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:

- Recognise the importance of selfmanagement of health and well-being for people with dementia.
- 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.
- Describe the common mental health and wellbeing issues that are experienced by people with dementia.
- 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 checkups 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.

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, comorbid 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.



- 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.



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.

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 wellbeing. 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.