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:

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

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.

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.

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

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.

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

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 2: Promoting person and family centred care and community connections

Module summary

In this module we have explored what a person-centred approach to care means. We also looked at a range of ways that people with dementia can continue to maintain valued roles and relationships and be supported to remain 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

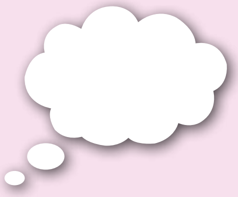
What happened?

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: