity means that you are capable of a good enough understanding of the nature, implications and consequences of your decisions.

The AWI Act takes into account all the things that may affect a person's capacity to make decisions, such as being able to communicate, being ill, or the person's understanding of what they are being asked to make decisions about. The Act defines incapacity as being incapable of:

- (a) Acting.
- (b) Making decisions.
- (c) Communicating decisions.
- (d) Understanding decisions.
- (e) Retaining the memory of decisions.

Capacity is **not** an all or nothing concept – a person may not have capacity at a particular point in time or for a particular decision, but this does not mean that they will never have capacity to make any decisions. Capacity to make decisions may be diminished temporarily or permanently, partially or totally.

For example, as a person with progresses through the stages of the dementia journey they may have difficulties understanding complex information. As a result they may not have capacity to decide whether the benefits outweigh the risks to have an eye operation. The person's capacity to process the information could be affected by being tired, anxious or not having time to process the information. It may be that after a period of time, when relaxed or with help from another person they are able to make an informed decision.

The key elements of the AWI Act which may be relevant to you in your practice to enable you to understand, support and protect people with dementia are as follows:

Power of Attorney

'Power of Attorney' is the name given to a person who has been granted the power to make decisions on behalf of the person who is incapable to make decisions on their own. A power of attorney is taken out in the same way a person creates a will, by providing a statement in writing, usually with legal help. The document must include a certificate from a solicitor or medical practitioner who has interviewed the person immediately before the document was signed.

How the Power of Attorney works is that a person gives permission to someone they trust, to make decisions when they are no longer capable of making them. A solicitor or medical practitioner has to agree that the person has capacity, knows and understands what they are doing when they sign the statement. We can support people with dementia by ensuring they have information about the different powers within the Act to empower and enable them to make decisions and draw up advanced plans. The legal terms relating to power of attorney are, the person giving permission to someone else is known as the **granter** and the person, who is given the powers, is called the **attorney**, or may be known as the **proxy**.

There are two types of power of attorney: **continuing** and **welfare** attorneys.

Continuing Attorney

Continuing powers of attorney only manage the **finances and property** of another person and their powers can start immediately after the agreement is signed. The person giving permission (the granter) may not want this to happen and can specify that the powers should start only when they have lost capacity to manage their own financial affairs. For example, when continuing attorney is in place, the power of attorney would have access to the person's finances and could arrange to do things like to pay household bills and collect pension payments.

Welfare Attorney

Welfare attorneys have power over the person's **personal welfare**. These are things that affect the person's physical and emotional well-being, for example, physical and mental health and protected from of abuse and harm (other than financial harm). It can include choice of medical care and treatment, diet, hygiene, clothing, meaningful social contact, and where the person lives.

Welfare attorneys can only start making decisions on behalf of the person, once the person has been assessed and it is agreed they no longer have capacity.

We can see that this could potentially allow the Welfare Attorney to have total control over the welfare decisions of another person. In reality, this is where the principles guide us, and any action should always be the least restrictive option chosen for the person with incapacity. Under the principles the welfare attorney also has the duty to encourage the maximum use of the person's skills. For example, a person with dementia may require treatment to have a cyst removed which medical staff suggest they have under general anesthetic despite the usual treatment being delivered under local anesthetic. Their welfare attorney could give consent but may suggest that the person retains enough understanding to have the treatment under local anesthetic upholding their right to least restrictive option and maximum use of their skills.



Remember

The welfare attorney cannot give consent for medical treatment for a mental disorder against the person's wishes.

For example if a person with dementia is in hospital being treated for depression and medical staff want to prescribe medication but the person refuses. In this instance the welfare attorney cannot give permission. This would require consideration of the mental health Act for which the criteria would need to be met before any medication would be given and even more stringent safeguards are in place to give medication against a person wishes under compulsory powers.

While both of these examples are health care related it is not unusual for similar situations to occur in social services. An example of this is a welfare attorney agreeing with social services that the person with dementia would benefit from being supported to engage in meaningful activities in their local community rather than support in their home for 2 days per week. Talking mats could be used to enable the person to decide what activities they want to engage in.

All continuing and welfare powers of attorney must be registered with the Public Guardian. In return, the Public Guardian issues the welfare attorney with a Certificate of Registration. This is a new office created by the AWI Act and anyone can contact them for information www.publicguardian-scotland.gov.uk.



Reflection

We are all encouraged to make a will and have advance statements or plans in place for what we would want to happen if we are unable to make decisions.

How would you feel if it was suggested to you to appoint a continuing and welfare power of attorney?

Would it be easy to decide who to appoint and what would influence your decision?

Record your thoughts below.



Activity

Think about someone with dementia that you work with who may be unaware of the AWI Act. Based on what you have learned so far what information would you give them.

Record your answers here:

Intervention Orders

Intervention orders give permission for one-off decisions which the person does not have the capacity to make. The decision may be to do with property, finance or personal welfare. An example of this could be to deal with income tax or sell a property in which case the person making an application to the court for the order would not have to have power of attorney or guardianship, it can be anyone who has an interest or concern about the person such as the local authority. An example of a welfare intervention order could be to do with a complex medical treatment which the person is assessed as not being able to consent to but can still make most other decisions. When other decisions need to be made, such as moving a person to a care home, an intervention order can only be applied for by a welfare attorney or welfare guardian if the powers they already have does not include this.

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Guardianship Order

Guardianship is different to power of attorney in that it can only be applied for when the person is assessed as not having capacity for decisions, has not appointed an attorney and an intervention will not meet their needs. It can cover property and financial matters or personal welfare, including health, or a combination of these. Anyone with an interest in the person may apply to the courts for guardianship such as a family member or the Local Authority. The guardian can then make decisions on behalf of the person in the same way as the Attorney.

The decisions the attorney or guardian can make will be specified in the order granted and it should not be presumed that they have the power to make all decisions regarding the care of the person. The attorney can insist that their decision on behalf of the person is carried out, but if the person who lacks capacity refuses the attorney cannot insist and they would have to apply for guardianship if it was felt necessary to protect the person. Likewise if anyone including the person who lacks capacity is unhappy about the decision made by the attorney, they can apply to the court for an order requiring the local authority to supervise them.



Remember

If you are working directly with a person who is unhappy about decisions being made for them, you may be the only person who is aware of their unhappiness and you have a duty to act in the interests of the person you care for.

Ellen's story

You are working with Ellen and supporting her at home following a brief visit to hospital. Carolyn her daughter visits regularly and has informed you that prior to going into hospital Ellen appointed her as Continuing Power of Attorney and Welfare Attorney. Six months have passed and you have got to know Ellen very well and she continues to have capacity for most decisions. You notice that every time Carolyn visits they argue about money and Ellen gets very upset and distressed. Carolyn reassures her that she is only paying her bills and using money to buy new clothes for Ellen. After Carolyn leaves Ellen is still distressed and states "I will soon have nothing left".

What action should you take?

While Carolyn says she has power of attorney we do not know this is the case and even if she does the use of finances should be in Ellen's best interest. It may be that Ellen cannot recall that she agreed to this when she had capacity to do so.

Regardless of what we speculate, there may be a potential issue of abuse of Ellen. You are required to report it to your manager who must contact the local authority and the public guardian. If you do not have a manager you can contact these agencies yourself. They have been set up in this way to allow you to contact them directly. They can then carry out a monitoring visit to Carolyn and take any necessary steps. It is also important that Carolyn continues to involve Ellen in her finances as much as possible and doing so may be enough to allay any concerns.

Module 5 - Supporting and Protecting People's Rights

The act created roles and functions for a number of organisations and bodies to ensure people who are considered under the act are protected. These are:

The Public Guardian

The Office of the Public Guardian has duties to register powers of attorney, intervention and guardianship orders, and to give permission for the withdrawal of funds from the person's bank account. It also receives and investigates complaints and has a duty to give advice and information on request.

The Mental Welfare Commission

The Mental Welfare Commission for Scotland is required to protect people who are assessed as incapable due to mental disorder. The term mental disorder is used because of its legal description in the mental health act and we recognise it is not very person centred. We would usually refer to working with or along side people who have mental health issues. The Mental Welfare Commission also has a duty to enquire into any potential ill-treatment, deficiency in care or treatment, improper detention or possible loss or damage to the property of a person with mental disorders.

The Local Authority

The local authority has a variety of duties:

- Supervise welfare guardians
- Investigate complaints and circumstances in which the personal welfare of an adult with incapacity seems to be at risk
- Provide information and advice
- Take the necessary steps to safeguard the property, financial affairs or personal welfare of the adult
- Apply to the Sheriff for an intervention order for the protection of the adult's property, financial affairs or personal welfare
- Prepare reports to accompany applications for intervention and guardianship orders
- Apply for intervention and guardianship orders if necessary
- Recall guardianship and intervention orders in relation to the welfare of adults



Activity

Think of someone who you know as a friend or family member that you care about who has made a decision that you think is not in their best interests, this could be a financial or personal decision.

Why do you think they made that decision?

Did you tell them how you felt about their decision? If not, why not?

If you did, how did they react?

Record your answers here:



Reflection

Now think of a decision that you have made for yourself that you do not think was in your best interest. Why did you make this decision?

Now think of a decision that you have made that has been criticised by someone whose judgement you respect? How did that make you feel about the decision you made?

It is likely that thinking about those questions aroused some strong feelings. The right to make decisions for ourselves that are not questioned is something we value but also take for granted. We generally believe that no-one has the right to question our decisions unless we ask them to, even if we are aware of decisions we have made that may not have been always seen as wise.

By contrast we can find it very difficult when people we know make choices that we think are not in their best interests and want to intervene. This is especially true when that person has a condition that we think may be affecting their ability to make good decisions.

People often think that there should be an easy way for families and the state to take over decision making in these situations. The reason there is not, is because of the right we all have to make our own decision with no interference from others. We need to remember that people with dementia, their families and carers are entitled to these same rights.

Assessment of Capacity

The act gives medical practitioners the main responsibility in deciding whether a person is incapable of making particular decisions or taking specific actions. The doctor's assessment of whether the person is incapable of certain decisions or actions is central to most parts of the Act. A number of factors should be considered in making this assessment, these include whether the person has the following:

- Information appropriate to the person's ability to understand.
- Ability to consider choices, reason, and reach a decision.
- Ability to receive information and express views sufficiently to communicate a decision.
- Freedom from pressure from others.
- Ability to be consistent in decision-making.

The medical practitioner makes the final assessment of capacity but he/she will be expected to use multi-disciplinary information as part of the overall assessment. Reports from social workers nurses, occupational therapists, clinical psychologists, speech therapists, care staff and others will often be asked for. Under the principles of the Act, the doctor must consider the person's past and present wishes and feelings and, where reasonable and practicable, seek the views of significant others.

Despite an assumption which is often made, people with dementia can retain capacity to make decisions until the very later stages in their journey. However their ability may fluctuate from day to day and hour to hour, and this needs to be considered during assessment. It is often staff that work directly, and on a regular basis, with the person who will notice these fluctuations and have a central role in contributing to assessment of capacity.

Likewise people should be supported and encouraged to exercise what is referred to in the Act as 'residual capacity'. This means that although they may not have capacity to make major decisions they should be enabled to make decisions where ever possible. For example, the person who is assessed as lacking capacity to manage their finances or understand the implications of medical treatments, may still be able to make choices about food, clothing and activities they want to engage in and every effort needs to be made to ensure this happens.



Activity

How could you ensure that you make the effort to make sure the person with dementia you work with or care for has as much choice as possible in their day-to-day life?

Record your answers here:

Consent to Medical Treatment

Medical treatment refers to 'any healthcare procedure designed to promote or safeguard the physical or mental health of the person.' This could include food and drinks, skin care, continence care, pain relief, mobility, communication, eyesight, hearing, dental care and oral hygiene, as well as medicines.

If the person is unable to consent to any of these treatments the doctor assessing them will sign a treatment plan, at the same time as signing the Certificate of Incapacity. This will allow the person to receive the daily treatment interventions without having to get consent for each one when it is needed. You need to remember to continue to consider the principles before making any decisions.

If for example, the person is refusing to have a bath you need to adopt some of the measures outlined in Module 3. Again the medical practitioner or other health professional qualified to assess capacity will follow the same process described earlier and

complete a certificate of incapacity if the person lacks capacity to consent. It is essential that valid consent is sought and if the person does not have capacity if there is a proxy such as a welfare Attorney, welfare Guardian or person with permission under an intervention order, they can give consent on behalf of the person and a certificate would still be completed. Treatment cannot automatically proceed if the proxy refuses consent although there is a mechanism for independent opinion to resolve disagreements.



Remember

It is illegal for a family member or other relative to consent to treatment if they are not a proxy with permission to do so.

Jim's Story

Jim, who we met earlier lives in a care home but this situation could happen in an acute hospital, community hospital or his own home.

Jim is on medication for angina and although he can become resistive and upset when being given his medication, his wife Jane has said staff can give it to him crushed up in his food. You are working in the home one afternoon and when you offer Jim his medication he pushes your hand away. A senior member of staff asks you to give Jim some bread and Jam with his medication crushed up inside.

Do you give Jim his medication covertly?

You should **never give medication covertly** unless it has been agreed with a pharmacist and the health and social care team working with the person, and it is detailed in the prescription as a means of administration. Otherwise it is regarded as an assault on the person.

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Covert medication is the administration of any medical treatment in disguised form. This can involve disguising medication by administering it in food and drink. Sometimes it may involve medicines being administered in an altered form e.g. tablets crushed or capsules opened. However, other medicines can be given covertly without being altered or mixed with food or drink e.g. patches or liquid medicines. You need to be aware that altering medication in this way can mean it will not have any effect or it could have fatal consequences where the person is left disabled or dies. The essence of covert administration is that the person is unknowingly taking medication

While there may be occasions where there is no alternative and it is medically and ethically justified it must never be given to someone who is capable of deciding about medical treatment. Every effort to gain consent must be recorded and details of multidisciplinary discussion and the pharmacist recommended approach must be recorded in the care plan and the prescription which must be signed on each occasion.

Mental Health (Care and Treatment) (Scotland) Act 2003

The Mental Health Act describes what is required when working with people who are being treated for 'mental disorder' under this Act. It includes people who have mental health issues, learning disabilities or personality disorder. It may apply to someone with dementia if they have mental health issues and require treatment. You do not need to know details of the provisions of the Act but some of its safeguards can help support a person with dementia to have their rights protected such as 'advanced statements', 'personal statement' and 'independent advocacy'.

An **advance statement** sets out the way a person wishes to be treated, or not treated, for mental disorder in the event of becoming mentally unwell and unable to make decisions about their treatment. It is intended to improve the person's participation, in line with the principles of the Act and requires tribunals and others providing treatment to take account of the past and present wishes and feelings of the person. It is one potentially important way of recording these wishes. An advance statement can be made by anyone, even if they are under 16, as long as they understand what they are putting in the statement and the effect it may have on their care and treatment in the future. In order for an Advance Statement to be valid it must be in writing, signed and witnessed by an

'appropriate' person as outlined in the Act.

A **personal statement** can be attached to an advance statement but does not have the same effect in law. It sets out what the person would like to happen if they, for example, have to go into hospital. Things like what to tell their employer, care arrangements for pets and other domestic matters can be included. It is helpful if a personal statement is signed and dated but there is no requirement for a personal statement to be witnessed.

Alzheimer Scotland suggest people can also make a **General Advance Statement** although this is not related to the Mental Health Act and again does not have the same effect in law. It can say what general treatments the person would like, or not like, when they are no longer able to tell people.

Alzheimer Scotland recommends it contains the following five sections;

- Specific treatments the person does not want, for example regarding resuscitation. This is referred to as an advanced directive
- Instead of specifying treatments the person could say they did not want any life sustaining treatment if they were irreversibly ill and had no chance of getting better.
- Request how they want to be treated such as all treatments that would help
- Include a Statement of Values (described in Module 2).
- Who they want to be consulted when a decision about their care and treatment needs to be made. This lets doctors know who to consult but does not give them power to make decisions on the person's behalf. This would require a welfare Attorney mentioned earlier.

Independent advocacy supports a person's right to have their own voice heard in decisions made about their health and well being if, for whatever reason, they find it difficult to put their own case to service providers or do not feel in a strong position to exercise or defend their rights. It is particularly helpful for people who are at risk of being mistreated or ignored, or who wish to negotiate a change in their care, or are facing a period of crisis. The Act makes

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it a right for people who have a mental disorder and places a duty on NHS Boards to ensure it is provided.

Adult Support and Protection (Scotland) Act 2007

The Adult Support and Protection (Scotland) Act 2007 came into force in October 2008 and aims to protect adults who are unable to protect themselves and are at risk of harm. There are many circumstances that can place a person at possible risk of harm, such as mental health difficulties, dementia, learning disabilities and acquired brain injury. It is important to recognise that having a particular condition such as dementia does not automatically mean an adult is an 'adult at risk'. To be an 'adult at risk' the person must meet the 'three- point test'. If an adult meets only one or two elements of the three-point test, they cannot be considered an adult at risk.

Three-point test

1. Unable to safeguard their own well-being, property, rights or other interests.
2. At risk of harm.
3. Are more vulnerable to being harmed because they are affected by disability, mental or physical ill health.

An example of not meeting the 3 point test is, a young man who lives a chaotic lifestyle and drinks heavily. When drunk he invites strangers he meets in the pub back to his home. Frequently these people threaten him and take money from him leaving him with no money for food and household bills. He meets points 1 and 2 but not 3.

If however this man also had a learning disability, dementia or physical disability he would meet the 3 point test.

The Act includes duties, powers and responsibilities particularly for local authorities, who have a lead role in adult protection. However, NHS boards, police forces and other public agencies have a duty to cooperate with all measures relating to adult protection. The Act includes a number of orders which the local authority may use to protect a person at risk, these are;

- Assessment Orders
- Removal Orders
- Banning Orders

Assessment Orders

If it is not possible to interview or examine the person at risk during a visit the local authority can apply to the sheriff court for an assessment order. This allows the person to be moved to a specified place so that medical or other health professional examination can take place.

Removal Order

This gives the local authority permission to move the person they believe to be at risk of harm to a specified place to allow steps to be taken to protect them and includes power to enter premises to move the person. It is primarily aimed at protecting the person rather than assessing their needs. As we can imagine, this can have a major impact on the person we are trying to protect. It should only be used when there is no other option.

A straight-forward example may be that it transpires that a person with dementia has been found to be a victim of physical and emotional abuse by someone who lives with them and there is no other way of protecting the person or getting the person causing the abuse to move because they have an equal right to stay in the property. There are also many very complex reasons why this is the only option but given the complexity of these it would not be legal or ethical to suggest examples. except where all the facts are known.

Banning Orders

This is granted by the Sheriff and bans the third party from a specified place. It can prohibit the third party from moving anything from a specified place as well as requiring them to do or refrain from doing anything else considered necessary. Again your role is likely to be in contributing information for assessment, investigations and reporting suspected abuse.

Harm and Abuse

In chapter 5 of the *Informed about Dementia* DVD attached to this resource we describe the different categories of harm and abuse and the common signs and symptoms. It is important to emphasise again that **if you suspect someone is being harmed or**

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you observe them being harmed, you have a duty to report it to your line manager. Under the new legislation, your manager has a duty to report it to an Adult Protection Lead Officer who has access to an Adult Protection Committee. These have been set up in all local authority areas across Scotland and are multidisciplinary committees with representation from various public bodies.



Remember

Never dismiss your information as being unimportant or trivial, you do not have to be certain a person is being harmed to report it, only to suspect. Your information may be the crucial part of the full picture.

Margaret's story

Margaret has now returned home following her stay in a community hospital and you are one of 4 staff supporting her. You notice that she has become very quiet in the past couple of weeks and jumpy at the slightest noise. You continue to encourage her to engage in conversation and mention another team member's name who will be visiting the next day. Margaret does not respond but you notice that she is crying when you ask her what the matter is she does not respond but shakes her head.

What would you do?

You tell your manager what has happened and that you suspect this member of staff is shouting and teasing Margaret because of the way she speaks to you about Margaret.

Your manager agrees to visit Margaret and later lets you know that she does not think there is any problem. You notice that over the next couple of weeks Margaret continues to respond in the same way.

You have already reported your concerns so what can you do now?

You have the option to go back to your manager. Additionally, you may report it immediately to the local authority lead officer directly if you believe your concerns are not being responded to. It is very important that you do not engage in further investigation yourself as this may well become a police matter and you could be seen to be tampering with evidence.

You should ensure you know how to contact your Local Authority Lead officer. It does not matter if it transpires that there is no case of abuse - you will have taken the appropriate action to protect Margaret.

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Risk and risk enablement

Until recently the focus of risk and risk assessment has been to concentrate on minimising or eliminating risk without considering the potential impact of over protection on the person's rights and freedoms. A new approach of 'risk enablement' was introduced by the Department of Health in England in their guidance published in 2010 *Nothing ventured nothing gained- Risk Guidance for people with Dementia*.⁽²⁾ It shifts the focus to recognising the many positive benefits to supporting people with dementia to take risks.

Life is never risk free, it is part of all our lives, but assumptions about the capacity of people with dementia to make decisions can result in their quality of life being restricted. In the *Informed about Dementia* DVD we mention the need to balance risk and autonomy, but it is also a balance between these and staff duty of care, when we are working with the person with dementia. In terms of best practice the recommended approach is 'risk enablement' which takes a tailored approach to risk by acknowledging that dementia affects different people in different ways. Ideas about risk are personal and are built up over a lifetime and it should be the person with dementia that is at the heart of decisions.

The development of risk enablement plans can enable staff to support the person in taking risks. This will involve detailed discussion with the person with dementia, their family and carers as well as other care providers working with them. We have already looked at the range of assistive technologies available to support the person with dementia to minimise risk, or the provision of a support worker to accompany them to engage in activities they want to continue to enjoy.

You may be working with people to help them maintain their independence and will need to contribute to the ongoing review of the risk enablement plan.

In looking at capacity we drew your attention to the fact that capacity may fluctuate and will diminish as the person progresses to the later stages of dementia. It is at this point that staff working with the person may feel under considerable pressure to eliminate risk. Careful assessment remains important and we have already explored the impact of the environment and other factors which may cause stress and distress to the person as well as the benefits of engaging in meaningful activity. The suggested approaches are also relevant in reducing risk and supporting independence.



Remember

People with dementia need to feel safe and secure and are able to be as independent as possible.

Restraint

At times actions may be taken by staff or families and carers with the intention of minimising risk but in effect amount to either direct or indirect restraint.

The term 'restraint' includes a range of actions intended to limit the ability of a person to do something which another person considers undesirable (Mental Welfare Commission, 2006) ⁽³⁾. It may be regarded as a criminal offence committed by an individual worker rather than their employer, unless carried out within the legal processes described earlier in this module. It may take the form of direct physical/mechanical restraint, modification of design and medication or psychological restraint to prevent or restrict the person's movements within their own home, a care home or hospital.

Physical and mechanical restraint may include, laying a hand on the person to stop them moving, use of restraining chair, trays fixed to chairs, bedsides, restrictive bed clothes or night attire. Modification of design could be locked doors, doors with code number pads, electronic tagging devices and video surveillance. The use of sedative or tranquillising drugs purely to prevent someone moving, can never be justified.

Restraint also includes the use of covert medication (given without consent and hidden in food or drink). Psychological restraint refers to bullying attitudes, shouting, or excluding the person, leaving the person afraid to ask for help.

Walking about in what appears to be an aimless manner, referred to as 'wandering' is seen in many care settings as a problem behaviour to be stopped. It frequently results in the person with dementia being

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restrained using one of the methods mentioned. The term 'wandering' has very negative connotations and is demeaning to the person.

While on occasion the person may appear to be walking aimlessly it usually will have meaning for the person and we need to understand where the person is going to and provide them with a safe means of moving around freely.

Many of the assistive technologies/ telehealthcare described in Module 2 are being used in people's own homes, care homes and hospitals to enable people to take risks and improve their quality of life. This recognises the positive benefits of being able to move around in promoting health and well-being as well as reducing the risk of falls.

However when considering these technologies we need to be aware of the ethical issues and potential for these practices to become a restraint as well as stigmatising for the person. This is particularly the case if it impacts on the person's privacy or reduces their choice of activity. For example if the person is having to be constantly brought back, this may lead to increased stress and humiliation for them.

Before considering the use of these technologies, changes in the physical and social environment need to be taken into account, with the person being engaged in person centred occupation and stimulation. Technology should not be used as a substitute for appropriate levels of personal support, care and human interactions in care settings as well as the person's own home.

As with all risk, a full assessment and involvement of the person with dementia through support for residual capacity, their family and carer, care providers and specialist advisors is paramount to find alternative approaches. Restraint should then only be used through the Adults with Incapacity Act in accordance with the principle of least restriction under clear guidance, monitoring and review.

The Equality Act (2010)

The Equality Act 2010 updates other laws relating to discrimination and bans unfair treatment as well as helping to achieve equal opportunities in the workplace and in wider society for everyone. It applies to all service providers and those providing goods and facilities in the United Kingdom.

The Act protects people from direct discrimination, discrimination arising from disability, harassment and indirect discrimination. The act increases the protected characteristics to nine, which cannot be used as a reason to treat people unfairly. These are:

- age
- disability
- gender reassignment
- marriage and civil partnership
- pregnancy and maternity
- race
- religion or belief
- sex
- sexual orientation

For example, in terms of protecting people with disability, which may include people with dementia, where service providers are required to make changes, and 'reasonable adjustments' to ensure they are not discriminated against.

Self assessment quick quiz

Check whether you have understood the main point of this Module

1. How can we contribute to ensuring the human rights of a person with dementia are protected?
2. What are the main powers of the Adults with Incapacity (Scotland) Act 2000?
3. When a person is diagnosed with dementia they are no longer capable of making major decisions. True or False?
4. What are the main powers of the Adult Support and Protection (Scotland) Act 2007?
5. What can you do to protect people with dementia from harm?
6. We can use any restraint necessary to ensure we protect a person with dementia from risk and harm. True /False?

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Module summary

In this section we have explored the rights of people with dementia and how we can use the range of protective legislation in Scotland to support them in exercising their rights and choices. We examined the concepts of capacity, risk, harm and restraint and considered their relevance to your practice. We hope it will give you greater confidence in recognising and challenging when a person with dementia is being denied their rights.

Action into practice

How does your work setting actively promote the rights of people with dementia?

Find your organisations policy on risk enablement and restraint.

Check that it is consistent with your learning in this Module and list 2 changes you will make in practice to ensure your policies are implemented in a person centred and rights focused way.

Record your answers here

References

1. Cross Party Group on Alzheimer's (2009) *The Charter of Rights for people with dementia and their carers in Scotland*. Edinburgh. Alzheimer Scotland. <http://www.dementiarights.org>
2. Department of Health (2010) *Nothing Ventured Nothing Gained: risk guidance for dementia*. London .DOH
3. Mental Welfare Commission for Scotland (2007) *Safe to Wander* Edinburgh. MWC

Suggested further reading

Mental Welfare Commission for Scotland (2006) *Working with the Adults with Incapacity(Scotland) Act* Edinburgh. MWC

Mental Welfare Commission for Scotland (2006) *Covert Medication Legal and Practical Guidance*. Edinburgh. MWC

NHS Education for Scotland (2011) Learning Resources Mental Health (Care and Treatment) (Scotland) Act 2003. Edinburgh. NES. <http://www.nes.scot.nhs.uk/education-and-training/by-theme-initiative/mental-health-and-learning-disabilities/publications-and-resources.aspx>