Scottish Social Services Council

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Dementia Skilled Improving Practice

Learning Resource (Updated 2016)

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Introduction

Introduction to this resource

Introduction

Welcome!

Welcome to the **Dementia Skilled – Improving Practice Learning Resource**. This resource has been designed for health and social service workers to develop their ability to support people with dementia, and their families and carers. The resource is designed to help improve workers' knowledge and skills and to make them feel more confident about the work they are doing.

This resource will also help health and social service workers' develop their understanding about dementia, and to think differently about the people with dementia they work with - whether they are 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.

Who is this learning resource for?

This learning resource is for anyone who works directly with people with dementia, and also for people who have substantial contact with people with dementia, and their families and carers.

The learning in this resource will help support workers to develop the knowledge and skills set out at the 'Dementia Skilled Practice Level' of **Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families and carers**. While designed particularly for the health and social service workforce, it may be valuable to other groups working in related services or organisations.

Please note this resource has also been produced as an e-learning resource available via LearnPro.

Accessing the LearnPro e-learning resource will enable links to be made to wider learning resources and assessment activities.

Why is dementia so important?

As people live longer, there are more and more people living with dementia in Scotland. However dementia is not just a condition affecting older people. People in their 40s or 50s or even younger can have dementia.

Dementia has a profound impact on the families, friends and the wider networks of people with dementia and they need our support to help them have the best quality of life. Wider communities also have a role in supporting people with dementia stay 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, and families or communities. We will explore these issues in more depth throughout this resource.

Introduction

What is the background to this resource?

Scotland has been developing and implementing National Dementia Strategies since 2010. Key elements to support implementation of the strategies have included the Promoting Excellence framework and the Standards of Care for Dementia in Scotland. 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.

Promoting Excellence

Promoting Excellence describes various levels of the knowledge and skills required by **ALL** of the health and social service workforce - whether they work in a care home, in a clinic or community hospital or in someone's own home. The levels set out in Promoting Excellence framework are the:

- Dementia Informed Practice Level
- **Dementia Skilled Practice Level**
- Enhanced Dementia Practice Level
- Expertise in Dementia Practice Level.

This resource is designed to help workers achieve the knowledge and skills set out at the Dementia Skilled Practice Level of Promoting Excellence. Before starting using this resource individually, or facilitating or delivering training with this resource, you should ensure that you have gained the knowledge and skills set out at the Dementia Informed practice level.

To enable this we have produced the Informed about Dementia: Improving practice DVD. 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 have not 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.

How is the resource structured?

This learning resource has 5 modules. It is important that you work through 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. The modules include suggestions for further learning for people who choose to explore issues in greater depth.

The Modules are:

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 a number of different types of learning activity that help learners reflect on how they can best support people with dementia, and their families and carers, and put this learning into practice. The activities that appear throughout each of the modules will play a key part in helping learners' develop the knowledge, skills and attitudes that are central to their role. The focus is on practical applications of the learning, reflective practice and putting learning into action.

Introduction

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.

What is the best approach to getting started?

We would encourage individual learners, teams and organisations to consider the knowledge and skills set out at the Dementia Skilled practice level of the **Promoting Excellence** framework as a first step in planning. You can find the framework on the Scottish Government, NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) web sites, and also on the Dementia Managed Knowledge Network, which has a specific **Promoting Excellence** web page.

This will assist:

- **Organisations** to think about priorities and plans for workforce development, considering the current levels of knowledge and skills in the organisation, and aspirations for future developments.
- **Teams** to consider the current knowledge and skills held as a team - including existing strengths and priority areas for development.
- **Individual Learners** can also consider their existing strengths and learning needs and this will help them prioritise working through the various modules in the resource.

What are the best approaches to learning and teaching?

This resource can be used for individual learning, learning as a group or team, in a facilitated teaching and learning event, or in a mixture of all of these approaches.

Learning can:

- focus on one module at a time, using the variety of activities we have provided (but we do recommend Module 1 is completed first);
- prioritise particular modules/areas of learning based on the analysis of learning needs undertaken at an organisational, team or individual learner level;
- use the resource for individual learners to discuss their thoughts and responses with their colleagues, e.g. in team meetings, workshop or study sessions;
- use the resource for learner's individual study, reflecting on the activities in their own time;
- use the resource with a facilitator in dedicated teaching/learning sessions;
- 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;
- build a portfolio of evidence which may support learners to confirm they have met requirements for their continuing development or gain qualifications.

Whatever approach is favoured, we recommend that learners are provided with opportunities for reflective discussions with their supervisors, and group discussions with peers and teams. This will help to put learner's individual experiences into a broader context and enhance their learning.

Introduction

How long will it take to complete the modules/resource?

This will depend on the starting point for the learner, their prior knowledge and skills, and whether the activities or the optional reflective accounts are completed in full. However, we would suggest that an individual learner would need a minimum of 4 hours of study to develop the knowledge and understanding contained within each module. Facilitated learning/ teaching sessions for each module should be at least 2 hours in duration with self study prior to or after the session.

How does the learning in this resource contribute to wider development opportunities?

The varied learning activities, reflective exercises and action points contained in this resource:

- Invite reflection on the learning gained, and how learning can be integrated into practice.
- Help you to make connections with relevant standards, continuing professional development (CPD) opportunities, and qualifications.

Social Service Workers

Social Service workers who use the activities in this resource to record their learning may include this as evidence of their learning in a portfolio for a Scottish Vocational Qualification (SVQ) in Social Services and Healthcare.

This includes people who may be working towards:

- qualifications for registration with the SSSC;
- other qualifications, for example the **Professional Development Award in Promoting Excellence in Dementia Skilled Practice**;
- furthering continuing professional development (CPD) and Post Registration and Learning (PRTL).

In all cases the extent to which learners can apply evidence from their learning journey throughout this resource will depend on the quality and depth brought to their reflective writing.

To support social service workers gather and express this evidence more fully, reflective account exercises are included at the end of each module. These are designed to help meet the learning outcomes of each module at Level 7 of the SCQF. These reflective exercises will also be useful for wider social service staff in recording CPD and in meeting PRTL requirements.

SVQ assessors and others who are supporting and assessing the learning of workers may find use of the reflective account exercises of benefit in planning, teaching and assessing.

Learning guidance to accompany this resource can be found online on the **Promoting Excellence** website.

Nurses and Midwives

The Nursing and Midwifery Council (NMC) introduced a revalidation process in 2015. The revalidation process has a number of requirements, including registrants submitting evidence of continuing professional development, and the submission and verification of reflective practice accounts.

NMC registrants should be able to use the learning enabled via this resource to:

- verify that they have undertaken the CPD required;
- evidence successful completion of the modules by completing the assessment on the NES Learn Pro version of this resource.
- apply learning to reflect on, and improve their practice.

Introduction

Getting started with the learning

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'.

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 their carers even more. Recognising the rich and varied backgrounds and interests that 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.

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 Caroline 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 has never married and has 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.

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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.

Joan

Joan is 85 and has lived in the same small Scottish town all her life, as have her daughters. Joan is part of a close and sociable family. Joan hardly spent any time on her own until the death of her husband 8 years earlier. Joan 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 Joan.

We use the stories of people with dementia and their families and carers throughout this resource to support application of learning. Readers may recognise aspects of these journeys their own experience. We want you to consider how the quality of the people with dementia's experience can be improved through you using your knowledge and skills. 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**

Module 1

Understanding dementia

Module 1: Understanding dementia

Introduction

As life expectancy rises in the developed world, more people are being diagnosed with dementia. In 2015 there were approximately 90,000 people living with dementia in Scotland. Over the next 20 years it is predicted that the number of people in the population who are over 65 years will increase significantly. As a result there will be a disproportionately greater increase of people in the oldest age groups, so it is likely that numbers of people with a diagnosis of dementia in Scotland will increase considerably. These numbers may change over the years, as will many of the statistics given in this module, and it is important that you should keep up to date by checking the Scottish Government website, or Alzheimer Scotland website.

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.

Module 1: Understanding dementia

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 that 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.

Types of Dementia

Alzheimer's disease	
Prevalence	Alzheimer's disease is the most common cause of dementia, and is estimated to affect more than 520,000 people in the UK in 2015. There are around twice as many women as men over 65 with Alzheimer's disease.
Age groups affected	Most 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. You can find out more about younger people with dementia later in this module.
Typical symptoms	Alzheimer's disease involves a general decline in a range of cognitive abilities. Typical symptoms include poor memory for recent events and learning new information, 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. Memory loss due to Alzheimer's disease will increasingly impact on daily life as the condition progresses.

Atypical forms of Alzheimer's disease

Atypical Alzheimer's disease is found in around 5% of people diagnosed when over 65. However, it accounts for around one third of people who are diagnosed under 65.

Posterior cortical atrophy (PCA)

The early symptoms of PCA often include difficulties identifying objects or reading, even though the persons eyes are healthy. People may also have problems judging distances when going down stairs, or appear uncoordinated when carrying out tasks.

Logopenic aphasia causes difficulties with language. The person's speech can become slowed and lack fluency due to word retrieval difficulties.

For further information see the Alzheimer's Society factsheet '**What is Alzheimer's disease?'** available on their website.

Vascular dementia	
Prevalence	Vascular dementia is the second most common type of dementia affecting around 150,000 people in the UK in 2015.
Age groups affected	The risk of vascular dementia increases with age, but it is one of the most common types of dementia among younger people with dementia in the UK.
Typical symptoms	Symptoms of vascular dementia will vary depending on the underlying causes. These can include problems with concentration and verbal communication, visuospatial difficulties and memory problems (though this may not be the first symptom), periods of acute confusion and epileptic seizures. Planning and making decisions or problem solving can be difficult. 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.

For further information see the Alzheimer's Society factsheet **'What is vascular dementia?'** available on their website.

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.

Remember

Some people may be affected by more that 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) may account for about 10 % of those with a diagnosis of dementia 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 types of dementia, memory loss, shortened attention span, disorientation and verbal communication difficulties. Additionally, people with DLB will often experience symptoms associated with Parkinson's disease, 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 and sleep disorders can be common.
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. As the condition progresses many people have problems with speech and with swallowing with additional risk of choking.

For further information see the Alzheimer's Society factsheet **'What is dementia with Lewy bodies?'** available on their website.

Fronto-temporal dementia	
Prevalence	Fronto-temporal dementia (previously known as Pick's disease) is a relatively rare type of dementia.
Age groups affected	Fronto-temporal dementia is more likely to affect people under the age of 65 than other types of dementia.
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 into what is happening to them, lose the capacity to empathise with others, behave in socially 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 **'What is frontotemporal dementia?'** available on their website.

Other types of dementia

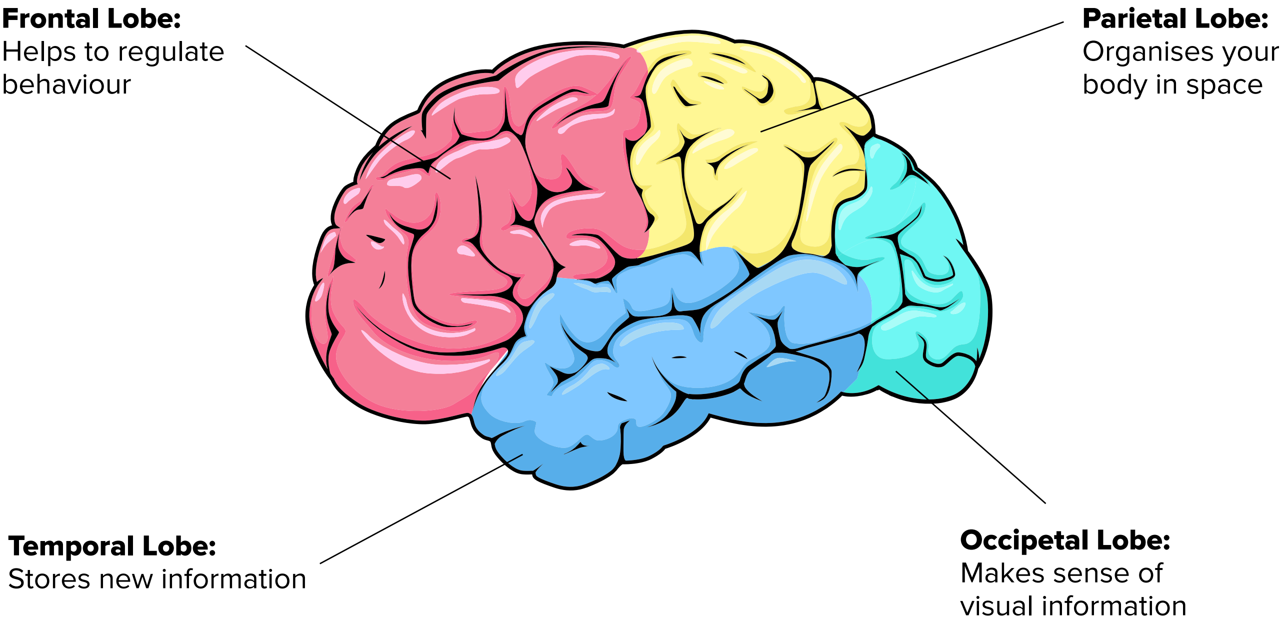
Approximately 23,000 people in the UK have a rarer form of dementia. Two of these are conditions caused by alcohol: Korsakoff's syndrome and alcohol-related dementia. These are serious brain disorders but will only be progressive if the person continues to drink alcohol. There are some other rarer types 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



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 choice 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.

Occipital Lobe

The occipital lobe receives visual information from the eyes. It transfers this information to the parietal lobe to support the construction of 3-D visual images. Damage in this area:

- Can lead to difficulties in the perception of shape, movement and colour.
- Can contribute to the inability to recognise or identify objects that a person sees.

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.

For further information - the Open Dementia Programme from Social Care Institute for Excellence, module: 'What happens in the brain' may help you understand the effects of damage in different areas of the brain in dementia. This can be accessed on their website.

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

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.

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 exact 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 or religious and beliefs they have.

End of life and dying well

Dementia is a progressive condition. The 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.

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 GPs 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

- How did reading about George’s difficulties make you feel?
- How would you feel if you were experiencing these difficulties?
- How do you think George and his son feel about these difficulties?
- What problems could be caused by these kinds of memory difficulties?
- 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 and 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.

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 Caroline lives nearby and visits every evening. While raising her own children, Ellen worked 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.

Caroline 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. She is thinking about getting the cooker disconnected because she is worried about her mum.

Reflection

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

Record your answers here

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 circumstances, 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 tele-healthcare solutions that can support people to remain independent for longer. We will explore tele-healthcare in more detail later in this learning resource.

Remember

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

Quality of Life Outcome 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 when they become disorientated to the time of day, the place they are 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.

Joan’s Story

Joan is 85 and has lived in the same small Scottish town all her life, as have her children John and Elaine. Joan is part of a close and sociable family. She hardly spent any time on her own until the death of her husband 7 years earlier. Joan 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 Joan.

Joan was diagnosed with dementia a year ago. She lives alone but receives a lot of support from her children who take it in turns to have her over to their houses on different days during the week, bringing her home in the evenings. Joan’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 Joan went to stay with her daughter Elaine for a while and felt frightened to go back home again.

Reflection

- How did reading about Joan’s difficulties make you feel?
- How would you feel if you were experiencing these difficulties?
- How do you think Joan’s family were feeling?
- What other problems could be caused by experiencing confusion or disorientation?
- 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 if 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. 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

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

Record your answers here

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 do not 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 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, and 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. There is a risk of confusing the 3 conditions, especially delirium and dementia, because they all have symptoms in common. Older people and people with dementia are more at risk of developing delirium.

Remember

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

Although it can sometimes come on fairly quickly as a result of a stroke or other brain injury, dementia symptoms usually progress 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 is a common and serious medical condition that results in a person becoming more confused than usual with disruptions in thinking, consciousness and behaviour. The person may have difficulty paying attention to what is going on around them. They may not seem like their usual self and may be more agitated, have hallucinations and become suspicious, or they may become drowsy, withdrawn and difficult to wake. Delirium develops rapidly over hours or days and tends to vary during the day with the person confused at some times, and appearing like their usual self at other times.

Delirium is commonly triggered by infection, changes in medicines or trauma such as surgery. Anyone can develop delirium, but older people and people with dementia are at much greater risk. When a person has delirium it is often the only sign of physical illness and can range from confusion and sleepiness to being extremely anxious, agitated and unable to sit still. It can last for several months and will continue to get worse if not treated.

Delirium can be prevented and treated if dealt with urgently. It is therefore essential that if you work with people with dementia in hospital and the community you are aware of how to prevent it and how to ensure that someone with suspected delirium receives rapid assessment and appropriate management.

NES have produced learning resources to support you to develop your knowledge and skills about delirium that you can access from their website.

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 the ability to orientate themselves in time and space are unusual.
- People with depression will occasionally experience an inability to remember things, but are 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, and 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.

Activity

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

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.
- Every type of dementia involves a process of progressive damage to the brain which affects people differently at different stages of their dementia journey.
- 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 and 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 and behaviours 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.

As you read further in this module check your answers against the information provided.

- Growing old.
- Occasionally drinking moderate amounts of wine.
- Taking regular exercise.
- Having a close relative with dementia.
- Having high blood pressure.
- High blood cholesterol levels.
- Suffering severe or repeated head injuries.
- Drinking large amounts of alcohol regularly.
- Smoking.
- Eating large amounts of saturated fat.
- Eating polyunsaturated fatty acids (for example, oily fish).
- Being obese.
- 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.

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.

Age Prevalence	Estimated prevalence
20–64 years	0.1%
65–69 years	0.7%
70–74 years	1.4%
75–79 years	3.1%
80–84 years	6.4%
85–89 years	10.5%
90+ years	15.9%

Estimated prevalence rates of dementia by age group in 2015

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.

Gender

Women are slightly more likely to develop Alzheimer's disease than men, even if we take account of the fact that women are more likely to live longer. The reasons for this are unclear.

Age	**Estimated prevalence**	
	Male	**Female**
20–64 years	0.1%	0.1%
65–69 years	0.6%	0.8%
70-74 years	1.3%	1.5%
75–79 years	2.8%	3.4%
80–84 years	5.2%	7.2%
85–89 years	7.6%	11.9%
90+ years	10.2%	17.8%

Estimated prevalence rates of dementia by age group and gender in 2015

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.
- Atrial fibrillation (the heart beat is irregular and usually faster).

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 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 people's 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.

In later modules we will discuss early interventions which can promote the best possible health, 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 influence this. These appear to relate to people's 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 if 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 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.

If you wish to increase your knowledge and skills about dementia and diagnosis to the Enhanced Practice Level of **Promoting Excellence** - you can find the learning resource **'Promoting Excellence in supporting people through a diagnosis of dementia'** on the Mental Health and Learning Disabilities page of the NES website.

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;
- poorly fitting dentures;
- sight or hearing difficulties.

Communication skills are increasingly affected as dementia progresses. 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. The loss of language skills for the person with dementia tends to start with those words used least and those 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. The person 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.

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.

Augmentative and Alternative Communication (AAC) is a term used to describe a huge range of methods and means that can help people to get their message across when they find speaking difficult. You can find information about this on the **'Now Hear Me'** website.

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 effect on the quality of life that 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?

Record your answers here:

The physical environment

Living well with dementia can pose significant challenges. Something that might seem simple to a 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"
>
> **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 strengths 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.

SCIE have a useful section of their website to help you explore this area. Visit the **'Dementia friendly environments'** section on the Dementia Gateway to find out more.

Where there is a desire to create environments which are safe and secure, it is also important to adopt positive approaches to risk for people with dementia. 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 affect on well-being, morale and self confidence and, when well considered, can support people to flourish.

What do you need to consider when creating 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 in later modules.

Dementia Friendly Communities

A key way to enable people to live well with dementia is to support them to remain in their own homes and communities for as long as possible. In order to do this it is important that communities are inclusive, i.e. the members do everything that they can to respect all citizens, ensure full access to resources, and promote equal treatment and opportunity. As well as this the community values diversity, works to eliminate all forms of discrimination and engages all its citizens in decision-making processes that affect their lives.

In relation to people with dementia such communities are often called dementia-friendly communities. This can be described as being a place in which it is possible for the greatest number of people with dementia to live a good life and where people with dementia are enabled to live as independently as possible and to continue to be part of their community. For example people are supported to find their way around, and feel and be safe. They can access the local facilities that they are used to and where they are known (such as banks, shops, cafes, cinemas and post offices). Most importantly people with dementia are able to maintain their social networks so they feel they continue to belong.

There are a number of Dementia Friendly Communities in Scotland and you might like to find out what is happening in your local area.

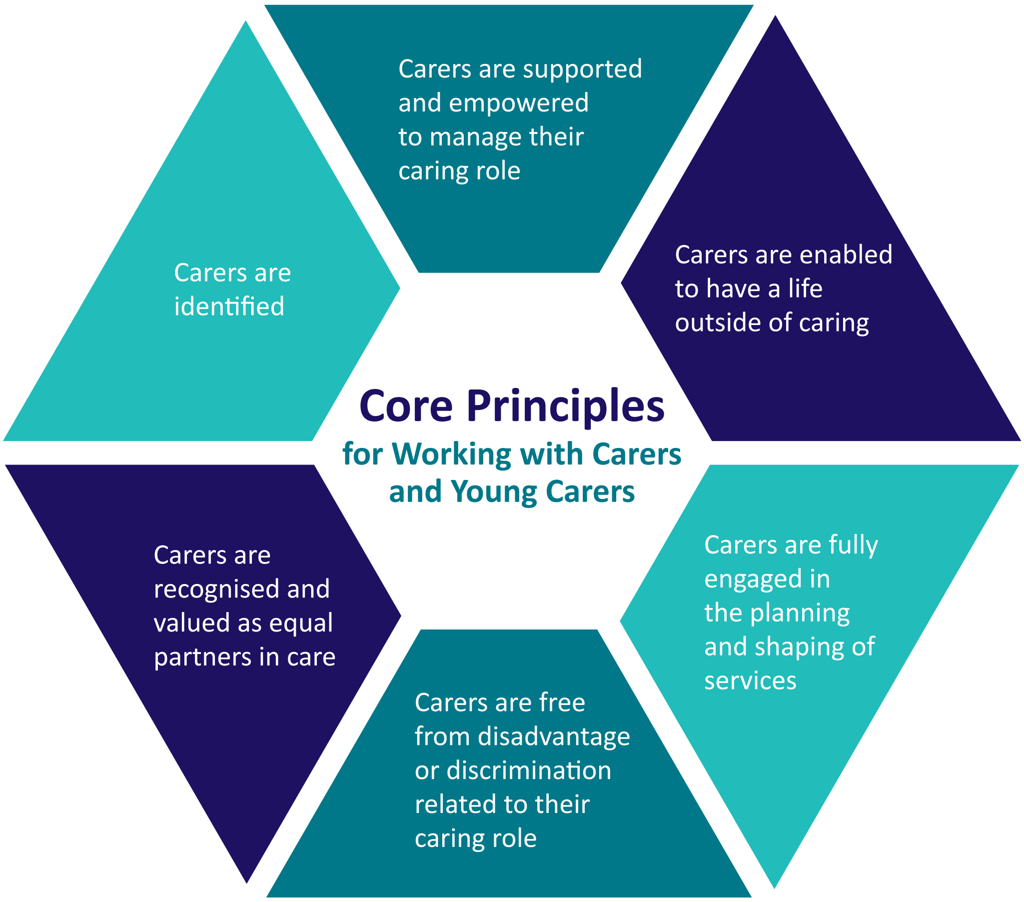
Carers, families and people with dementia

Carers and families can be an essential source of support in enabling people to live well with dementia. If a person with dementia is supported by an unpaid carer, such as a family member or close friend, it is important that we also take that person's views into account when planning care and support. However, despite the important role they hold, carers may experience distress, and even depression, as a result of the pressures associated with the caring role. Carers may describe a feeling of frustration at not being involved as an equal partner in discussions about care and support, even though they are often directly affected.

You will need to be skilled at recognising the needs and wishes of carers, whilst ensuring the rights of the person with dementia remain paramount.

It can be difficult to get the balance right, however, if you work with the carer in a person-centred way, and appreciate how hard their role can be, you will find it easier to build a positive relationship based on empathy and understanding.

To support you to work better with carers, the Scottish Social Services Council and NHS Education for Scotland developed core principles for working with carers and young carers.



Core Principles
for Working with Carers and Young Carers

Carers are identified

Carers are supported and empowered to manage their caring role

Carers are enabled to have a life outside of caring

Carers are fully engaged in the planning and shaping of services

Carers are free from disadvantage or discrimination related to their caring role

Carers are recognised and valued as equal partners in care

Activity

Take a look at the core principles below.

Identify an occasion where you have interacted with an unpaid carer and think about what you said and did. Would you have done anything differently? With the core principles in mind would you have done anything differently?

Record your answers here:

The first step towards working better with carers is to become 'Carer Aware'. This includes understanding the definition of the word carer, and becoming more aware of the impact caring may have on a person's physical, emotional and mental health, and well-being and overall quality of life.

If you would like to become Carer Aware you can complete the free online E-learning module. Find out more at the **Equal Partners in Care** website on the Knowledge Network.

Remember

"I have the right to have carers who are well supported and educated about dementia".

Standards of Care for Dementia in Scotland (2011)

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 sections, at a range of ages. Dementia can also affect people alongside other conditions including physical and mental health conditions and learning or physical disabilities. It is important to recognise that social inequalities and experiences of discrimination or prejudice may have a significant impact on people with dementia, their families and carers. 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.

A person's experience of dementia is informed by their cultural background, core values, beliefs and identity. This calls for sensitive approaches to dementia support and care. It is critical that staff consider the experience of the person with dementia within their own context and provide culturally appropriate care and support.

However, if we always use a person-centred approach we will identify individual needs and preferences. For example, we will not assume that all people who speak the same language practice the same religion, or that everyone who follows the same religion will 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. Around 3200 younger people under 65 are currently living with dementia in Scotland in 2015.

Younger people often experience difficulties and delays in the process of diagnosis. They 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 respond to their unique needs for support and care. A further issue facing younger people living with dementia is stigma and discrimination. This can be particularly heightened because dementia is especially associated with older people.

Remember younger people with dementia that you work with are likely to:

- Have a job at the time of diagnosis.
- Have a young family.
- 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 further information about the physical and social impact of dementia on younger people with dementia see the Alzheimer's Society factsheet **'Younger people with dementia'** on their website. You can also find a booklet called **'Young onset dementia'**, designed for younger people, on the Health Scotland website.

For children and young people in families where someone is living with dementia it can be particularly difficult and it is important that the whole family is supported.

For more information see the Alzheimer's Society factsheet **'Explaining dementia to children and young people'** on their website. Health Scotland have also produced a booklet **'Understanding dementia: A guide for young people'** available on their website.

People with dementia and sensory impairment

Living with both hearing loss and dementia can often make communication more difficult and this can either result in, or exacerbate, social isolation. If a person's hearing loss is managed well, this can help them to cope better with their dementia.

It is important to remember that there are significant cultural and language differences between people who are born deaf and use sign language – and those who lose their hearing, or who prefer to use spoken language.

The early signs of dementia are often missed in Deaf people, because of difficulties with communication. Awareness of dementia in the Deaf community is low and poor access to information in accessible languages and appropriate media can make this problem worse.

Deterioration in sight is very common among older people, and yet it can frequently be missed as the symptoms may be misinterpreted as resulting from dementia. It is important to understand and recognise the signs of sight loss and to ensure that people have regular eye examinations. There are many ways in which communication can be improved with people with sight loss and dementia. We should make the most of what sight a person has and always ensure that the correct glasses are worn for the activities undertaken and that they are kept clean. Environmental improvements, and specialist equipment and technology can also support people with sight loss and dementia to be more independent.

For people with any type of sensory loss it is important that they have access to interpretation or other types of communication support where required.

There is more information about supporting people to live well with dementia and sensory impairment in later modules.

People with a learning disability and dementia

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 with up to 75% over the age of 60 years of age likely to develop dementia. The prevalence of dementia in older people with other forms of learning disability is higher than in the general population. However as is the case with any suspected cognitive decline it is important that other causes for any changes are eliminated.

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 environment should be appropriate for people offering a stable, predictable and calming atmosphere. It is also important that any other physical, mental, social, and emotional health needs are met. In particular, older people with learning disabilities are more likely to be affected by arthritis and other conditions that can affect mobility. People with Down's Syndrome are also particularly susceptible to thyroid conditions and hearing problems. It is essential that people with a learning disability who are living with dementia are not disadvantaged by lack of access to general healthcare.

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.

As a result of the improvements in health care and the resulting ageing population an increasing number of people with learning disabilities are still living at home with family carers who are now 70 or older. Those carers may be parents, siblings, grandparents, other close relatives or friends. As family carers start needing more support themselves, the families have often developed routines and ways of coping that mean that both the older person and the person with a learning disability are looking after each other. This is known as mutual caring. Taken alongside the increasing prevalence of dementia with age it is quite possible that any or all those involved in a mutually caring relationship may be living with dementia.

A critical factor for families in this situation is that they do not fit neatly into services and support. Often, nobody is sure which service should take responsibility for provision of support and they may be passed around and fail to get adequate support from anyone. This can result in an inequitable access to appropriate health and social support and difficult situations can deteriorate and a crisis may arise.

The only way to deal with this is by ensuring that a 'joined up' approach is taken. The key thing is that you are able to recognise mutual caring, appreciate the complexity and sensitive nature of the situation and have some ideas about how you can offer different levels of support.

You can find a useful resource on the University of the West of Scotland website called Jenny's Diary that can support you to have conversations about dementia with people who have a learning disability.

Lesbian, gay, bisexual and transgender (LGBT) communities

Before considering the experience of people from LGBT communities who are living with dementia it is important to clarify some terminology commonly used.

- **Sex** refers to a person's biological status and is typically categorised as male, female, or intersex (i.e. atypical combinations of features that usually distinguish male from female).
- **Gender** refers to the attitudes, feelings, and behaviours that a given culture associates with a person's biological sex.
- **Gender identity** refers to a person's sense of oneself as male, female, or transgender and the way in which they act to communicate gender within a given culture; for example, in terms of clothing, communication patterns and interests is referred to as their **gender expression**.
- **Sexual orientation** refers to the sex of those to whom a person may be sexually and romantically attracted. Categories of sexual orientation usually include people who are attracted to members of their own sex (gay men or lesbians), attraction to members of the other sex (heterosexuals), and attraction to members of both sexes (bisexuals). Although these categories continue to be widely used, there is a school of thought that suggests that sexual orientation occurs on a continuum.

Previous experiences of discrimination can make people from LGBT communities who are living with dementia reluctant to disclose their sexual orientation and/or gender identity. This can sometimes mean that people avoid using formal care and support services.

The fear of discrimination may act as a barrier to early diagnosis of dementia and may also cause distress for people in the later stages of their dementia journey. We should ensure that when talking about LGBT people or issues, or discussing relationships, gender or sexuality in everyday conversation, that this is done in a non-judgemental and affirmative way, even if you don't know if there is someone who is LGBT present.

Lesbian, gay, bisexual and transgender people living with dementia

It is important that we avoid making assumptions that the people living with dementia that we are working with are heterosexual. This includes assumptions about people based on our own expectations, regarding the nominated next of kin. It is also important that do not force people to talk about their sexual orientation if they do not wish to. Older people may not be comfortable with the phrases lesbian, gay or bisexual so we should employ the terminology favoured by the person we are working with. It is also important to include same-sex partners in planning care where it is the wish of the person with dementia.

Transgender people living with dementia

It is critical that transgender people should be recognised as and treated according to their gender identity. Their body may not match assumptions made on the basis of their gender identity, and where they require personal care this should be handled sensitively and without unnecessary questions or comments. Transgender people may have specific personal care needs relating to their transition, and they may also wish to have a higher degree of privacy. They may also be cared for by non-traditional families, who should be included in planning care where it is the wish of the person with dementia.

You will find a number of useful resources to support your practice on the 'LGBT Health and Wellbeing website' on the **'Resources for professionals'** page.

Race and ethnicity

Current evidence has its limitations, but suggests the estimated prevalence rates for dementia in Black and minority ethnic (BME) communities are similar to the general population. However, there appears to be a higher prevalence of younger people with dementia, and people with Vascular Dementia. Evidence also suggests that people from BME communities, who experience dementia, may be less likely to seek support from services, tend to make contact at a later stage of the dementia journey, and are less likely to receive an early diagnosis.

Some key points to consider include:

- Misunderstandings may indicate language barriers and may not just be due to the impact of the person's dementia.
- There may be a need to provide access to translators. This will need to be handled sensitively -- using a family member as a translator is not always appropriate.
- The term 'dementia' is not always easily translated into some languages in lay people's terms.
- Carers in minority ethnic communities may not identify with the term 'carer'.
- Minority ethnic communities differ and it is important to be person-centred and listen to individuals and their families.

Top ten tips to support equality and diversity issues

1. Always use a person-centred approach that recognises all the aspects of someone's identity, such as race, religion, beliefs and sexual identity. This is essential to promote positive engagement with staff and services at all stages of the dementia journey.
2. Identify and support the cultural, language and spiritual needs of people with dementia in all care plans and reviews.
3. Remember that differences in family structures may mean that the person who is most important to the individual and who may really need to be involved may not always be the person you might have assumed it would be.
4. Make sure that communication reflects appropriate cultural, spiritual and religious values and beliefs.
5. Provide people with dementia and their families with information in their preferred language or format.
6. Make sure that cultural and spiritual diversity and gender identity is reflected in all services, including health and personal care, food services and religious practices and beliefs.
7. Ensure that people with dementia have access to culturally appropriate emotional and spiritual support.
8. Support people with dementia to engage with activities and therapies that reflect their cultural, spiritual, religious beliefs, sexual orientation or gender identity.
9. Make sure that the living environment is appropriate to support cultural, spiritual and religious values and beliefs.
10. Use professional interpreting services familiar with the care setting for dementia assessments.

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)

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.

A final thought for your reflection:

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 love ones spoken about in such disparaging terms. Sadly the media love these terms, despite my protests, and I cannot blame people for being mislead 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

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 considered the importance of equality and diversity in dementia care and support.

Reflective Account

Write a reflective account taking into consideration your learning from Module 1.

Below is a suggested structure that you may find helpful in writing your reflective account.

Please ensure that you anonymise any information

What happened?

Identify and describe a situation or incident where you were supporting a person with dementia. When recalling this situation you may wish to consider the following:

- The type of dementia that you think that the person may be living with.
- The changes and difficulties that the person may have been experiencing.
- Communication issues.
- The impact of the physical and social environment.

Describe what you did or how you responded.

Describe the outcome of your actions or response.

So what does this mean?

How did you feel about the outcome of the support that you provided at the time?

What do you feel about that now in light of your learning, having completed the module?

What did you do that went well?

Do you think your actions helped to improve quality of life for the person you were working with?

What might you now do differently?

Now what will you do in the future?

How will this affect the way you work with people with dementia in the future?

Would you act differently or would you be likely to do the same?

What further learning do you need to undertake to enhance your understanding of dementia that will help you to support people to improve their quality of life? You may want to record this using the **Action into practice** activity at the end of this module.

Action into practice

From your learning in this module

- Make a note of 3 new things you have learned about dementia and about people with dementia and their families and carers.
- Make a note of 3 areas of dementia practice you would like to learn more about as you continue through this learning resource.
- Make a note of 3 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.

Make notes of your responses below:

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 people who work in health and social service 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 live valued lives and remain connected with their communities. We explore strengths, asset- based and personal outcome focussed approaches in working with people with dementia.

We also look at the ways that can be used to support people with dementia continue to live independent lives, for example Self-directed Support and tele-healthcare, 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 and their families and carers.
3. Identify and explain the relationship between person-centred care and support, personal outcome focussed approaches 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 families and 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 was 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 outcome indicators below:

Standards of Care for Dementia domains	QoL outcome indicators
■ 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	■ 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 outcome indicators would you consider to be of particular importance to you, and why?

Think about a person you know with dementia. How are the **Standards** and QoL outcome indicators outlined above being applied to shape his or her care and support?

Record your answers here:

To enable workers to ensure that the **Standards** and outcome 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 them.

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.

Kitwood first introduced the concept of 'personhood' (the essence of who we are) in the 1990s stressing that the pace at which the person's dementia progresses is not just due to medical factors, but is in fact greatly influenced by how they are treated by people and society.

For example, stigma can lead to a person with dementia experiencing low self-esteem and feeling unable to participate in society as much as they did before. This in itself can lead to a person losing skills and interests that they once held. Such a loss can impact negatively on a person's ability to live well with dementia for as long as possible.

Kitwood saw person-centred approaches as ways of working with the lived experience of the person with dementia. So by adopting this approach we learn to focus more on people's emotions and feeling, and mobilise the **strengths** that people with dementia have in communicating and being part of relationships with others.

Kitwood's approach has been further developed and has become the cornerstone of many policy and practice initiatives.

If we are to practise in a truly person-centred way then we need to have a deeper understanding of what it means.

Module 2: Promoting person and family centred care and community connections

Reflection

Think about you own role.

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

Record your answers here:

There are many different approaches to person-centred care and this can be confusing. For this module we will be drawing on a model based on a review carried out by Dawn Brooker. She concluded that most approaches are essentially made up of 4 key elements.

Four 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.

Valuing the person with dementia as an individual; appreciating 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.

Valuing people with dementia

Valuing people is at the heart of person-centred care and underpins how the other 3 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."
>
> **Standards of Care for Dementia in Scotland** (2011)

Module 2: Promoting person and family centred care and community connections

People with dementia have sometimes been portrayed in the media very negatively, with the additional suggestion that services and resources are not set up to meet their needs. This can lead to people with dementia, and their families and carers, feeling stigmatised and excluded from their communities. These feelings may increase as people's social contact and their meaningful activities diminish, leading 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 to the policy focus in health and social services mean that services are moving towards *'strengths'* and *'asset based'* approaches, which utilise personal and community resources. This enables people with dementia, and their families and carers, to be much more involved in decisions about care, treatment and support than was the case in the past.

The term *'personalisation'* is often used to describe the policy and practice shift, and culture change, taking place across Scotland in which people using services are involved as equal partners in the planning, design and delivery of care and support. This approach enables the person to find the right solutions for him or her self and to participate in the delivery of a service. From being a recipient of services, people can become actively involved in selecting and shaping the services they receive. A key output of personalisation was the introduction of Self-directed Support which we will explore later in this module.

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 existing role within their family, social networks and communities.

People with dementia may need to make a range of adjustments to their life throughout their journey and 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. Strengths based approaches take this a step further and recognise 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.

Reflection

Think about some community based activities that you engage in.

- How would you feel if you were unable to do these activities anymore?
- Do you think this would impact on your own view of yourself as a valued person?

Record your answers here:

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 - 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 had 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 became 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 ensure 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 and in Module 1 of this resource.

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

Ellen is getting ready to attend the lunch club. Her Support Worker has helped her to 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:

It is easy to see how disrespectful the behaviour in this scenario is and how it shows a disregard for Ellen as a person.

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.

Module 2: Promoting person and family centred care and community connections

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.
- Personal outcomes.

Knowing the person with dementia

Activity

Does knowing the person who 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 led 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:

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

Life Stories

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 their skills and past experience.

Finding out about the person can be achieved in many different ways. ***'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 enables us to support the person with what they want and need rather than guessing.
- It helps us to have a better understanding of the causes of someone's behaviour or their distress.
- 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 for 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 Life Story can also be very therapeutic in developing a trusting relationship with people. 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 the person with dementia considers 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 Outcome 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 this;
- and it must be developed at a ***pace that suits them*** - as a continuous process that is developed over time.

Personal Support Planning

A timely diagnosis of dementia can allow the person to begin to plan for the future and they should be supported to undertake personal support planning, which can enable people to plan the shape of their future care. This should be supported by using personal outcomes-focussed approaches, which start with an understanding of what is going on in people’s lives and what they want to achieve. Using personal outcomes-focussed approaches requires us to work with the person to consider the following open questions:

- What is important to you in life and what is it that you want to achieve (outcomes)?
- How will you know that you have achieved these outcomes?
- What are your strengths, abilities and the resources available to you that will enable you to achieve what you want (assets)?
- What is already working and what has been changing to help you get what you want?
- What will be the next small signs of progress towards what you want?

We can then go on to identify barriers to people achieving their outcomes and how they can be overcome, building on their abilities, assets and strengths.

Advance Planning

A key aspect of personal support planning is to enable the person to begin to think about future health and care needs, as at some future point in time it may become less easy for them to do this. These wishes and decisions about future care should be recorded and this is known as ‘advance planning’.

Some people with dementia and their families and carers may be unaware of Advance Plans and it is important that we explain them and their benefits. It is also important to remember that only decisions made by the person can be included in the Advance Plan. It is also important that palliative and end of life care planning is discussed as early as the person with dementia wants, and this 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. We will explore some of these issues further in Module 5.

Reflection

Take some time to consider what is important to you and key aspects that you would wish to incorporate into your advance plan.

- How would you feel about sharing this information?

Record your answers here:

Did you consider any of the following?

Preferences

For example: the things you like to wear, eat, drink; music you like; hobbies or pastimes you enjoy; special interests; what items you like to have around you.

Your spiritual and philosophical beliefs

What makes life worth living; things that have special meaning in your life.

Dislikes

Things that you do not like to do, do not like others around you doing, or like or do not like about the environment you live in.

What you fear most

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

Attitudes to making decisions

How you like to make decisions – are you ‘independent-minded’ or do you tend to depend on the advice of others.

People who matter

Your friends and family - how and who you would like to be involved if you were not capable of making certain decisions, and the people you might not want involved.

Attitudes to professionals

Those who are treating you and caring for you. Your relationships with doctors, nurses or others in the other caring professions, especially the degree to which you tend to rely on their judgements.

Attitudes to illness and disability

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

Attitudes to death and dying

For example, your views on giving and withholding treatment that may hasten or delay your death. Where you would like to be when you die and who you would like to have around you.

After your death

Your wishes, for example, about your funeral and who to tell about it.

Anything else

Not mentioned above but something you identified as important to you.

Activity

How would you support a person with dementia to start thinking about what is important to them when they are considering their future plans?

Record your answers here:

Working with people who have just received a diagnosis of dementia to make plans

As you will remember from Module 1 a person's dementia journey begins before they receive a formal diagnosis. Receiving a diagnosis of dementia is life changing, and can be an emotional and frightening time for the person and their family as they begin to worry about what the future will bring. At this time a person receiving the diagnosis needs to be supported by specialist workers who hold Enhanced Levels of knowledge and skills as set out in the **Promoting Excellence** framework.

If you wish to increase your knowledge and skills about dementia and diagnosis to the Enhanced practice level of **Promoting Excellence** you can find the learning resource **Promoting Excellence in supporting people through a diagnosis of dementia** on the Mental Health and Learning Disabilities page of the NES website.

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 Scotland.

You should be aware that this is a very sensitive time for the person and their family and carers, so it is important to ensure that this is the appropriate time and circumstance to start talking about future plans. If you have any concerns you should seek advice from your manager.

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

Module 2: Promoting person and family centred care and community connections

Alzheimer Scotland has developed **5 pillars of support** which everyone must be offered for a minimum of one year following their diagnosis.

5 Pillars of Post Diagnostic Support

- **Help to understand dementia and manage their symptoms** – by providing accessible information for the person, their family 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 some people to 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.
- **Help to plan for their future decision-making** –this includes all the advance 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 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.

Person-centred care planning

As the person progresses to the later stages of their dementia journey it is important that we find out if they have developed Advance Plans and Life Stories and use them to inform all aspects of our care and support. Even if they have not got plans in place we can still do a lot to get to know the person and support them to identify their needs, wishes and aspirations.

Through skillfully and sensitively communicating with the person, and their family and carers, 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.

Often a person in the later stages of their 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. This 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 in people's lives as they can be relived as their dementia progresses, in the same way positive ones are, but are more likely to lead to distress.

When a person does not have an Advance Plan this template may be useful in helping to gather information to support person-centred care 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.

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.	Joanne was a farmers' wife and 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 that the person's Life Story and Advance Plans are not just developed, but that they should be used all the time. They are key in developing positive partnership relationships with the person, their family and carers and delivering person-centred care and support.

Meaningful engagement

When we are working with people with dementia in a person-centred way we need to strive to understand the world from their point of view. We can support this through effective communication, empathy and relating directly to them to understand their individual wishes and needs. This will give focus to all our interactions to 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 this contributes to a good quality of life, as well as improving their health and well-being.

In the earlier stages of dementia the person will be 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, rather than set activities that everyone is 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 stressed and distressed behaviours.

Activities can:

- Help the person maintain their independence.
- Help maintain skills.
- Improve self esteem.

- Improve quality of life.
- 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 in 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 that 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 and 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 answer here:

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 use or understand language is severely limited.

We should always ask the person's permission before any intervention or activity, even when someone is at a more advanced stage of their dementia journey. 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 for people we need to look for clues in how the person behaves and responds, as well as trying to understand 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 Outcome 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 in their personal history which makes them more interested in discussing this topic?

Communicating with a person at the later stages of the journey

Communicating positively is crucial throughout the person's journey, including when supporting the person in dying well at the end of their life. Consider the 'top communication tips' below.

As you will see, they reflect the important aspects of person-centred care that we have been discussing so far.

Top communication tips

Before implementing the following tips it is important that you remember that a person-centred approach means that you should take into consideration the person's culture, their individual preferences and personal history. Earlier in this module we looked at Life Story work and really knowing the person can help to ascertain whether your communications strategies are appropriate.

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 to 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 persons 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 to 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. While it is tempting to hurry when you are busy, strategies like simply slowing down your rate of speech can be very helpful. Try to increase your communication time both in speaking and listening.

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, including 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 to use words the person with dementia will understand, and that are 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 such as “he” or “she”. 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 be inappropriate when the person with dementia may be 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 service professionals involved with their care – in fact anyone who knows the person well. For example using the person’s first spoken language, British Sign Language (BSL), lip reading, Makaton or communication aids such as pictures or speech mats.

Remember

Never assume that the person with dementia cannot understand you.

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 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 will 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?

Record your answers here:

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 could the risk be for Jim when the staff are busy and preoccupied?

If Jim is regularly taken in a wheelchair 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 several problems. Another reason why we need to take the perspective of the person is that sometimes when someone cannot communicate verbally in a busy environment it is easy to overlook their needs.

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 spent can mean a lot of time saved.

When care settings are very busy there may be 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. Carers, and wider social networks are so important in helping a person with dementia remain connected and active in the community. They are an important natural resource, and they will share many years of memories that can help a person with dementia to remain connected to the emotions, relationships and experiences in life that they enjoy.

In the early stages of dementia, following a diagnosis, the person may be at risk of withdrawing from their family and social network because of their fears and how other people respond to them.

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.”

In order to support the person’s social environment, we need to have a valuing, respectful and enhancing culture of care. 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.

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.

Sometimes because we are busy and in a hurry we might be tempted 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 and including them in discussions and actively encouraging them to engage with their social network.

All of these issues are important to consider when we think about social environments that may ‘support’ or ‘alienate’ people. The following table outlines characteristics 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.

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.

From your experience do you think these different characteristics also apply to and influence the staff working in these settings?

Record your answers here:

Supporting people to maintain networks and community connections

Self-directed Support

So far in this module we have explored the features and approaches that can support truly person-centred care. We have looked at: valuing the person with dementia; seeing them as a unique individual; taking their perspective; and supporting their social environment.

The Scottish Government introduced the Social Care (Self-directed Support) (Scotland) Act 2013 which came into force in April 2014. The Act places a duty on local authority social work departments to offer people who are eligible for social care a range of choices over how they receive their social care and support.

The underpinning values of Self-directed Support (SDS).

Respect	Having due regard for the feelings, wishes, or rights of others
Fairness	Treating people as individuals and providing accurate information about the choices available
Independence	People are supported to maximise their aspirations and potential
Freedom	People have the freedom to make choices
Safety	People feel safe and secure; they enjoy safety but are not discouraged from taking risks that could increase their well-being and enjoyment of life

SDS allows people, their carers, and their families to make informed choices on what their support looks like and how it is delivered, making it possible to meet personal outcomes.

Having more choice and control is empowering. We should all be equal partners in making decisions that affect us. This leads to more of us being confident and independent and achieving our aspirations for a happier, healthier and more fulfilled life.

Support and care have a vital role to play in ensuring everyone can enjoy the same human rights i.e. dignity, and equality of opportunity. If people have greater control of their lives and decision-making this can contribute to improved health and well-being.

SDS can include a range of options to ensure that everyone can exercise choice and control and can include:

- a Direct Payment (a cash payment);
- funding allocated to a provider of choice. This is sometimes called an individual service fund, where the council holds the budget but the person is in charge of how it is spent;
- the council can arrange services for the person;
- the person can choose a mix of these options for different types of support.

Families and carers of people with dementia can be involved in arranging or supporting people to manage this. Some of the legal issues that may need to be considered in relation to this are explored in Module 5.

Self-directed Support can be used in many ways, for example:

- People can get support to live in their own home, such as help with having a bath or getting washed and dressed.
- People can be supported in engaging in hobbies, interests, exercises and leisure pursuits.

- It could also be used to provide a short break (respite) or for equipment and temporary adaptations.
- People can choose whether they would prefer to get support from a service provider such as a voluntary organisation or care agency, or by employing a Personal Assistant, or a combination of both.

SDS can enable workers and services to take a more creative approach to providing support that builds on people's assets. Earlier in the module we examined the outcome indicators for people with dementia and the **Standards of Care for Dementia in Scotland**. Using the scenario below we can explore how SDS can be used in meaningful ways to support quality of life for people with dementia.

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 empty 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 QoL outcome 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 QoL 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 his children and grandchildren.
- Attending support groups.
- Having time apart to engage in personal interest and activities they both value.

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 Outcome Indicators.
Promoting Excellence (2011)

Tele-healthcare

SDS and people having their own budgets means, amongst other things, that innovative use of tele-healthcare 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 and feels it is the best option to support them.

Examples of the range of tele-healthcare 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 people to find things such as keys or wallets. They flash or make a sound to guide people to them.
- **Remembering to do things -** such as signs in words or pictures, notice boards and 'post it' 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 provide voice recorders to remind people 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 and automatic pill dispensers that make a sound or flash when it's time to take medication.
- **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 and 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 to react, for example: phoning 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 -** that 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.

Joan's Story

You will remember in Module 1 we met Joan 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 Joan 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 Joan was physically in good health.

Activity

Do you think there were any other options for Joan?

Record your answers here

Here is what happened.

Joan'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; 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 Joan had left her house after a certain time at night.

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.

Joan 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 8 am to be ignored until they arrived to disarm the device.

This solution has worked very well for Joan and her family. Joan feels safer and the family have peace of mind in the reassurance that the tele-healthcare 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 tele-healthcare, means that Joan is now able to stay in her own home.

Tele-healthcare 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 family 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 story will help inform the evaluation process.
- Consideration must be given to **capacity and consent**.
- **Risk assessment** and **enablement** which includes the assessment of risks in the home as well as outside the home.
- **Families and carers also need appropriate training** and support in the use of tele-healthcare.

We will examine ethical issues relating to tele-healthcare in Module 5.

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 independently for as long as possible within communities.

Reflective Account

Write a reflective account taking into consideration your learning from Module 2.

Below is a suggested structure that you may find helpful in writing your reflective account.

Please ensure that you anonymise any information

What happened?

Identify and describe a situation or incident where you were supporting a person with dementia to achieve a personal outcome. When recalling this situation you may wish to consider the following:

- The relationship between person-centred care and support, personal outcome focussed approaches and personalised services.
- The steps, supports and resources used to achieve this outcome for example Life Story work.
- Relationships and valued roles.

Describe what you did or how you responded.

Describe the outcome of your actions or response.

So what does this mean?

- How did you feel about the outcome of the support that you provided at the time?
- What do you feel about that now in light of your learning, having completed the module?
- What did you do that went well?
- Do you think your actions helped to improve quality of life for the person you were working with?
- What might you now do differently?

Now what will you do in the future?

- How will this affect the way you work with people with dementia in the future?
- Would you act differently or would you be likely to do the same?
- What further learning do you need to undertake to enhance your understanding of person-centred approaches to working with people with dementia that will help you to support people to improve their quality of life?

You may want to record this using the **Action into practice** activity at the end of this module.

Action into practice

From your learning in this module

- Make a note of 3 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.

Make notes of your responses below:

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 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 are experienced by people with dementia.
4. Describe the common mental health and well-being issues that are 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 manage their own well-being enables them to 'be all they can be' and to maximise their quality of life. Self-management approaches recognise 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. Promoting self-management sometimes requires staff and services to think differently and creatively, to 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 care setting;
- providing **personalised** services that are tailored to the person's 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;
- **using 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.

We have explored some of these issues already in Module 2.

A well-being focussed 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 have personalised support. This could be through having an assessment of their physical and emotional needs. They should also be able to have the right information to enable them to access services and provide the best possible care and support.

Find out more by visiting **Care Information Scotland** or your local Health Board website. Each Health Board in Scotland is required to produce a ‘Carers’ Information Strategy’ which sets out how they will inform carers of their right to a ‘Carer’s Assessment’ or a ‘Carer Support Plan’ and give them information which may help them in their caring role.

Later in this module we will explore common physical health, 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 their involvement and self-management of mental and physical health conditions at all times.

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

Many factors can combine together to influence our health and well-being and these are no different for a person with dementia.

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, including:

- Genetics.
- Education.
- Health behaviours.
- Our 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 we also 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 is alert to the person's physical health. In the earlier stages of the dementia journey 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 at all stages of their dementia journey. It can also provide opportunities for people to socialise and engage with other people, reduce any feelings of isolation they might be experiencing, and help 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;
- help maintain a healthy weight.

Additionally it can:

- prevent stiffness, muscle wasting and reduction in joint strength;
- maintain or improve bone density and reduce the risk of osteoporosis;
- improve balance and strength - this can reduce the risk of falls, the negative outcomes related to falls, and importantly the fear of having a fall.

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;
- reducing the likelihood of anxiety, stress and depression developing.

In the earlier stages of dementia people should be encouraged and supported to maintain any physical activities they have routinely 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 exercises, physical activity sessions and exercise classes - including music and dance, yoga and tai chi, indoor bowls, or swimming.

Some of these activities can be modified and carried out at home if preferred.

In addition, walking, golf, gardening and housework are also good forms of exercise. Regular physical activity is beneficial for us all and adults should aim to be active daily. To stay healthy, or to improve health, the ideal is for adults to do 2 types of physical activity each week: aerobic and muscle-strengthening activity. It may be that adaptations to exercises and the surroundings are necessary to allow people to participate in this. There is evidence to tell us that muscle-strengthening in particular can, for older people and those with long term conditions, reduce the risk of falls. Around 30 minutes 5 times a week is recommended, although this can be broken up into shorter sessions. Also, a range of different physical activity can help to maintain interest by introducing variety.

Remember

think about the things that people **can** still do for themselves. Promote independence whenever you can.

As people progress along their dementia journey regular physical exercise can help to reduce or delay the need for adaptations to the person's living environments, or for increased support with daily living and care. 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 throughout the day. A daily routine involving moving around the home, walking rather than using a wheelchair for example, whenever and wherever possible, can help to maintain muscle strength and joint flexibility which, in turn, can reduce the risk of falls. Evidence suggests that remaining active in these ways helps to reduce the incidence of falls.

Dancing can help improve physical, psychological and emotional well-being and can easily be incorporated into everyday activity. 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 incorporated into daily life can make all the difference.

It is always important however 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 individual or group exercise programmes.

It is not unusual for people who have dementia and live 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 physical and psychological well-being.

Activity

Think about the people with dementia who you work with. Think of 3 ways that you could support them to incorporate more physical exercise or activity into their daily routine.

Record your answers here:

Remember

whether you are supporting someone in their own home or in a care home, you can encourage movement through all aspects of daily living.

Relationships and sexuality

Dementia causes many changes in a person's life and as time passes it may be difficult to maintain relationships and social contacts, leading to feelings of isolation and loneliness. Keeping in contact with others is good for people with dementia because it helps them to keep active and stimulated.

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 which supports their choices.

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 is possible that what appears to be sexual behaviour 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 or 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 from the mental health team or psychologist. Behaviour is deemed to be inappropriate if anyone is distressed by it and it should be addressed. As we have already explored in Module 2, 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 these and visuoperceptual difficulties from the Alzheimer's Society website and the Royal National Institute of Blind People (RNIB) which has dementia specific literature for people with dementia and families and carers.

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 making sense or navigating their environment it can be helpful to make adaptations to eliminate confusing features, including:

- 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.
- Avoid 'visual obstacles' such as changes in floor surfaces or patterns.
- Consider the use of contrast generally e.g. in crockery so people can see their food.

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

Problems with oral health experienced by people with dementia

It is important to support a person with dementia to maintain all aspects of their physical health including their oral health. A regular programme of dental and gum care should be undertaken because poor oral health can lead to pain and tooth loss, and can negatively impact self esteem and the ability to eat, laugh and smile.

The wearing of dentures can sometimes be an issue and a great source of discomfort for a person with dementia particularly if they are not cared for properly. It is important to ensure they are appropriately looked after and regularly reviewed to ensure they fit properly. See Alzheimer's Society for more information and worksheets, and, staff working in care homes will find the NHS Health Scotland '**Caring for Smiles - Guide for Care Homes'** of interest.

Problems with hearing experienced by people with dementia

Despite being common conditions, dementia and hearing loss are not an inevitable part of getting older. However, families, carers and staff should remain vigilant and be aware of any changes to a person's hearing capacity especially if the person with dementia is unable to identify the changes themself. A major source of hearing difficulty is impacted wax so it is important to eliminate this as a cause. The person's GP can check this.

Simple steps can be taken to ensure the person continues to be engaged in the world around them. You should also consider the top communication tips listed in Module 2.

Use the most favourable strategies to support communication

- Find out how the person usually communicates, for example, do they use speech, British Sign Language (BSL), lip reading, Deafblind alphabet, or other means. This information should be available in the person's Life History or support plan.

  If alternative communication methods are used, you should seek further assistance from local Sensory Support services. You can find more information about these alternative means of communication on the **Action on Hearing Loss** website.
- Check for any sight issues or problems with glasses, especially if the person uses BSL or lip reading. Ensure sight is checked regularly.
- Avoid turning away or covering your mouth as you speak.
- Ensure that you are at the same eye level and facing each other.
- Arrange yourself to be within 1 metre of the person.
- Do not sit in front of a window and make sure that your face is well lit.
- Make sure that the room has good acoustics - a room with lots of hard surfaces e.g. large windows, bare floors and tables will make it difficult for the person to hear speech.
- Reduce distractions and background noise.
- Remember that someone may cope well on a 1:1 basis but have difficulty in a group situation.
- Do not shout as this can look aggressive and frightening and does not help the person to hear any better.

Hearing Aids

- Find out if hearing aid(s) have ever been issued for the person. An audiologist can help you with this.
- If the person uses hearing aids ensure that they are available and in working order.
- Check that batteries are inserted correctly and not out of charge.
- Make sure that the aids belong to the person and are in the appropriate ear. They can be marked with an identifier. Hearing aids are colour-coded – red for the right ear and blue for the left ear.

- Check that the ear mould and tubing are not blocked with wax.
- If the person is not hearing well, or has difficulty tolerating the hearing aids, arrange an appointment with their audiologist to check the fit and functioning of the hearing aid. People who wear hearing aids should have their hearing assessed about every 3 years, and hearing aids need at least yearly maintenance to work well.
- Ensure that it is documented that the person uses hearing aids and that all staff are aware of this fact.

Tinnitus

Tinnitus is the term for hearing sounds that come from inside your body, rather than from an outside source, and is often described as ‘ringing in the ears’. 10% of the general population experience tinnitus frequently and around 5% of the adult population in the UK experience persistent problematic tinnitus which can have a serious impact on their quality of life. Factors which can exacerbate tinnitus include stress, anxiety, depression, tiredness and some medications.

Tinnitus can be very distressing for a person with dementia who may not be able to explain what they are experiencing.
It can result in disturbed sleep, anxiety and stressed behaviour. There are a number of potential means of managing this condition, so if tinnitus is suspected you should consult an audiologist.

Visit the Alzheimer Scotland website and read the document **‘Dementia and Deafness - what you need to know’.**

Remember

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

Quality of Life Outcome 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) when speaking to her manager suspected there was something other than dementia that was contributing to her distress. Leanne’s Manager visited Ellen and Caroline (Ellen’s daughter) and suspected that Ellen may be having hearing difficulties.

Caroline went with Ellen to her GP 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 Caroline 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.

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, constipation and dehydration, or even weight gain.

Other early signs of poor nutrition can include dry or flaky skin, dry wiry hair, listlessness and apathy, loose clothes and jewellery. Using the 'Malnutrition Universal Screening Tool' (MUST) could provide useful information to guide decision making. MUST is a 5-step screening tool to identify adults, who are malnourished and at risk of malnutrition (undernutrition). It also includes management guidelines which can be used to develop a nutritional care plan. It is designed for use in hospitals, community and other care settings and can be used by all care workers.

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 or forgetting how to use 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 food or drink 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.
- People might not be able to associate the names of food with the actual food itself.
- People might not be able to remember all the options given to them, or what they ordered in advance.
- 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 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.

Issues such as social isolation, stigma, co-morbid medical conditions and aging compound the nutritional related problems that can be encountered.

It is very important that you are vigilant to any signs that people may be experiencing swallowing difficulties as this can lead to serious health difficulties.

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.

If you think someone has swallowing difficulties you should speak to your manager as they may require urgent referral to a Speech and Language Therapist for specialist assessment and support.

Activity

In your care setting, what practical steps could you take to support people with dementia who have nutritional difficulties?

Record your answers here:

Helping people with dementia to have good nutrition

Now reflect on your answers in relation to the points below:

- Always adopt a person-centred approach. We should not assume that if a person is not eating that they do not want to and it is up to us to try to identify what the difficulties are. The more we know about a person with dementia, the easier it is to meet their nutritional needs.

- Regularly monitoring weight, and completing and appropriately responding to the MUST assessment can help to alert us to changes.
- Use the person's Life History, and information contained in any personal documents such as 'Getting to know Me' or 'This is Me' 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 has difficulty communicating 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. Avoid too much clutter on tables and try to prepare the person ahead of meal times. A walk in fresh air can stimulate appetite.
- 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. Use clear jugs with a coloured fluid to prompt drinking and snack plates to encourage eating.
- Using bold contrasting primary colours for crockery and cutlery can help it to be more obvious and visible.
- Showing the person with dementia the food, or a picture of 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, and is also useful for someone who is unable to sit down for long enough to complete a plated meal.
- Providing soft textured foods for people who cannot chew can help. 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.
- It may be that someone needs to be present at mealtimes to demonstrate what should be done by eating alongside the person, or to encourage and prompt eating and drinking.
- Some people can benefit from small frequent meals every 2-3 hours, or to have longer to eat a meal. In this instance plate warmers, or pre-heated ceramic plates, can be a good way to keep food warm.
- Providing high calorie/high protein foods and nourishing foods based on milk can be ways of supporting a person with dementia to improve their nutritional intake.

Remember

Seek specialist help if there are any concerns about a person with dementia and their nutritional status.

Many of the Allied Health Professions (AHPs) can provide specialist advice, guidance and solutions for example:

- Dietitians will be able to complete a comprehensive nutritional assessment and provide a range of therapeutic advice to help in the management of various physical health conditions as well as poor nutrition and hydration. This might include anaemia, diabetes, gastrointestinal conditions and osteoporosis.
- If chewing and swallowing food or drinks is problematic, a Speech and Language Therapist should be consulted to provide advice and strategies to help the person at mealtimes.

- Occupational Therapists can advise on the eating environment, adapted kitchen equipment, food reminiscence, and memory aids to assist eating.
- Physiotherapists may advise on posture and positioning for comfortable and effective eating and drinking.
- It is also vital that a person with dementia has access to dental services to ensure that any dental health problems, or difficulties with poorly fitting dentures, can be addressed as soon as possible.

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 difficult 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 outlined in Module 2.

Remember

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

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 present 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, while helping them to maximise their independence and manage their own care as far as they are able. However, washing and bathing can become a source of great distress for the person with dementia, and it can also be physically and emotionally challenging. There can be a number of reasons for this which may include 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.
- Having care carried out by someone of a different gender.

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 may also be subject to many of the same challenges that people might face with an immersion bath.

Today, many people bathe or shower daily, but 30 years ago it was normal to have a bath only once or twice a week. If the person you are caring for does not choose to wash as often as you would wash yourself, that is not necessarily something to worry about. 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.

Remember

washing is a matter of personal choice. However this needs to be considered within a context of supporting the person's overall good health.

Margaret's Story

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 help her to have a bath, something she had enjoyed before her admission to hospital. Margaret 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

- How did reading about Margaret's experience make you feel?
- How would you feel if you were experiencing these difficulties?
- 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 for them, and for the staff supporting them. 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 this. If you try to prise their hand off they will automatically try to grip harder, often causing pain and injury. A possible solution may be to give the person something to hold.

If the person already has a hold of something and you want them to release their grasp, they may respond if you demonstrate the action of opening your hand where the person can comfortably see it. At the same time give the person a one word instruction for example 'open' or 'release'. Knowing the person and using the communication approaches described in Module 2 will also support this interaction.

How to support a person with dementia to 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 profound difficulties performing 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.

Of course there may be people who manage very well with little or no assistance, and other people who may benefit greatly from a referral to an Occupational Therapist for further assessment to maximise their abilities. Other people may require more intensive help and support, however, everyone must be supported, in what may be an embarrassing or sensitive situation, in a way that protects and maintains their dignity.

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.

Sometimes leaving doors open so the toilet is clearly visible can be a 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, including:

- Urinary tract infections - these usually respond to treatment with medication.
- Various conditions related to the Prostate Gland - this affects men, and may be resolved with medication or surgery.
- Side-effects of medication - the GP can address this by changing the person's prescription or altering the dose.
- 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.

It is essential that an assessment is carried out by an appropriately qualified professional with access to appropriate investigations and treatment where necessary. People with dementia who use continence aids may require additional support and this and a specialist assessment can be sought from a specialist nurse, physiotherapist or continence advisor.

It may be that everything has been tried to support the person with dementia to remain continent but without success. In this case the use of aids can help maintain the person's comfort and dignity. Simple aids which may be used include incontinence pads, pull up pants for day and night wear and male continence sheaths. There are also aids to help protect furniture and bedding.

The use of an indwelling urinary catheter should only be considered when all other avenues have been exhausted as there is a high risk of infection associated with their use, which can lead to the development of delirium.

To further explore issues about continence and people with dementia - access the **'Caring about Continence'** resource on the Care Inspectorate website

Helping with mobility

There are a number of important factors to consider when supporting a person with dementia to remain mobile and to mobilise. The Alzheimer's Society has produced a range of information sheets which list a number of strategies which might be used to approach specific situations.

They advise that healthy feet are essential if the person with dementia is to remain mobile and active. The following tips should help:

- Make sure the person is wearing well-fitting shoes. Although slippers are comfortable, they should not be worn for more than a few hours at a time, as they do not offer enough support. Shoes with 'Velcro' fastening provide good support and advantages over laces and they are easier to fasten. This also reduces the likelihood of tripping over laces.
- Address problems such as corns or ingrown toenails by consulting a Chiropodist or Podiatrist.
- Make sure the person's feet are kept clean and dry as this can help to prevent the development of fungal skin infections.
- Toenails should be cut short, but not too short, to prevent in-growing toenails. This should be done routinely by a suitably trained person. A nail file can also be used to keep nails short. It is important to consult with a Chiropodist or Podiatrist to help with cutting nails, particularly if the person has diabetes, rheumatoid arthritis or peripheral vascular disease.
- Contact the person's GP, or seek other medical advice, if you notice other problems - for example, if any part of the foot becomes swollen or painful, or if the skin changes colour.

Pressure ulcers

If someone with dementia has difficulty walking, or has any other movement difficulties, it is very important to take particular care that they do not develop pressure ulcers, especially if they are older. Pressure ulcers can be easy to treat early on, but if they are left untreated they do get worse, can be very painful and lead to serious health problems.

Remember

Someone with dementia may not be able to let you know if they are uncomfortable and in pain.

Pressure ulcers can develop when a large amount of pressure is applied to an area of skin over a short period of time. They can also occur when less pressure is applied over a longer period of time. Pressure ulcers tend to affect people with health conditions, like dementia, that make it difficult to remain mobile. It is estimated that around 1 in 20 people who are admitted to hospital with a sudden illness will develop a pressure ulcer and people over 70 years old are particularly vulnerable to pressure ulcers, as they are more likely to have mobility problems and ageing skin. **If you have any concerns, it is crucial to seek professional advice, for example, from a tissue viability specialist.**

In this module so far we have also covered nutrition, hygiene and continence support. Paying attention to these important areas helps to maintain healthy skin and prevent pressure ulcers.

Additionally, you may want to access the NHS Education for Scotland **Skin Tears** learning resource and **Tissue Viability** website to learn more.

Preventing falls

As we get older falls often become more common and the consequences of falls can become more serious. Risk factors that can contribute to a person falling include:

- weak muscles;
- poor balance;
- side effects of medication;
- dizziness;
- foot pain and deformity;
- visual problems;
- poor nutrition and hydration.

Environmental factors can also contribute to the risk of people falling, including: poor lighting; uneven floors; inappropriate seating and clutter.

Most falls amongst older people result from a combination of these factors.

People with dementia have the same health conditions that increase the risk of falls as people who do not have dementia. Falls are not an inevitable part of living with dementia, however, people with dementia are at greater risk because they:

- are more likely to experience problems with mobility, balance and muscle weakness;
- can have difficulties with their memory and finding their way around;
- can have difficulties processing what they see and reacting to situations;
- may take medicines that make them drowsy, dizzy or lower their blood pressure;
- are at greater risk of feeling depressed;
- may find it difficult to communicate their worries, needs or feelings.

Confusion, disorientation, memory loss, restlessness and agitation can also contribute to their risk of falls. Earlier in this module we discussed the impact of the physical environment and perceptual problems which can also increase the risk of falls.

Memory loss can also 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, and some medications can also have adverse effects on movement and walking.

Falls can be very serious for people with dementia and can result in loss of mobility and independence, or hospitalisation. Earlier in this module we also discussed the importance of regular activity and exercise in helping to reduce the risk of falls.

To help prevent falls consult a Physiotherapist about a falls screening risk assessment which can identify the specific things that contribute to a person's risk of falling, including hazards in the home or other settings. Following the screening assessment a personalised plan, focusing on the risks identified, can help to manage or reduce risk.

A personalised plan to help prevent falls may include:

- Exercises to improve strength, balance and walking.
- Help to check the home or care setting for trip hazards, and to make changes to make the environment safer.
- Occupational Therapy or Physiotherapy to help the person carry out daily activities more easily and safely.
- A review of medications.
- An eyesight and eye health check.
- Advice on foot care and, if required, podiatry to manage any foot problems.
- An assessment by a doctor to investigate, and treat, any heart, circulation, blood pressure or other medical problems.
- An osteoporosis screening and treatment if diagnosed.
- Assessment and management of any continence problems.
- Advice on what to do in the event of a fall, including how to get up safely and summon help.
- An assessment for equipment — such as walking aids, hand rails and community alarms.

The plan should be designed to suit the person's needs and way of life. It is extremely important to manage risk whilst enabling a person to keep active and continue to do the things that matter to them.

Further information is available on the NHS Inform website **Falls Information Zone**.

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 to have difficulties in getting to sleep in the first place and then managing a full night's sleep. Poor sleep quality and sleep disturbance, for whatever reason, can lead to a number of detrimental consequences for the person with dementia, and their family and carers, if their sleep is also affected.

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:

- having a regular time for going to bed and getting up that reflects the person's past sleeping habits;
- getting outdoors during daylight hours;
- ensuring a range of stimulating day time activities - someone is more likely to nap during the day if they are bored;
- reducing fluid intake in the evening, and avoiding stimulating drinks such as tea and coffee;
- doing some form of activity and exercise during the day;
- engaging in relaxing activities at the end of the day and before bedtime;
- ensuring the bedroom is comfortable, personal and familiar.

If the person is awake during the night it is important **not** to try and get them to return to bed without finding out why they are not sleeping. Do not assume that it is because of their dementia. There are many different reasons why the person may be awake, for example, they may be in pain, feeling unwell, uncomfortable, or feeling lonely or afraid. There is also evidence that having dementia may cause the person to not experience deep sleep and as a result be more sensitive to environmental stimuli such as noise and lighting. Similarly the person may have had sleep difficulties prior to their dementia or had a routine of getting up very early. You may notice that the person gets up at the same time every night.

Knowing the person and taking a person-centred approach will help you in finding out why they are awake and respond appropriately to their needs.

Supporting people with dementia experiencing pain

There are many causes of pain and discomfort in people with dementia, however, it is often not recognised and can be poorly treated, or go untreated altogether. The main reason for this is that as people's dementia journey progresses their ability to communicate their needs becomes more difficult. Families, carers and staff need to work hard to observe and understand the signs that the person with dementia may be displaying that indicate they may have pain.

The person with dementia's response to the distress the pain is causing can result in verbal outbursts, 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. We will discuss this in more detail in Module 4.

There are a range of observational pain tools available to assist staff to establish whether a person with dementia is in pain, especially if the person cannot tell you in words. It is important to use an evidence based tool as part of the person's overall care plan. One example is the 'Abbey Pain Scale' which is quick to complete, but is not always accurate in assessing pain in people with dementia. The 'Doloplus 2' is more widely used as it recognises the difficulty of identifying pain in people with dementia, and highlights that distress may be caused by pain.

Observational tools alone may not detect complex, or chronic pain, experienced by a person with dementia and it is important to ensure that:

- You get to know as much as possible about the person's pain history.
- The person's family and carers who know them well are involved from the outset of care.
- You do not automatically attribute the cause of any changes to the person having dementia.
- Appropriate tools are used to discern pain and discomfort and the causes addressed.
- If the person is distressed consider that pain might be the cause in the first instance.

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, creating a calm comfortable environment, and social contact which can all help to alleviate pain. Knowing and understanding the person, their likes and dislikes, will help with choosing the most appropriate intervention.

What if the person with dementia is admitted to hospital?

A person with dementia may be admitted to a general or specialist hospital 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. 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.

You will recall that we discussed delirium in Module 1.

Remember

delirium is a serious condition and a medical emergency.

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.

You may be familiar with the document ‘**Getting to Know Me’** which is used in many places to support person-centred approaches. This can be completed before the person goes into hospital, however, it can be very useful in any setting.

The risks of hospital admission to people with dementia can include one, or more, of the following (this list is not exhaustive):

- Increase in mortality.
- Increase in time in hospital.
- Earlier admission to residential care.
- Development of incontinence.
- Reduced cognitive function.
- The risk of developing delirium.
- Decrease in mobility.
- Increased 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 all care environments have a sound knowledge of prevention and control of infection.

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, and reduce the risks associated with a hospital admission?

Record your answers here:

Palliative and end of life care for people with dementia

Palliative care is an approach to working with and caring for a person with a life limiting or terminal condition. It supports a person-centred approach and concentrates on the individual person rather than their specific disease. It gives equal focus to the psychological, physical and spiritual and social aspects of the person's life. It aims to improve the quality of life for the person and their family and enable them to die with dignity and in a place of their choosing.

The term 'Palliative Care' is also used to describe the specialist care and interventions required as the person approaches the end of their life. This may also be referred to as 'end of life care' and aims to make the person comfortable and attend to their needs and wishes as the end of life approaches.

Working with the person with dementia and supporting them to live well includes supporting them to die well. We need to ensure the care, treatment and support they receive at the end of life reflects their decisions and expressed wishes and preferences. The development of Personal Support Plans and Advance Plans described in Module 2 should provide the person with an opportunity to discuss and record their wishes and preferences. Everyone working with the person should be aware of the plan, and the wishes documented in it, and use these to inform care and support at the end of life.

We know that improvements need to be made to the support people with dementia receive as they near the end of their life. Some of the reasons for this are that:

- The person may be less able to express their wishes and preferences for end of life care at the time they require it.
- Difficulties in recognising when a person with dementia is nearing the end of their life.

Recognising when a person is at the end of their life

There is no agreed definition of 'end of life care' but the General Medical Council suggest that people are approaching the end of their life when they are likely to die within 12 months. This can be extremely difficult to determine when a person has dementia. As we explored in Module 1 the progression of dementia will be very different for each person, and it may be likely that other illnesses and conditions are the primary cause of death, rather than their dementia.

There is evidence to suggest that in the final months of their lives, people who are in the later stages of their dementia journey may experience symptoms such as pain, depression, incontinence, constipation, appetite disturbance, breathlessness, difficulty swallowing, weight loss, dehydration and pressure ulcers.

To help identify when a person with dementia is at the end of their life it is suggested that they may experience a range, and combination of changes and symptoms, including:

- The person is no longer able to walk.
- The person is no longer able to communicate verbally.
- They require maximum assistance with activities such as washing or dressing.
- This can be combined with developing complications such as weight loss, recurrent infections, pressure ulcers, hip fracture or pneumonia.

Everyone working with the person should be aware of the range of changes and symptoms the person may experience at the end of life and communicate sensitively with their family and carers.

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

Mental health and well-being and dementia

Dementia impacts different people in different ways. However, there are some common mental health issues that can affect a lot of people living with dementia. 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.

Modules 1 and 4 discuss these issues in more detail.

Depression and dementia

As we explored in Module 1 depression and dementia share many of the same symptoms. This can make it difficult to identify depression in people with dementia. Depression is a common condition and around 1 in 5 of the population of Scotland will experience depression at some point in their lives.

Depression is much more than feeling a bit low. It is a persistent condition in which a number of feelings, such as sadness, anxiety, hopelessness and a lack of energy, or agitation - can dominate a person's life and make it difficult for them to cope. In the early stage of the dementia journey this may be a reaction to the person's awareness of their diagnosis. We outlined the features of depression in Module 1 and you may want to look back on this information for reference.

A person who is depressed 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 have depression

For people in the earlier stages of dementia, talking about their 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.

Medication for depression

Antidepressants 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.

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 taking them you are aware of this.

Remember

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

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 other 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.

How to help people with dementia experiencing perceptual problems – top tips

- 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 e.g. hearing aids that are working, and spectacles which are clean.
- Do not assume that suspicions are delusions. In some circumstances they may be true (in Module 5 we explore harm and abuse further).
- Attempt to distract the person if possible and appropriate. 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.
- If you have concerns about a person's mental health you should raise this with your manager.

Supporting people with dementia and memory problems

In the early stages of a person's dementia journey there is a range of ways to support their 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, for some people, improve symptoms, or temporarily slow down their progression.

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 diarrhoea. Other side effects include stomach cramps, headaches, dizziness, fatigue and insomnia, increased blood pressure and constipation.

Remember

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

Practical steps to help people with memory difficulties

In previous modules we have already explored a number of practical steps to support people with dementia who may experience difficulties with their memory in a number of different situations.

To recap there are 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.
- Providing information and answers where necessary rather than pressuring the person to guess.
- Avoiding repeatedly correcting the person's mistakes. This 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 correcting 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.

Other approaches to help with memory problems

Cognitive Stimulation is a recommended evidence based intervention for people with dementia. It 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.

If you want to explore psychological approaches to supporting people with dementia in more depth access **'Promoting psychological wellbeing for people with dementia and their carers: An enhanced practice resource'** available on the NES website.

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.

Reflective Account

Write a reflective account taking into consideration your learning from Module 3.

Below is a suggested structure that you may find helpful in writing your reflective account.

Please ensure that you anonymise any information

What happened?

Identify and describe a situation or incident where you were supporting a person with dementia to promote their health and well-being. When recalling this situation you may wish to consider the following:

- The specific physical and/ or mental health issues the person was experiencing.
- The impact that dementia may have on the person’s ability to manage their health and well-being.
- The steps taken to help the person manage their own well-being for example to support memory.
- Strengths and asset based approaches.

Describe what you did or how you responded.

Describe the outcome of your actions or response.

So what does this mean?

- How did you feel about the outcome of the support that you provided at the time?
- What do you feel about that now in light of your learning, having completed the module?
- What did you do that went well?
- Do you think your actions helped to improve quality of life for the person you were working with?
- What might you now do differently?

Now what will you do in the future?

- How will this affect the way you work with people with dementia in the future?
- Would you act differently or would you be likely to do the same?
- What further learning do you need to undertake to enhance your understanding of promoting health and well-being in dementia that will help you to support people to improve their quality of life?

You may want to record this using the **Action into practice** activity at the end of this module.

Action into practice

From your learning in this module

- Make a note of 3 new things you have learned about how you could support people with dementia to maintain their health and well-being.
- Reflect on your current practice in relation to supporting people with dementia with their personal care needs.
- Identify 3 changes you could make that you think would enhance your approach to supporting personal care for people with dementia.

Make notes of your responses below:

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 also examine how you might understand and respond to distressed behaviour. Through case examples 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.

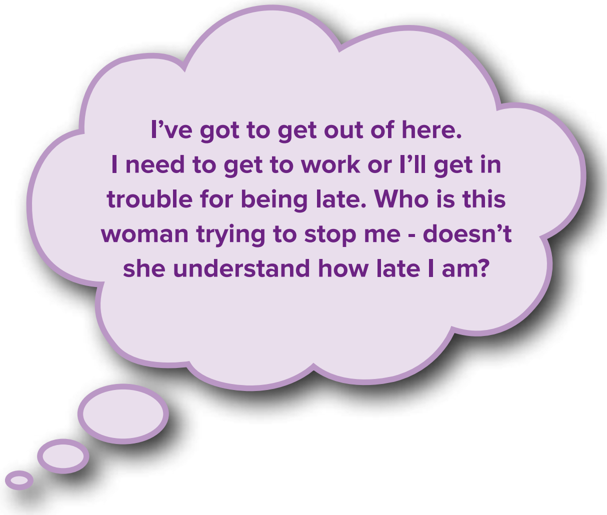
Now consider someone who has dementia who feels distressed, agitated, angry, or anxious. In Module 1 we explored the difficulties that people with dementia have in communicating and we developed this more in Modules 2 and 3. People with dementia can have difficulties in communicating what has caused their emotions. The way they may act when feeling distressed may be viewed as 'challenging' by other people, including families and carers. 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 families and 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 and 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

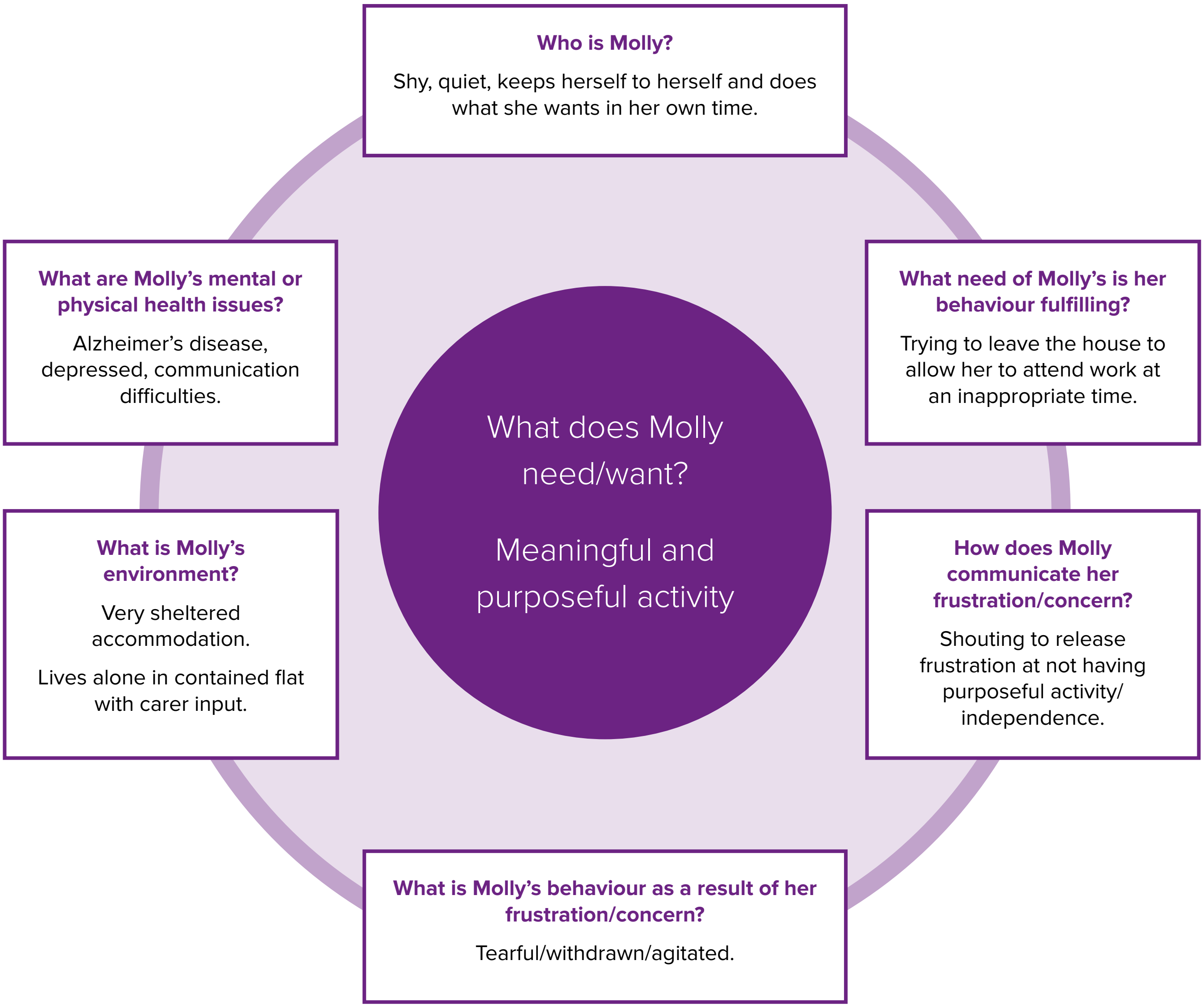


I've got to get out of here. I need to get to work or I'll get in trouble for being late. Who is this woman trying to stop me - doesn't she understand how late I am?

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 the 'Unmet Need Model' developed by Cohen-Mansfield



Who is Molly?

Shy, quiet, keeps herself to herself and does what she wants in her own time.

What are Molly's mental or physical health issues?

Alzheimer's disease, depressed, communication difficulties.

What need of Molly's is her behaviour fulfilling?

Trying to leave the house to allow her to attend work at an inappropriate time.

What does Molly need/want?

Meaningful and purposeful activity

What is Molly's environment?

Very sheltered accommodation.

Lives alone in contained flat with carer input.

How does Molly communicate her frustration/concern?

Shouting to release frustration at not having purposeful activity/ independence.

What is Molly's behaviour as a result of her frustration/concern?

Tearful/withdrawn/agitated.

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, hoarding items or doing something different?

Using the model above as a guide, answer the questions above 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 many other things.

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

People with dementia can express stress and distress in many ways and this can vary between individuals. 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 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”.

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 you answers here:

Module 4: Meeting the needs of the person with dementia who is distressed

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

Ian James, an eminent writer in this area, also suggests it can be useful to differentiate between:

1. **Non-active forms of behaviour (related to apathy and 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.

Triggers and causes of distressed behaviour

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

Biological

- Having a physical illness
- Experiencing pain
- Being dehydrated
- Being constipated

Psychological

- Disinhibition
- Loneliness
- Low mood
- Missing family or pets

Social and Environmental

- Being too hot or too cold
- Wearing clothes that rub, or are too tight
- Too much stimuli from light, noise and activity
- Misidentifying other people as one's partner

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

Remember

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

Sudden onset of distress

Where there is a sudden onset of distressed behaviour (over hours, days or even weeks) it is absolutely crucial to rule out specific medical factors, including pain and conditions such as delirium. Untreated physical conditions are a common cause of distressed behaviour.

For more information please refer to the NES Delirium learning resource on Learnpro.

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 Caroline 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 Caroline 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

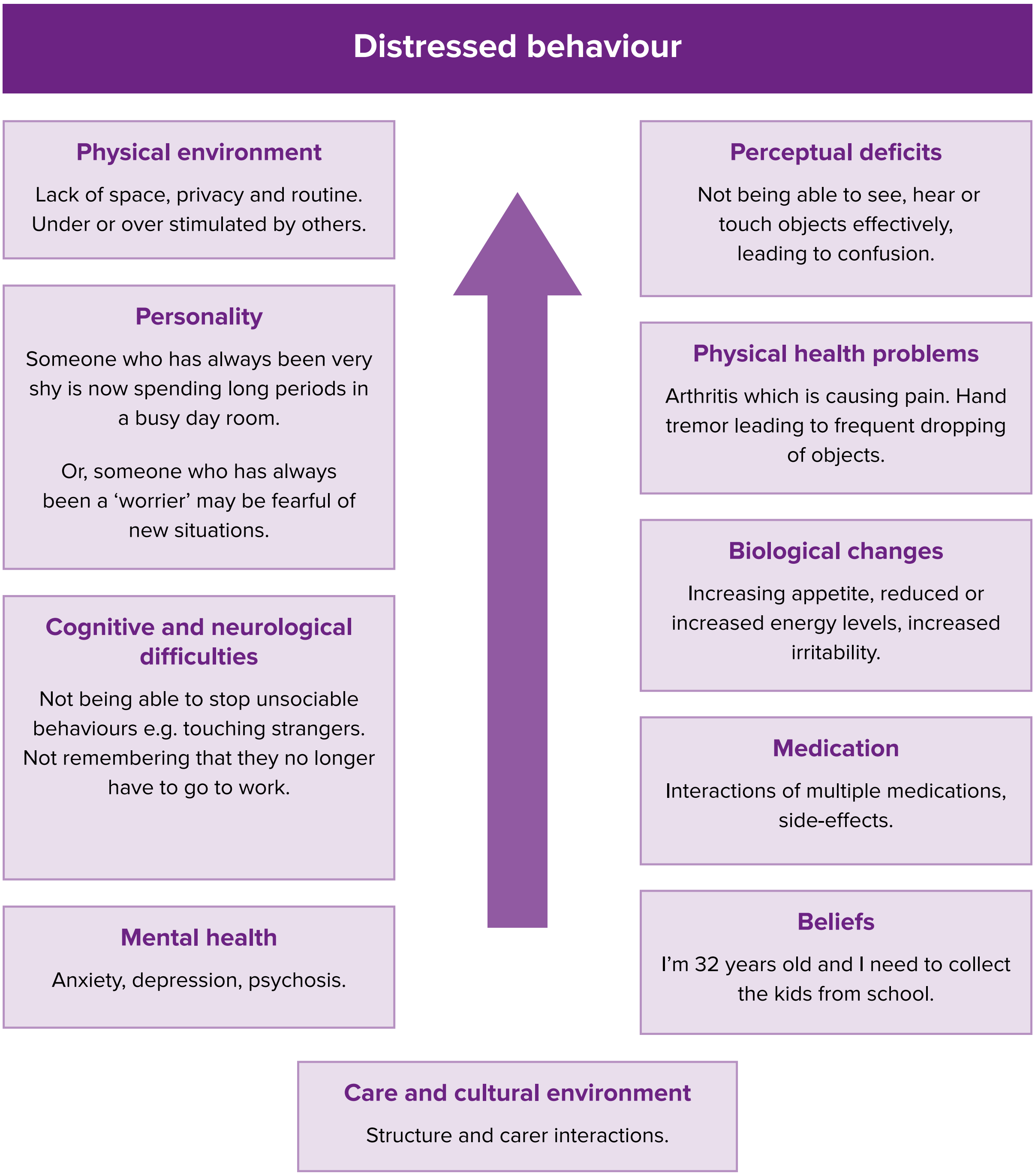
What do you think might have been causing Ellen's distressed behaviour?

Record your answer 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. Not remembering that they no longer have to go to work.

Mental health

Anxiety, depression, psychosis.

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.

Care and cultural environment

Structure and carer interactions.

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.

Biological

- Area in brain damaged by head injury (frontal lobes) or dementia, leading to disinhibition
- Medication causing agitation/pacing
- Underlying physical conditions causing pain, such as arthritis
- Dehydration or constipation causing confusion
- Beliefs/misperception that someone is trying to harm them
- Pain reducing threshold of mild agitation

Psychological

- Frustrated by inability to communicate needs
- Belief that their rights are being disregarded
- Belief that they are being treated like a child
- Belief that they are being rushed/told what to do
- Think they are being ignored
- Feeling humiliated during tasks of personal care
- Feeling their personal space is being invaded
- Belief that abilities and skills are being limited by others
- Pre-existing mental health issues

Social and Environmental

- Inconsistent care approaches
- Cultural beliefs differing from others
- Misidentifying other people
- Not understanding other people's intentions
- Interpersonal over-stimulation
- Being touched by someone else
- Not being allowed to leave the building/home/centre
- Being restricted in activity
- Over or under stimulation (noise, lights)
- Temperature too warm and close, or cold

Activity

Now that you have looked at the previous table 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

Record your answers here:

Approaches to understanding distressed behaviour

As part of providing person-centred 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 person 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;
- 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.

The following is an adapted ABC chart, originally developed by Ian James and other professionals in Newcastle in 2011.

Adapted from James, I A (2011)

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?				**10. What emotion were they expressing during the incident?**			
Angry	☐	Frustrated	☐	Angry	☐	Frustrated	☐
Anxious	☐	Happy	☐	Anxious	☐	Happy	☐
Bored	☐	Irritable	☐	Bored	☐	Irritable	☐
Content	☐	Physically Unwell	☐	Content	☐	Physically Unwell	☐
Depressed	☐	Restless	☐	Depressed	☐	Restless	☐
Despairing	☐	Sad	☐	Despairing	☐	Sad	☐
Frightened	☐	Worried	☐	Frightened	☐	Worried	☐

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.

5. **Completing the As:** How noisy was the environment? Was the temperature hot/cold? How was the lighting? Who else was there? Was someone else distressed? 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 Bs:** 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 Cs:**
   - 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 “It’s 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).

   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.

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Here is an example of Penny's completed ABC chart for a specific incident of distress:

Penny's ABC chart (Adapted from James, 2011)

1. Distressed Behaviour: Shouting "Help me, Help me".

2. Date and Time Monday 12th June at 8pm	**3. Where was the distress observed** In the day room	**4. Who was there at the time?** Iain (resident), Penny, myself (nursing assistant)

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

Penny was sitting in the corner of the day room watching television. Iain walked behind her and touched her head. It was warm and quiet in the day room.

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

Penny screamed after Iain touched her head and shouted "Help me! Help me!" for approximately 30 minutes.

7. Record what the person said during the incident.

"Help me! Help Me!"

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

Two other staff came to assist, but Penny increased her shouting. Staff left the day room and re-directed Iain away from Penny. I tried to reassure Penny by saying "you're OK now Penny, you're safe" in a soft tone while stroking her hand.
I started to talk about the dog she had when she was younger.

9. What emotion were they expressing before the incident?

Angry ☐
Anxious ☒
Bored ☐
Content ☐
Depressed ☐
Despairing ☐
Frightened ☐

Frustrated ☐
Happy ☐
Irritable ☐
Physically Unwell ☐
Restless ☐
Sad ☐
Worried ☒

10. What emotion were they expressing during the incident?

Angry ☐
Anxious ☒
Bored ☐
Content ☐
Depressed ☐
Despairing ☐
Frightened ☒

Frustrated ☐
Happy ☐
Irritable ☐
Physically Unwell ☐
Restless ☐
Sad ☐
Worried ☒

Why do we have to fill in ABC charts?

By completing ABC charts, we are learning about the person 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-centred 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 I).

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 person's distress, its causes and some of the thoughts and emotions which may have triggered this. Once we understand this, we can then develop an understanding of what we can do to reduce their distress and meet any needs which are currently unmet. This will form part of the person-centred care plan.

Remember

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

Frequency charts

You may find that the behaviour, response or emotion varies very little, but that it happens very frequently. Examples would include repetitive shouting, screaming or skin picking. In these situations it may be more appropriate to use a frequency chart. These can help identify potential patterns or environmental triggers by looking at **when** the behaviour is most likely to occur.

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Here is an example of Penny's day time frequency chart.

Time of Day	05:00 to 07:00	07:00 to 09:00	09:00 to 11:00	11:00 to 13:00	13:00 to 15:00	15:00 to 17:00	17:00 to 19:00	19:00 to 21:00	TOTAL
Monday					I	II			**3**
Tuesday					II	IIII I	I		**9**
Wednesday					I	II	I		**4**
Thursday					IIII II	IIII			**12**
Friday					I	II			**3**
Saturday						I			**1**
Sunday								I	**1**
TOTAL					**12**	**18**	**2**	**1**	

In this example you can see that Penny appears to be distressed and shouting more on Tuesday and Thursday afternoons rather than any other time. Your next step might be to investigate:

- who was around at those times;
- whether there are specific activities on at those times (such as activities that may involve invading personal space or touching).

It is very important that all staff/carers are told when frequency charts are being used with a person to ensure all episodes of distress are recorded.

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-centred 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 summarised below and you may want to revisit previous modules where many of these issues are explored in more depth.

Always use helpful communication approaches

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

In previous modules we have spent a lot of time exploring communication issues and 'tips'. Remember these simple 'tips' 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 and make sure their fundamental care needs are being met

Always support the person to be as independent as possible. For example, encourage people if they are having difficulties completing some tasks. Do not 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.

> These are explained in more detail in earlier modules.

In summary you can prevent and alleviate distressed behaviour by always taking a person-centred approach to supporting people with dementia, and their families and carers in undertaking a range of care activities, including:

- Supporting good nutrition and hydration.
- Supporting them with their personal hygiene, including washing and bathing and maintaining their continence.
- Responding to sensory, memory and perceptual problems.
- Ensuring that people are not experiencing pain - checking factors such as pain levels and by providing pain relief on a regular basis before this leads to distressed behaviour.

Respect the person and always make sure they have opportunities to engage in activities that are meaningful to them.

- Always 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 people 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.
- Providing appropriate stimulation can be both a 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).

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

Now 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 Caroline) about trying to find her tablets and was pushing Caroline 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 "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 whether to attend.
- If Ellen states that she is in pain, ask her "where are you sore?". If Ellen indicates that she is in pain you could speak with Caroline 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.

Module 4: Meeting the needs of the person with dementia who is distressed

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 are: '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

Now put yourself in a similar situation to Penny.

Imagine that you found someone you hadn't met before in your kitchen cooking a meal when you got home tonight?

- How would you feel?
- How would you react?
- How would you expect the person to behave towards you?

Record your answers here:

How could you best respond?

Use good **verbal communication:** Tell the person who you are e.g. "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.

- **Use non verbal communication**, for example, 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. It is important to make sure that the person recognises him or herself in the photo in order to avoid increasing or triggering distress.

An example – A person communicating distress by physical aggression

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

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”.

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 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

Iain lives in a care home and has recently started to stand at the front door for long periods of time. As people approach the door to enter or leave the care home Iain tries to push past them in an attempt to leave.

Points to consider:

- Is Iain 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?

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.

It would be important to consider the level of risk to Iain of going out of the care home and how he may be supported to do this. We will discuss risk and risk enablement in more detail in module 5.

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

Peter lives in a care home 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 Peter 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?

- It may be that Peter is seeking comfort. If it is known that he responds positively to contact with family, friends or carers you may consider an approach to provide comfort when they are not available. This involves playing a personalised audio or video tape of a family member, friend or carer to the person with dementia, recalling a positive shared memory such as a family trip.

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

- Are the female residents wearing similar clothes to Peter's wife?
- Do they have similar glasses or hairstyles?
- Does Peter believe he is a young man and is he misinterpreting approaches from staff?
- 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?

Finding the most appropriate approach to supporting a person with dementia who is communicating distress by touching or inappropriate sexual behaviour is often very complex, and it may be necessary to make a referral to a specialist, such as a clinical psychologist.

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

This 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 and 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.

To enhance your understanding of how memory impairment can alter a person's reality and trigger distress you should access the **'Promoting psychological wellbeing for people with dementia and their carers: An enhanced practice resource'** available on the NES website.

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 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 people.

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

Possible side 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 **The Pharmaceutical Care of People with Dementia** available on the NES website.

Accessing professional support and interventions to alleviate stress and distress

Remember

Prevention is best!

There will be times when the person with dementia whom 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 you 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 may be important that you support the person to access professional assessment and review. We should always ensure that families and carers are involved in their decisions.

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 Mental Health Nurse, Psychiatrist, or other mental health professional who can assess and intervene, if you need additional support. We all have a responsibility to contribute to 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 intervention.

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.

Module 4: Meeting the needs of the person with dementia who is distressed

Module summary

In this module we have we have explored:

- The experiences of people with dementia that can lead to stress and distress.
- How it is important to try to prevent stressful situations arising to avoid the person with dementia becoming distressed.
- The complex inter play between the effects of dementia and the needs of the person, and how the physical and social environment surrounding them can often be difficult for them.
- The use of ABC charts as a way of analysing, monitoring and understanding the distressed behaviour people may experience.
- A range of possible responses designed to alleviate stress and distress, including 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 for everyone.

Reflective Account

Write a reflective account taking into consideration your learning from Module 4.

Below is a suggested structure that you may find helpful in writing your reflective account.

Please ensure that you anonymise any information

What happened?

Identify and describe a situation or incident where you were supporting a person with dementia when they were distressed. When recalling this situation you may wish to consider the following:

- The cause and indicators of stress and distress.
- The biological, psychological, social and environmental factors.
- The professional support available to support the person's well-being.
- The information recorded about the person's behaviour.

Describe what you did or how you responded.

Describe the outcome of your actions or response.

So what does this mean?

- How did you feel about the outcome of the support that you provided at the time?
- What do you feel about that now in light of your learning, having completed the module?
- What did you do that went well?
- Do you think your actions helped to improve quality of life for the person you were working with?
- What might you now do differently?

Now what will you do in the future

- How will this affect the way you work with people with dementia who are distressed in the future?
- Would you act differently or would you be likely to do the same?
- What further learning do you need to undertake to enhance your understanding of stress and distress in dementia that will help you to support people to improve their quality of life?

You may want to record this using the **Action into practice** activity at the end of this module.

Action into practice

From your learning in this module

- make a note of 3 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 3 changes you could make that you feel could enhance your practice.

Make notes of your responses below:

Appendix I

Adapted from James, I A (2011)

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 Caroline and Lunch Club support worker Leanne

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 Caroline was trying to communicate that she had to go to the lunch club. Leanne was standing in the lounge also. Caroline 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 Caroline 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?

Angry	☐	Frustrated	☐
Anxious	☒	Happy	☐
Bored	☐	Irritable	☒
Content	☐	Physically Unwell	☐
Depressed	☐	Restless	☐
Despairing	☐	Sad	☐
Frightened	☐	Worried	☐

10. What emotion were they expressing during the incident?

Angry	☒	Frustrated	☐
Anxious	☐	Happy	☐
Bored	☐	Irritable	☐
Content	☐	Physically Unwell	☐
Depressed	☐	Restless	☐
Despairing	☐	Sad	☐
Frightened	☐	Worried	☐

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 legislation, policy and guidance in Scotland can be used to protect the rights of people with dementia.

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 and their Carers 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 so that they can experience 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 may not be supported or treated as equal partners in supporting and caring for the person with dementia.

However, legislation in Scotland enables all workers to 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:

Module 5: Supporting and protecting people's rights

The Charter of Rights for People with Dementia and their Carers in Scotland

In 2009 a Cross Party Group on Alzheimer's in the Scottish Parliament published **The Charter of Rights for People with dementia and their Carers in Scotland**. 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.

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

Summary of the 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.

Summary of the Charter of Rights (continued)

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:

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; people with a learning disability; 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 to, 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:

- Human Rights Act, 1998.
- Adults with Incapacity (Scotland) Act, 2000.
- Mental Health (Care and Treatment) (Scotland) Act, 2003.
- 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. As changes and amendments to legislation may occur over time it is important to check the Scottish Government website.

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' mean to you and make a list below:

Record your answers here:

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 decisions when we use each Act. It is important that you know the principles of each Act and can use them to influence your practice.

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 a benefit for the person 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:** People should be provided with any necessary care, treatment and support, in the least invasive manner and in the least restrictive manner, and in an environment compatible with the delivery of safe and effective care - taking account, where appropriate, the views and safety of relevant 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:** People 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 decisions on person’s behalf.	**Respect for carers:** Those who provide care 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:** These must be taken account of including family carers and others appointed to make decisions on person’s behalf.

Adults with Incapacity Act 2000 (continued...)	Mental Health Act 2003 (continued...)	Adult Support and Protection Act 2007 (continued...)
Encourage the adult to act: By using their existing skills and developing new skills.	**Informal care:** Wherever possible care, treatment and support should be provided to people without recourse to compulsion.	**Encourage the adult to participate:** Providing information and support to enable them to do so.
	Non discrimination: People with mental health problems should retain the same rights and entitlements as those with other health problems.	**Non discrimination:** The adult should not be treated less favourably than another adult.
	Respect for diversity: People 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/ belief background.	**Respect for diversity:** The adult’s abilities, background and characteristics must be taken into consideration in any intervention.

Please be aware that the Mental Health (Care and Treatment) (Scotland) Act, 2003 contains additional principles that we have not listed here.

We can see that that many of the principles are the same across all 3 Acts - particularly the need to take account of: benefit; the least restrictive option; people’s past and present wishes; the views of others, and encouraging the person to participate. These are also in line with the Charter of Rights for People with Dementia and their Carers in Scotland, and the Human Rights Act which you will read about a little later in this module.

Activity

Consider the principle of 'benefit'.

Read Hugh's story. Do you think David and Nicola are considering the benefit of their actions for Hugh?

A brother and sister, David and Nicola, both support their dad Hugh, who is at an advanced stage of his dementia journey. They have been arguing about how much of his money each of them spend. 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 Hugh to her daughter.

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

Record your answer here:

There is no absolute right answer, but if Hugh had always bought birthday presents for his grandchild and it is known that he did this as part of a loving and sharing relationship then it would be acceptable. However, the amount spent would also need to be in keeping with previous exchange of gifts, and reflect any change to Hugh's income that may impact on his overall financial circumstances.

Now read the next scenario.

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

Would this be of benefit to Hugh?

Record your answer here:

It would be very difficult to justify this expenditure when the benefit may 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 the Second World War and provides 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 a range of areas including freedom from inhumane treatment, to everyday things like respect for 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 Charter of Rights for People with Dementia and their Carers 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 for people with dementia 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, without offering help when they are unable to eat or drink without assistance.
- Speaking about people in a derogatory way, or in a way that labels or stereotypes them, e.g. 'walkers', 'feeders', 'wanderers'.

The right to respect for private and family life, home and correspondence

- Separation from families and other key people the person has relationships with, due to a hospital or care home admission.
- Not receiving support to participate in activities meaningful to the person.
- Staff working with people in different settings such as care homes or hospitals, controlling people's mail and phone calls.

The right to freedom or liberty

- Detaining a person in a hospital or care home 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.

Examples of human rights that may be disregarded for people with dementia in practice (continued)

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 influenced:

- The person's complaint is not investigated by an organisation.
- The person is not made aware of the right to complain and not given information about the procedure to enable them to make a complaint.

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.
- A person with dementia is 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 in relation to the examples of human rights that may be disregarded for people with dementia.

- Can you identify any risks, or examples, that might suggest the people with dementia you are working with may have their human rights disregarded?
- What changes, or improvements, could you make to contribute to protecting the rights of a person with dementia?

Record your answers here:

Activity

To explore this issue further read Bill's story.

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.

Imagine you support Bill in his home and discover this is happening.

What would you do?

Record your answer here:

In a situation like this you should speak to your manager. Later on in this module we will explore the Adult Support and Protection Act, 2007 in more detail. This Act provides a further legislative framework to support and protect people.

The Adults with Incapacity (Scotland) Act, 2000

The Adults with Incapacity (Scotland) Act, 2000, provides 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 people 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?

Under the Adults with Incapacity (AWI) Act 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 might seem unwise.

'Capacity' means the person's ability to use and understand information to make a decision. The person needs to be given appropriate information, provided in a way that they can understand, so they can make a decision based on this information.

Capacity in relation to **consent to treatment** means people are capable of understanding the nature, implications and consequences of their decisions.

A person is considered to have capacity to consent to treatment if they:

- Understand in simple language what the treatment is, its purpose and nature and why it is being proposed.
- Understand its principal benefits, risks and alternatives and be able to make a choice.
- Have a general understanding of what the consequences will be of not receiving the proposed treatment.
- Can retain the information long enough to use it to weigh up the possible outcomes in order to arrive at a decision.
- Can communicate that decision to others.
- Can hold this decision consistently. This includes occasions when a person has difficultly in remembering a decision but, given the same information at another time, they make a consistent decision. This makes their decision valid.

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.

The ability of a person with dementia to make a decision can vary enormously. Most people can make decisions about some aspects of their lives, but may need support in other areas. For some people the ability to make decisions can vary depending on their capacity at any point in time, and this can be influenced by many factors, including:

- Personal, physical, psychosocial and situational demands placed on the person, such as pain, discomfort or illness. It may be that they are in a noisy or unfamiliar place, or the room temperature is too hot or cold. Also the person may be more able to make decisions at different times of the day.
- The resources and supports the person has available to them to help them make decisions, such as communication aids.
- The impact on the person's capacity to make decisions if they are in pain or discomfort, or taking medication that causes drowsiness.
- Conditions that can affect decision making capacity can include infections such as pneumonia, urinary tract infection, influenza and delirium.
- The person may be experiencing mental health problems or become emotionally distressed by a situation. For example if the person's capacity to consent to admission to hospital is being assessed the person may be distressed because of past negative experiences, or a specific fear of hospitals.
- Relationships between people may impact on the person's ability to make an autonomous decision. For example if the person feels threatened, or put under undue pressure by another person.

People's capacity to make decisions may be diminished temporarily or permanently, partially or totally. For example, as a person progresses through the later stages of their dementia journey they may have difficulties understanding complex information. An example is someone considering having planned surgery, like a knee replacement or cataract surgery. They may not have capacity to decide whether the benefits outweigh the risks of the surgery. 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.

The legal terms relating to power of attorney are:

- the person giving permission to someone else is known as the **granter**;
- the person, who is given the powers, is called the **attorney**, or may be also known as the **proxy**.

There are 2 types of 'Power of Attorney' - **Continuing** and **Welfare** attorneys.

Continuing Attorney

Continuing powers of attorney mean others can 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. When continuing attorney is in place, the 'Power of Attorney', when necessary, would have access to the person's finances and could arrange to do things like 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 protection from 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.

It may seem that the 'Welfare Attorney' could potentially have total control over the welfare decisions of another person. In reality, this is where the principles of the AWI Act guide us, and any action should always be the least restrictive option chosen for the person with incapacity.

Under the principles of the AWI Act 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, therefore, upholding their right to least restrictive option and maximum use of their skills.

The Welfare Attorney cannot give consent for medical treatment for a mental disorder. An example is if a person with dementia is in hospital being treated for depression and the Psychiatrist wants them to take anti depressant medication, but the person refuses this. In this instance the Welfare Attorney cannot give permission and this would require application of the Mental Health Act to ensure even more stringent safeguards are in place to give medication against a person wishes.

Remember

the Welfare Attorney cannot give consent for medical treatment for a mental disorder against the person’s wishes.

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 moving from their own home to a care home. The Welfare Attorney could give consent to the move but suggest that the person has enough understanding to make a decision about their choice of care home. This would support the person to exercise their residual capacity and take account of their wishes.

All ‘Continuing’ and ‘Welfare’ Powers of Attorney must be registered with the Public Guardian. In return, the Public Guardian issues the attorney with a Certificate of Registration. The role and function of the Public Guardian are described later in this module.

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 answers here:

Activity

Think about someone with dementia, their family and carers 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 answer here:

Intervention and Guardianship Orders

Intervention and Guardianship Orders provide legal authority for someone to make decisions and act on behalf of a person to safeguard and promote their interests. They can only be applied for when no relevant Power of Attorney is in place and the person has been assessed as lacking capacity to make decisions. Both orders can cover property and financial matters, or personal welfare including health, or a combination of these. The main difference between them is that an Intervention Order gives permission for a one off action or to make a single decision, for example selling a home or deciding what medical treatment is best for that person at a particular time. Whereas a Guardianship Order can be applied for when there are several issues to be dealt with, and decisions will need to be made to manage someone's affairs on an ongoing basis.

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.

We will explore this a bit more with Ellen's story.

Ellen's Story

You are working with Ellen and supporting her at home following her brief admission to hospital. Caroline, Ellen's 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 Caroline visits they argue about money and Ellen gets very upset and distressed. Caroline reassures her that she is only paying her bills and using money to buy new clothes for Ellen. After Caroline leaves Ellen is still distressed and states "I will soon have nothing left".

What action should you take?

While Caroline 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 financial 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 Caroline and take any necessary steps. It is also important that Caroline continues to involve Ellen in her finances as much as possible and doing so may be enough to allay any concerns.

The AWI 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. Anyone can contact the Public Guardian for information, or to raise a concern.

The Mental Welfare Commission for Scotland

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. 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, including a supervisory role in relation to the provisions of the Act. They will also often make applications for Intervention and Guardianship Orders and investigate complaints.

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?

Record your answers here:

It is likely that thinking about those questions aroused some strong feelings. The right to make decisions for ourselves is something we value and 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 that decisions we have made may not always be seen as wise.

We can also 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 AWI Act gives medical practitioners the main responsibility in deciding whether a person is incapable of making particular decisions or taking specific actions. Nurses, dentists and ophthalmic opticians can also assess capacity and authorise treatment but only within their own speciality, for example a nurse can only authorise nursing interventions. The 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 and agency information and reports as part of the overall assessment. Under the principles of the AWI Act, the doctor must also consider the person’s past and present wishes and feelings and, where reasonable and practicable, seek the views of significant others.

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 the staff who 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 AWI 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. Every effort needs to be made to ensure this happens.

Activity

How could you ensure that you support the person with dementia that you work with to have as much choice as possible in their day to day life?

Record your answer here:

Consent to medical treatment

It will be normal practice for you to seek consent from the person you are working with before undertaking any intervention or treatment. In many instances this may be implied consent. For example, if you are supporting a person to wash and ask if they would like to have a bath the person may not respond verbally but accompany you to the bathroom; and their action implies that they consent. Similarly if a healthcare professional asks a person if they can take a blood sample and the person puts their arm out this implies their consent. However, if the person refuses or resists, their decision must be respected and you cannot continue with the intervention or procedure without an assessment of capacity under the AWI Act.

The AWI Act defines medical treatment as 'any healthcare procedure designed to promote or safeguard the physical or mental health of the person'. This could include the provision of: nutritional care and fluids; skin care; continence care; pain relief; help with mobility; communication aids; eyesight and hearing support; dental care and oral hygiene, as well as medication.

If a person is assessed as not having capacity to consent to the treatment, the responsible medical practitioner, or other health professional will complete and sign a **Section 47 Certificate of Incapacity** and a **Treatment Plan** detailing all the care and treatment covered by the certificate. This will allow the person to receive the daily treatment/ interventions without having to get consent for each one when it is needed.

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.

Medication issues

We will continue to explore consent to treatment in relation to the administration of medication. Consider Jim's story below.

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.

What things to you need to think about in this situation?

Record your answers here:

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. The essence of covert administration is that the person is unknowingly taking medication.

Remember

You need to be aware that altering medication in this way can mean it will not have the desired effect or it could result in serious health consequences for the person.

- You should **never give medication covertly** even if the person's family or carers request or insist it without ensuring proper assessment has taken place and safeguards are in place. **Otherwise it is regarded as an assault on the person**
- If medication is given covertly this is only when it has been agreed with a pharmacist and the health and social care team working with the person.
- It must be detailed and recorded in the prescription as a means of administration.

While there may be occasions where there is no alternative, and it is medically and ethically justified to give covert medication, 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 person's care plan and the prescription which must be signed on each occasion.

More guidance about covert medication is available on the Mental Welfare Commission for Scotland's website.

The Mental Health (Care and Treatment) (Scotland) Act, 2003

The Mental Health (Care and Treatment) 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 a personality disorder. It may apply to someone with dementia if they have mental health issues and require treatment. The Mental Health (Care and Treatment Act) sets out:

- When and how a person can be treated if they have a 'mental disorder'.
- When a person can be treated or taken into hospital against their will.
- The person's rights and the safeguards which ensure that these rights are protected.

Your role may require that you know details of the provisions of the Act and you may wish to access the NES **Mental Health (Care and Treatment) (Scotland) Act 2003 Learning Resource**.

However it is essential that you are aware of some of its safeguards such as 'Advance Statements', 'Personal Statement' and 'Independent Advocacy' as they can help to support a person with dementia to have their rights protected.

Advance Statements have a specific legal meaning in the Mental Health (Care and Treatment) Act. They set out the way a person wishes to be treated, or not treated, in the event of becoming mentally unwell and unable to make decisions about their treatment. They are intended to improve the person's participation, in line with the principles of the Act and require tribunals and others providing treatment to take account of the past and present wishes and feelings of the person. 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.

Personal statements can be attached to an Advance Statement but do not have the same status in law. They set out what the person would like to happen if they, for example, have to go into hospital, including issues 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. In addition (as discussed in Module 2) a person with dementia can make an **Advance Plan** detailing wider care and treatment options that would be considered at a later date if they do not have capacity to make decisions.

Independent Advocacy supports a person's right to have their 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. Independent Advocacy 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 it a right for people who have a mental disorder to have access to Independent Advocacy and places a duty on NHS Boards to ensure it is provided.

The Adult Support and Protection (Scotland) Act, 2007

The Adult Support and Protection (Scotland) Act, 2007 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 three 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 three point test.

Harm and abuse

A person with dementia is similar to many other groups in society who may be at risk of harm from other people. This may be from people close to them, or working with them. Forms of abuse include:

- **Physical abuse –** being hit or injured on purpose.
- **Financial or material abuse –** such as theft, or misuse of money, property or personal possessions.
- **Emotional abuse –** for example, intimidation, threats, humiliation, and verbal or psychological abuse.
- **Sexual abuse –** the involvement in sexual activity that is unwanted or not understood.
- **Neglect –** from not providing the basics such as food, clothing, attention or care, and includes the failure to provide appropriate access to health and social care.
- **Discrimination –** treating people negatively because they are older, more frail or confused.
- **The misuse of medication –** giving medication inappropriately, overdosing or withholding medication.

Signs and symptoms of abuse may include:

- Injuries, bruises or weight loss.
- Behaviour changes - such as being withdrawn or depressed.
- Self harm.
- A dishevelled or unkempt appearance.

It is important to emphasise that **if you suspect someone is being harmed or you observe them being harmed, you have a duty to report it to your line manager**. Under the legislation, your manager then has a duty to report it to an Adult Protection Lead Officer who has access to an Adult Protection Committee. These have been established 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 an admission to 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 looks upset and worried. When you ask her what the matter is she does not respond and shakes her head.

What would you do?

You tell your manager what has happened and that you suspect this member of staff has a negative attitude to supporting

Margaret because of the way she speaks about Margaret to you.

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 be increasingly withdrawn and upset.

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 directly to the Local Authority Lead Officer 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.

It does not matter if it transpires that there is no case of abuse - you will have taken the appropriate action to protect Margaret.

You should ensure you know how to contact your Local Authority Lead Officer. You can find this information by contacting your Local Authority Social Work Department.

Working with risk and risk enablement

Life is never risk free, it is part of all our lives, but assumptions about the capacity of people with dementia to make decisions and take risks can result in their quality of life being restricted. We need to balance risk and autonomy with our duty of care when we are working with the person with dementia.

In this section of the module we will explore these issues in more detail with reference to Iain's story.

Iain's Story

You will remember from Module 4 that Iain lives in a care home. He spends long periods of the day standing at the exit door of the home, and when anyone comes in and out of the door he tries to leave, and is prevented from doing so.

At other times Iain is restless and constantly walks around the home and goes into other residents' bedrooms. He is regularly escorted out of the rooms by staff.

Staff are finding this a difficult situation to manage - **but imagine how it must feel for Iain!**

Throughout this learning resource we have stressed the importance of really knowing the person, their life story and history, and working with their strengths and assets - so here is a bit more information about Iain.

- Iain worked as a Joiner.
- He is married to Mary.
- He has 2 children and 6 grandchildren.
- He is a keen bowler and enjoys gardening, and used to have an allotment.
- He is very physically fit and led an active life.
- He had pet dogs all his life, and used to walk them at least 3 times a day.

Activity

Drawing on the learning you have undertaken so far, and the information you read about Iain previously:

How could you draw on Iain’s strengths to support him in what must be a difficult situation for him?

Can you think of any meaningful activities that Iain could be involved with in the care home?

Can you think of any meaningful activities Iain could be engaged in outside the care home?

Record your answers here:

Walking about in what appears to be an aimless manner, often referred to as ‘wandering’, is seen in many care settings as ‘problem’ behaviour to be stopped. It frequently results in the person with dementia being restrained.

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, and provide them with a safe means of moving around freely.

Remember

People with dementia need to feel safe and secure and are able to be as independent as possible.

Risk and 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 Mental Welfare Commission for Scotland describes restraint as:

- The planned or unplanned, deliberate or unintentional actions of staff to prevent a person from doing what he or she wishes to do.
- Placing limits on the person’s freedom of movement.
- Defined in relation to the degree of control, consent and intended purpose of the intervention.

Being restrained can be frightening, potentially dangerous and undignified. Restraint 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; medication; or psychological restraint. All these methods 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 a restraining chair;
- trays fixed to chairs;
- bed sides;
- restricting the person's movement while they are in bed, for example, by tightly tucking in bed clothes.

Modification of design includes: locked doors; doors with code number pads; electronic tagging devices; and video surveillance.

Restraint also includes the use of covert medication (previously discussed in this module).

Remember

The use of sedative or tranquillising drugs purely to prevent someone moving can never be justified.

Psychological restraint refers to a number of things, including what could be seen as bullying attitudes, like shouting at, or excluding the person, and leaving the person afraid to ask for help. For example, telling the person they are not allowed to get out of bed in an unfriendly or brusque manner or placing their walking aid out of reach.

It is also important to be aware of the impact of restraint on the person. As well as being traumatic it may lead to feelings of shame, loss of dignity and self respect as well as social isolation. It is also likely to cause the person to become anxious and distressed.

Restraint should only be used if the Adults with Incapacity Act is applied and in accordance with the principles of the Act and supporting guidance, and be subject to ongoing monitoring and review.

Risk and risk enablement

People with dementia often feel that 'dementia' becomes the only thing others know about them. But they remain individuals in their own right and dementia is not the most important thing about them. Many people are still able to do what they did before, despite their life changing and some things becoming increasingly difficult to do.

In terms of best practice the recommended approach to working with risk and people with dementia is 'risk enablement'. This takes a tailored approach to risk by acknowledging that dementia affects different people in different ways.

Traditionally approaches to risk management with people with dementia focus on the **downside of risk**, for example the risk that an event will turn out worse than expected.

If we consider Iain's story we can see this:

- Staff feel Iain is at risk if he leaves the care home because: he may fall; he might get lost and not be able to find his way back; he might not be able to cross the road safely and get run down by a car.
- His wife Mary may also be very anxious about him leaving the care home, as prior to his admission he left their home several times and got lost and had to be brought home by the police.

However a 'downside' approach to risk can be very negative in focus with little room for optimism, or the potential for working alongside risks, or supporting people to take risks.

Another approach is to think about the **upside of risk** and this is essentially what risk enablement is about. Again thinking about Iain - what if he is enabled to leave the care home? Are there positive chances that this will improve: his quality of life; enhance his well-being and maintain his physical and mental health?

This alternative 'upside' approach to risk focuses on Iain's strengths and assets.

Remember

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.

Negotiating risk is neither the elimination of any activity that might produce a downside, nor an acceptance of all activities without boundaries. It is a conversation about who the person is, and asks:

- how they stand to benefit from engaging in an activity.
- what the downside risks are.
- can they be mitigated to an acceptable degree of support?

Frameworks for risk enablement decision making

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 professionals and care providers working with them. Risk enablement needs to be taken forward using a 'team approach' and will involve a range of professionals working at the 'Enhanced' and 'Expertise' levels of **Promoting Excellence**. At Skilled level your key contribution to this will be to:

- Support people with dementia in risk enablement by contributing to risk assessment and management.
- Provide information and access to supports for risk enablement and maintaining independence, such as tele-healthcare. This is covered later in this module.

The following framework for decision making can also help in this process:

- Have you got all the information you need?
- What are the risks associated with each available choice?
- What risk is being taken (and by whom?)
- What are the positive outcomes of taking the risk?
- What strengths can be identified?
- What steps need to be taken to manage risk taking?
- What could go wrong and how could that best be managed?
- Accept that some things can go wrong: who can help manage the fear or guilt?

Returning to Iain’s story we can apply this framework.

Iain’s Story – returned

Iain was having a distressing time in the care home. He was constantly standing at the exit door and trying to get out. At other times he was very restless and walked constantly, often going into other people’s rooms. Iain was constantly subject to a form of restraint from the staff who were worried about the risk to him if he left the home.

However, staff recognised this was an unsatisfactory situation for Iain and had also learned more about his strengths and assets by reviewing his Life History, speaking with his family, and noting wishes for the future Iain had identified in his Advance Plan. Iain had been very clear in his Advance Plan that the things that were important for him in the future were being able to enjoy his previous interests, and most importantly be able to get outside to enjoy his previous activities.

Following discussion with Iain and his wife Mary the following actions were agreed:

- Iain would be enabled to access the care home garden independently.
- A volunteer (Jim, and his dog Amber) would visit Iain on a twice weekly basis and they would go for a short walk outside.
- As an experiment Iain would be enabled to leave the care home on the occasions when he was standing at the exit door. A staff member would discreetly follow him and assess risk.

What happened next:

In terms of Iain's story the initial risk enablement plan went well, and everyone involved, including his wife Mary were in agreement that the benefits of the plan for Iain's well-being completely outweighed the risks to Iain's safety.

- Iain enjoyed spending time in the care home garden. Staff left a gardening trowel and fork around, which Iain sometimes used to work the soil in the borders. On a couple of occasions he had stumbled, but not fallen.
- Iain seemed to greatly enjoy his short walks with Jim and Amber the dog.
- The observation from the experiments of Iain leaving the care home for a walk were that Iain just tended to walk up and down the road a few times and then return.

Reflection

Consider the types of restraint described earlier in this module in relation to your role and the setting you work in:

- Are any people being subjected to physical or mechanical restraint?
- What are the reasons for this, for example: duty of care; or to manage risk to the person or others?
- Considering the protective legislation we have discussed already in this module - how is this being applied to safeguard the person who may be being physically or mechanically restrained?
- How do you feel about this given what you have learned so far about risk enablement?
- What changes could be made in the area you are working in and to your practice?

Record your answers here:

Risk enablement and assistive technologies

Many of the assistive technologies/tele-healthcare approaches described in Module 2 are being used in the people’s own home, care homes and hospitals to enable people to take risks and improve their quality of life. This recognises the positive benefits of the person being able to move around in promoting their health and well-being, as well as reducing risks.

There are many types of Global Positioning Systems (GPS) and tracking devices available, including: watch-based devices; smart phone applications; and key rings and pendants. They enable a person with dementia, who may be at risk of getting lost, or going missing, to have greater freedom, maximise their independence and improve their quality of life.

However they do impact on the person’s privacy and may restrict their independence.

Iain’s Story – returned

In Iain’s example, the observation from the experiments of Iain leaving the care home, with discreet staff support, were that Iain just tended to walk up and down the road a few times and then return. However on 2 occasions he walked a bit further and was not able to find his way back.

The team supporting Iain, and Iain’s family agreed that he should continue to be enabled to leave the care home independently, but any risks should be managed by him wearing a Global Positioning System (GPS) tracking device.

This would mean that in the event that Iain did not return to the care home the staff, and his family, would be able to detect his whereabouts via the device to make sure he was safe.

Iain’s Advance Plan had stated he would like such assistive technical supports to be used, if they enabled to him to enjoy and engage in his valued activities.

While use of such approaches may have been helpful to Iain, it is important to note that when considering these technologies, we need to be aware of ethical issues, including:

- if the person would have wanted them to be used;
- any potential for these practices to become a restraint, as well as stigmatising for the person;
- any impacts on the person’s privacy or reduction in their choice of activity;
- any adverse effects for the person - for example, if the person has to be constantly brought back to a care setting this may lead to increased stress and humiliation for them.
- that devices are only used for the right reason - primarily for the benefit of the person, although they are likely to also benefit the family or carer. But the person’s needs must always come first;
- they are never used without the person’s knowledge and consent – or if the person is not able to consent, appropriate legislation is applied.

Before ever considering the use of these technologies, changes in the physical and social environment of the care setting need to be taken into account, including ensuring the person being engaged in person-centred occupation and stimulation.

Remember

Technology should not be used as a substitute for appropriate levels of personal support, care and human interactions in care settings, including the person's own home.

In this module we have previously explored the issue of capacity. Remember that people's capacity may fluctuate, and will likely diminish as the person progresses to the later stages of their dementia journey. It is at this point that staff working with the person may feel under considerable pressure to eliminate risk. Careful assessment of risk and risk enablement remains important.

These considerations also apply to all tele-healthcare devices or systems to monitor people, or that allow someone else to track them, such as GPS devices and other technology. It is essential that the person with dementia, and their family and carers, are made aware of the potential benefits and limitations of these technologies as part of their post diagnostic support and to support their development of Advance Plans. This will enable the person to make an informed choice about the range of technologies they would consider and support decision making when the person is no longer able to give consent.

As with all tele-healthcare, if the person is not able to give informed consent to the use of monitoring and tracking devices they should only be considered through the application of the Adults with Incapacity Act, and in accordance with the principles of the Act.

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 identifies 9 characteristics 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

In Module 1 we explored some specific equality and diversity issues in relation to people with dementia.

Module summary

In this module 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, risk enablement, 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.

Reflective Account

Write a reflective account taking into consideration your learning from Module 5.

Below is a suggested structure that you may find helpful in writing your reflective account.

Please ensure that you anonymise any information

What happened?

Identify and describe a situation or incident where you were supporting a person with dementia and you had concerns about their well-being. When recalling this situation you may wish to consider the following:

- Adult Protection issues in relation to dementia.
- The principles of Adult Protection legislation.
- The range of legislation and policy that protects the rights of people with dementia in Scotland, for example capacity and consent and risk and risk enablement.

Describe what you did or how you responded.

Describe the outcome of your actions or response.

So what does this mean?

- How did you feel about the outcome of the support that you provided at the time?
- What do you feel about that now in light of your learning, having completed the module?
- What did you do that went well?
- Do you think your actions helped to improve quality of life for the person you were working with?
- What might you now do differently?

Now what will you do in the future?

- How will this affect the way you work with people with dementia in the future?
- Would you act differently or would you be likely to do the same?
- What further learning do you need to undertake to enhance your understanding of Adult Protection in relation to people with dementia that will help you support people to improve their quality of life? You may want to record this using the **Action into practice** activity at the end of this module.

Action into practice

From your learning in this module

- How does your work setting actively promote the rights of people with dementia?
- Find your organisation's 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 focussed way.

Make notes of your responses below:

This resource may be made available, in full or summary form, in alternative formats and community languages. Please contact us on **0131 656 3200** or email **altformats@nes.scot.nhs.uk** to discuss how we can best meet your requirements.

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