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FORGET-ME-NOT Training Modules

Intellectual Output 2.2

MODULE 2

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Culture Sensitive Care

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M.2.1 Ethnic, cultural and religious backgrounds in dementia care

When completing an assessment or admission form, it can be easy to tick a box (Hindu? Christian? Irish? Greek?) and think that the work of valuing a person's background stops there. In fact, this is only a starting point. When thinking about activities and encouraging meaningful engagement, a person's religion, nationality or culture are likely to have a major influence on their preferred music, food, clothes and everyday routines, to name a few things.

Cultural and religious needs of people with dementia

Find out about a person's cultural and religious background. If you do not know much about a person's religion or country of origin, be prepared to find out more, perhaps from the person, their family or local community representatives. The local library or the internet can offer a wealth of information.

When speaking with a person with dementia, the following questions might help: I don't know very much about … ('Nigeria', 'Poland' , 'Islam', 'Sikhism' and so on) Please tell me a bit more about your … (country) (religion) Are there any specific pieces of music that remind you of home? What is a favourite food or meal from your childhood? What times of the year are most important in your religion? What do you do to observe this … (festival)(tradition)?

Be aware that questions can be challenging for people who have dementia. Showing pictures of a country or symbols of a religion or possibly objects related to that culture might prompt different responses. A rice bowl, Chinese fabrics or a picture of a rickshaw might provoke memories for a person from China or Hong Kong. Spices, saris or Bollywood star pictures could be good starting points for an Indian patient.

Linking staff and patients from the same background

If you have a member of staff from the same religion or culture, this can be a really helpful way of offering tailored support and spreading knowledge among the staff team. Study the following example:

- Limetree Care Centre in south London is home to 92 residents, of whom 31 are from an African or Caribbean background, four are Irish and individual residents also come from places such as Spain, Cyprus and India. The staff team is also diverse – over half are from Africa or the Caribbean.
  Oxana Nesterenko, the manager at Limetree, is pleased to make links between staff and residents. She says, 'During induction, we make it clear that staff cannot speak their own language in front of residents who don't speak their language. This would obviously be disrespectful. But where a resident can enjoy communicating with a staff member in their language, this is an important part of the care plan.'
  The activity coordinator at Limetree, Devika Radhakissoon, is a Hindu from Mauritius and as such is able to give a Hindu resident, Mrs P, particularly individualised activities. When she arrives on shift in the morning, Devika will go to Mrs P's room and spend a few minutes saying a prayer together. She will then henna her hands and do the bindu mark on her forehead in preparation for the day. Mrs P also enjoys a good rapport with the receptionist Sweetie and the visiting doctor, both of whom are also Asian. Because she lived in Kenya for

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many years, she relates well to the African staff as well. Be aware though that within some countries or faiths, there may be very different traditions according to the person's particular background.

Paying attention to detail

Attending to small details can make a big difference to meeting a person's cultural or religious needs. Let's continue with some examples:

- A Greek Orthodox woman living at Limetree Care Centre (introduced above) wears black all the time and likes to have her hair taken back in a particular way. She also likes to hold a cross in her hand. Mrs P (Limetree resident introduced above) has a table in her room with pictures and ornaments relating to her Hinduism including Ganesh the God and portraits of her guru. At Diwali, the activities coordinator will light a candle with her in her room.
- Suna Tilley at the Alzheimer's Society in Leicestershire and Rutland recruited a Hindi volunteer who befriended two Asian gentlemen who wanted her to accompany them to the temple. The volunteer pointed out that she would not be able to do this when she was having a period as this is not permitted in the temple.

Avoiding assumptions and judgemental behaviour

The danger of any label is that we then make assumptions and say, for example, that 'No Jewish or Muslim person likes to eat bacon' or 'African or Caribbean elders have strong and active Christian beliefs.' Stereotypes do exist for particular cultures and religions, however it is important to find out what a person's actual likes and dislikes are, rather than being led by our assumptions. Mrs P, the Indian resident at Limetree Care Centre (introduced above) prefers not to wear a sari, for example, as she is anxious about falling.

Some types of behaviour that are acceptable in particular cultures – for example, spitting or talking loudly – may seem strange or even rude to someone outside that culture. The challenge for care staff in a communal care environment is to recognise and respect that this is a normal activity for that individual, while looking after the needs of others who might find that behaviour anti-social.

Offering support for non-English speakers

If a person with dementia has very little or no spoken English, it will be important to think of a range of ways to support them. The care facility should consider recruiting a volunteer visitor who speaks their language – this may help the person feel less isolated.

If you want to find out more about a person's wishes and interests or hold a review meeting, ideally a translator should be employed to ensure that you are not just relying on guess work. You may feel that a person's relative can act as a translator, but some individuals will not have relatives and a translator will ensure a more impartial representation of the voice of the person with dementia in any case. Some translators will have little experience of dementia, so you may need to explain that the person's communication may be less easy to follow.

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Make links with local community organisations and offer support to attend external events. If you are in a multicultural urban area, it may be possible to visit a Greek or Chinese restaurant, a Polish delicatessen or an Indian sweet shop, for example. For a person with dementia, the pleasure of seeing, smelling and tasting familiar foods may provide enjoyment and comfort.

Study the following examples of support for non-English speakers:

- At Limetree Care Centre (introduced above), a Spanish gentleman has struck up what seems a quite unlikely friendship with an English woman. They both appear to listen very carefully to each other, speaking in Spanish and English respectfully. The Spanish resident will sometimes serenade the woman with a song and they keep each other entertained for ages. Perhaps the language of love can transcend traditional communication barriers!
- The Greek Orthodox resident at Limetree Care Centre (introduced above) is from Cyprus and has very little spoken English, but she enjoys a friendly rapport with the maintenance man who is Turkish, so they can understand each other. This makes a significant difference to her wellbeing.
- Suna Tilley, befriending manager for the Alzheimer's Society Leicestershire and Rutland branch, finds creative ways of linking volunteers with her clients with dementia. She says, 'Sometimes the person who doesn't speak much English, whether because of their cultural background or their dementia, can enjoy going out for a drive in the car or going window shopping with a volunteer. This provides a focus for them spending time together and doesn't depend too much on talking.'

<u>Hosting events to celebrate diversity</u>

The Care Quality Commission (CQC) expects you to collect information about the ethnic origin and religions of your staff team and your service users. Use this information to think about how you might plan events in your activity calendar.

Do a general internet search under specific religions or events, such as 'Jewish festivals', 'Chinese New Year'. Some events have a celebratory tradition while others such as 'Lent' in the Christian religion or 'Ramadan' in the Muslim faith have a more serious aspect around self-restraint and sacrifice. It is wise to consult people from that particular culture or religion and find out about what might be appropriate or inappropriate things to do to mark those periods of time.

For more celebratory events, choose food, music and possibly costumes and decorations to fit the event. Many events – such as Chinese New Year or the Jewish Hanukkah celebration – will have very enjoyable and colourful elements. Paint lanterns or dragons for the Chinese New Year or offer doughnuts or potato pancakes for Hanukkah, for example.

An event with a specific national theme such as a Caribbean evening or an Irish pub night will bring many possibilities for new and fun experiences for service users. Staff members may enjoy dressing in traditional clothes or bringing in food or music for an event with an African or Asian theme.

Music plays a vital role in events. For a person with dementia, include songs and rhythms that relate to their earlier lives rather than only choosing traditional English music. There may be opportunities

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to bring in children from different cultural backgrounds where songs can be remembered or learnt together.

Using reminiscence to learn more about other cultures

Reminiscence-related activities can provide ways of making connections between staff and service users of different cultural backgrounds. For example, you might want to have a discussion about the differences and similarities between wedding or funeral ceremonies in a range of countries, or the ways in which babies and children are brought up in different religions and cultures. Ask staff members or family members to bring in photographs, fabrics, CDs and DVDs or objects to help stimulate memories and personal stories. Online reminiscence tools might be quite useful in one-on-one work.

Recognising when a person's preferences change

To what extent does a person's cultural and religious identity need to be preserved as their dementia develops? Most likely, your first response to this question will be that it is critical to person-centred care to continue to maintain a person's previous routines and observances. And yes, this is true. But the situation gets complicated if – as in the following examples – the person's views or preferences change: a person who has never drunk alcohol or never eaten meat suddenly develops a taste for these as their illness progresses a person who has apparently always led a heterosexual lifestyle develops a gay relationship while living in a care home, or a person who would normally have played bridge and hated bingo suddenly starts to enjoy bingo.

Some of these changes might be considered less major than others. There can be few negative consequences of a person developing a new enjoyment of bingo, but the other two changes might have more impact on the person's family and might represent a more fundamental change in the person's identity.

It will be important to consider whether a person's mental capacity is sufficient to make these decisions. Under the Mental Capacity Act, a person's capacity is assessed for each situation and decision rather than a general statement made about their ability to make decisions overall.

M.2.2 Communication and use of language in dementia care

Elderly patients may find it difficult to communicate because of a physical health problem – such as hearing difficulty, a problem with their eyesight or because of a disorder affecting their brain, such as Alzheimer's disease or stroke. Communication problems can come on gradually or happen overnight. If they're sudden, you will need to re-evaluate how you communicate with the person you care for. Consider your tone of voice, how quickly you speak, and how you use body language and gestures to emphasise what you are saying. Find out what helps them or makes your communication clearer.

M.2.2.1 Relation between dementia and aphasia

What is aphasia

Aphasia is an impairment of language, affecting the production or comprehension of speech and the ability to read or write. Aphasia is always due to injury to the brain-most commonly from a stroke,

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particularly in older individuals. But brain injuries resulting in aphasia may also arise from head trauma, from brain tumours, or from infections.

Aphasia can be so severe as to make communication with the patient almost impossible, or it can be very mild. It may affect mainly a single aspect of language use, such as the ability to retrieve the names of objects, or the ability to put words together into sentences, or the ability to read. More commonly, however, multiple aspects of communication are impaired, while some channels remain accessible for a limited exchange of information.

How does dementia relate to aphasia?

Most aphasia types are caused by stroke or other acute brain injury that damages brain tissue in areas important for language processing. However, a type of aphasia called primary progressive aphasia is a neurodegenerative disease, which results from progressive deterioration of brain tissue in areas important for speech and language. It is often caused by diseases such as s Alzheimer's or Frontotemporal Lobar Degeneration. Although the first symptoms are problems with speech and language, other problems associated with the underlying disease, such as memory loss and personality changes often occur later.

M.2.2.2 Communication and language

We all need to communicate with other people. We need to tell other people a wide range of things, including our needs, wishes and feelings. How well we can communicate will affect our quality of life, as well as how much we are able to keep our individuality and sense of identity. A person with dementia may have trouble finding the right word, they may repeat words and phrases, or may become 'stuck' on certain sounds.

In addition, people with dementia are likely to have other sensory impairments (such as sight or hearing problems) which can also make it harder to communicate. If someone is not able to express themselves properly, they can lose confidence, or feel anxious, depressed or withdrawn. They may also behave in ways others find odd, because they are trying to communicate what they can no longer say with words.

If a person with dementia is living in a hospital or care setting, any problems they have communicating can affect the care and support they receive. In part M.2.3.5 we are referring to the Alzheimer's Society's document called 'This is me' which can give information about a person, including how they like to communicate, any difficulties they have, and how care and support staff can best help them to communicate.

M.2.2.3 Dementia and language

How and when language problems develop will depend on the individual, as well as the type of dementia and the stage it is at. These problems will also vary day to day. In some forms of dementia - such as frontotemporal dementia - it is very likely to be one of the first symptoms that is noticed.

One sign that a person's language is being affected by dementia is that they can't find the right words. They may use a related word (eg 'book' for 'newspaper'), use substitutes for words (eg 'thing to sit on' instead of chair) or may not find any word at all.

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Another sign is that they may continue to have fluent speech, but without any meaning - for example, they may use jumbled up words and grammar. Dementia can also affect the person's ability to make an appropriate response, either because they may not understand what you have said or meant.

There may eventually come a time when the person can hardly communicate at all using language. This can be distressing for them and those supporting them, but there are ways to maintain communication and support the person to express themselves.

Dementia can also affect a person's cognitive abilities. A person with dementia may have slower speed of thought, or not be able to understand complex ideas. This can also affect their ability to communicate. For example, they may take longer to process thoughts and work out how to respond to what is being said. Other factors can affect a person with dementia's communication, including pain, discomfort, illness or the side-effects of medication. If you suspect this might be happening, talk to their GP.

M2.2.4 How to communicate with someone with dementia

Before you speak

- Make sure you're in a good place to talk - quiet, with good lighting and without too many distractions (eg no radio or TV on in the background).
- Get the person's full attention before you start.
- Position yourself where the person can see you as clearly as possible (eg with your face well-lit) and try to be on the same level as the person, rather than standing over them.
- Sit close to the person (although not so close you are in their personal space) and make eye contact.
- Make sure your body language is open and relaxed.
- Have enough time to spend with the person. If you feel rushed or stressed, take some time to calm down.
- Think about what you are going to talk about. It may be useful to have an idea for a particular topic ready. You can also use the person's environment to stimulate topics.
- If there is a time of day where the person will be more able to communicate (eg in the morning) try to use this time to ask any questions or talk about anything you need to. Make the most of 'good' days and find ways to adapt on 'bad' ones.
- Make sure any of the person's other needs are met before you start (eg they're not hungry or in pain).

How to speak

- Speak clearly and calmly.
- Speak at a slightly slower pace, and allow time between sentences for the person to process the information and respond. This might seem like an uncomfortable pause to you, but it is important for helping the person to communicate.
- Avoid speaking sharply or raising your voice.
- Use short, simple sentences.

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- Try to communicate with the person in a conversational way, not question after question (it can feel like an interrogation).
- Don't talk about the person as if they are not there or talk to them as you would to a young child - be patient and have respect for them.
- Try to laugh together about misunderstandings and mistakes - it can help. Humour can help to bring you closer together, and may relieve the pressure. However, be sensitive to the person and don't laugh at them.
- Include the person in conversations with others. This may be easier if you adapt what you say slightly. Being included can help a person with dementia to keep their sense of identity and feel they are valued. It can also help to reduce feelings of exclusion and isolation.

What to say

- Try to avoid asking too many questions, or complicated questions. People with dementia can become frustrated or withdrawn if they can't find the answer.
- Try to stick to one idea at a time. Giving someone a choice is important, but too many options can be confusing and frustrating.
- If the person is finding it hard to understand, consider breaking down what you're saying into smaller chunks so that it is more manageable.
- Ask questions one at a time, and phrase them in a way that allows for a 'yes' or 'no' answer (eg rather than asking someone what they would like to do, ask if they would like to go for a walk) or in a way that gives the person a choice (eg 'would you like tea or coffee?').
- Rephrase rather than repeat, if the person doesn't understand what you're saying. Use non-verbal communication to help (eg pointing at a picture of someone you are talking about).
- If the person becomes tired easily, it may be better to opt for short, regular conversations. As dementia progresses, the person may become confused about what is true and not true. If the person says something you know is not true, try to find ways of steering the conversation around the subject and look for the meaning behind what they are saying, rather than contradicting them directly. For example, if they are saying they need to go to work is it because they want to feel useful, or find a way of being involved and contributing? Could it be that they are not stimulated enough?

Listening

- Listen carefully to what the person is saying, and offer encouragement.
- If you haven't understood fully, rephrase what you have understood and check to see if you are right. The person's reaction and body language can be a good indicator of what they've understood and how they feel.
- If the person with dementia has difficulty finding the right word or finishing a sentence, ask them to explain it in a different way. Listen out for clues. Also pay attention to their body language. The expression on their face and the way they hold themselves can give you clear signals about how they are feeling.
- Allow the person plenty of time to respond - it may take them longer to process the information and work out their response. Don't interrupt the person as it can break the pattern of communication.

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- If a person is feeling sad, let them express their feelings. Do not dismiss a person's worries - sometimes the best thing to do is just listen, and show that you are there.

Body language and physical contact

- Non-verbal communication is very important for people with dementia, and as their condition progresses it will become one of the main ways the person communicates. You should learn to recognise what a person is communicating through their body language and support them to remain engaged and contribute to their quality of life.
- A person with dementia will be able to read your body language. Sudden movements or a tense facial expression may cause upset or distress, and can make communication more difficult.
- Make sure that your body language and facial expression match what you are saying.
- Never stand too close to someone or stand over them to communicate - it can feel intimidating. Instead, respect the person's personal space and drop to or below their eye level. This will help the person to feel more in control of the situation.
- Use physical contact to communicate your interest and to provide reassurance - don't underestimate the reassurance you can give by holding the person's hand or putting your arm around them, if it feels appropriate.

M.2.2.5 Communicating with someone with sensory impairment

All of the tips and suggestions in this factsheet may be useful for people with dementia who have difficulties communicating. A number of additional suggestions for people with sensory impairments are outlined below.

Sight loss

Many people experience some degree of sight loss as they get older. This may be age-related, or due to a condition such as cataracts or age-related macular degeneration. Many people with sight loss will need glasses to help them see.

People with sight loss are likely to experience more difficulties as a result of their dementia. Not being able to see what is around them can lead to a greater sense of disorientation and distress, as well as decreased mobility and a risk of falls. Having both dementia and sight loss can also make people feel isolated from those around them. This makes good communication extremely important.

Communicating with a person with dementia and sight loss may be difficult as the person may not be able to pick up on non-verbal cues or follow a conversation as easily. There is a lot you can do to help them.

- Check the person is wearing their glasses, if needed, and that these are clean and that the prescription is up-to-date. If someone has more than one pair of glasses, ensure they are labelled or marked for the activity they have to be used for - for example, reading glasses.
- Introduce yourself or try to gain the person's attention before starting or ending a conversation. If you don't, they may become confused about who is talking, be unsure if they are being spoken to, and may not know if people enter or leave the room. If you are helping the person with a task, let them know what you are going to do before and during it.

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- Use references when describing where something is - for example, your water is on the table on your right. It may be helpful to use imaginary hands on a clock face to describe where something is, especially for people who have lived with sight loss for many years (eg the cup is in front of you at 12 o'clock position).
- Make the most of the physical environment - for example, make sure there is good lighting, which is consistent, even and can be adjusted. Try to reduce shadows as the person may mistake them for obstacles.
- The person may not be able to pick up on non-verbal communication, such as body language. Bear this in mind when talking to them.
- If you are communicating with someone in writing, such as sending them a letter, think about the colour of paper and font size (for example, black text on white or yellow paper often makes text easier to read, as does larger text).
- People with learning disabilities are 10 times more likely to have serious sight problems than other people. They are also at greater risk of developing dementia at a younger age, particularly people with Down's syndrome. You should make sure a person with learning disabilities and dementia has a communication passport - a practical tool that gives information about a person's complex communication difficulties, including the best ways to communicate with them.

Hearing loss

Most people over 70 will have some degree of hearing loss. They may consider themselves as deaf, 'hard of hearing' or having 'acquired hearing loss'. This may be due to age-related damage or other causes (such as noise damage, infection, diseases or injury).

In comparison, people who are born deaf or become deaf at a young age are considered to have 'profound deafness'. They may consider themselves as Deaf (often referred to as Deaf with a capital D), use British Sign Language (BSL) as their first language and identify with the Deaf community.

How a person with hearing loss communicates will depend on a range of factors including:

- the type of hearing loss they have
- whether they use a hearing aid, BSL, lip-reading or a combination of all of them
- personal preference and life history.

There are strong links between dementia and hearing loss that suggest hearing loss can make developing dementia more likely. People with hearing loss are likely to experience more difficulties as a result of their dementia. They may already find it harder to communicate, and not being able to hear what is going on around them or hear other people speak can add to their confusion. Both dementia and hearing loss can also make people feel socially isolated, so having both conditions at once can be very difficult for someone. This makes good communication extremely important.

- If the person uses a hearing aid, check that it is fitted and working properly. If you think the hearing aid isn't working or if you need help checking it, speak to your GP or make an appointment with the audiology department at your local hospital. Ask the person if they would like to lip-read.

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- Turn your face towards the person and ensure your face is well-lit so your lip movements can be easily seen.
- Don't shout or over-exaggerate words or lip movements (this can actually make it harder for the person to understand you).
- Speak clearly and slightly slower, but keep the natural rhythms of your speech.
- Don't cover your mouth.
- Consider using visual clues such as objects or pictures to help.
- It may be helpful to check if the person has too much ear wax, as this may make any hearing loss and communication difficulties worse.

M.2.2.6 Communication at later stages of dementia

Dementia patients at later stages may not understand what is being said to them and are less likely to be able to respond verbally as they may have limited or no speech. They may repeat the same phrase or sound, or may only be able to repeat a couple of words. Some people may start talking lots but their words don't seem to make sense. In this case, try to identify the feelings that the person is trying to get across and respond to these. For example, if the person is smiling and chatting happily, respond to them in the same way.

Although the person may not be able to communicate verbally, they may still be able to show their needs and emotions in other ways. Rather than speaking, they may use behaviour, facial expression, gestures and sounds to try and communicate how they are feeling and what their needs are.

Try to support the person to communicate as much as possible. It can help to observe their body language, behaviour and facial expressions. Knowing the person and how they communicate will help you both to enjoy time together. It's important to keep communicating with the person and look for opportunities for meaningful engagement. Finding ways to engage the person's senses can help.

When you're thinking about how to communicate with the person, bear in mind their needs and background – including their cultural needs. For example, people from some cultural backgrounds may feel uncomfortable or distressed if you're too close to them when you're communicating with them.

- keep eye contact when communicating
- non-verbal communication (such as gestures, facial expression and body language) can help
- smile
- use appropriate physical contact (such as holding hands) to let the person know you are there and offer reassurance
- don't rush – allow plenty of time and look for non-verbal clues from the person
- even if you don't think the person can follow what you're saying, continue talking to them clearly. They may still feel a certain way even if they don't fully understand what you're saying
- consider responding to them in the way they respond to you ('mirroring' them).

M.2.3 Maintaining dignity in difficult conditions of dementia

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Accessing health care can be a very undignified experience. People are routinely stripped, prodded, punctured and photographed. They have to reveal intimate details to complete strangers about their smoking, alcohol consumption and toilet habits. Their clothes are taken away and replaced with a gown which, if they're lucky, actually has a fastener to close it. And they're removed from the cosy security of their own home and placed into a six-bedded ward with people on either side who can hear everything they're doing and everything they're saying.

M.2.3.1 Respecting patient's dignity

It all adds up to a very unusual, and very unreal, experience. Often the only thing people have to cling on to in the middle of that experience is their sense of dignity – that they are individual people with families, friends, jobs, histories and futures, and are not just some cog in a giant health care machine. And everything you do as a carer with and to these people has the power either to strengthen and restore that sense of dignity, or diminish and undermine it.

It means the way you approach the patient, whether you look engaged, interested and friendly, or whether you're thinking you'd rather be somewhere else. It means whether you ask the patient's permission to provide care or just get on and do it regardless of his or her wishes. It means the way you speak to people, whether you show in what you say and how you say it that you are genuinely interested, concerned and eager to help, or whether you are just going through the motions. It means the steps you take to ensure the person's privacy and modesty are protected (closing screens, making sure the patient is covered and keeping your voice level down when discussing personal issues), or whether 'getting the job done' is uppermost in your mind. It means the way you respond when a patient/client asks you something or asks you to do something, whether you show you're attentive and ready to help, or whether you're far too busy to concern yourself with such trivial things (have a look again at communication to refresh on these vital issues).

All of these things, things which in the midst of a busy day you might not even notice, will certainly be noticed by the person on the receiving end – your patient. He or she is in a particularly vulnerable position, which means their sensitivity to the signs you give out will be heightened. Positive signs from you will do much to boost their morale and confidence. Negative signs from you will feel like complete rejection.

Your biggest resource in terms of maintaining people's dignity is therefore yourself. Your **attitude**, your **manner** and your **enthusiasm** are the three 'tools' you can use to bolster people whose self-esteem is low, encourage people whose mood is negative, support people whose confidence is ebbing, and restore to people a sense of dignity. Use them wisely, and with care.

M.2.3.2 Apraxia in dementia

Apraxia is defined as the inability to carry out a previously learned motor activity, despite normal function of all the component parts (muscles, nerves, joints, etc.). Symptoms such as difficulties dressing or using a knife and fork, are often clues that apraxia is present. Testing for the presence of apraxia can be addressed throughout the visit, where problems such as using a pencil, undressing and dressing will be apparent. Other simple procedures include having the patient pantomime common activities such as combing their hair ("pretend you have a comb in your hand and comb your hair") and slicing bread ("show me, with both hands, how you would use a knife to cut a slice off

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a loaf of bread"). The abnormal response is to use the body part as the object, using a finger as the knife, or hand as the comb, gestures sometimes referred to as 'body-as-part apraxia.'

M.2.3.3 Specifics of dementia patients' dignity

Caring for someone with dementia is hugely rewarding and calls for you to use all of your skills as a carer. But it can also be very challenging. The person may mistake you for someone else, perhaps from their distant past, and hold false beliefs about where they are and what they're doing (a man who has been retired for many years constantly putting his jacket on and saying he's going off to work, for instance). Sometimes, the person can become agitated because of the confusion he or she feels and may be verbally or even physically aggressive. This can make some carers reluctant to care for people with dementia. Informal carers must remember that it's not a disaster if they don't do everything as well as a professional, they are still doing great.

To quote Teepa Snow: "Dementia doesn't rob someone of their dignity, it's our reaction to them that does. Teepa Snow is one of the leading educators on dementia and the care that accompanies it, in the US and Canada. For more information on her "Positive Approach to Care" you can follow her here: http://teepasnow.com/

Alzheimer's Disease International has produced brief advice for people caring for a loved one with dementia that we can use to guide our practice as carers. On dignity, the advice states that: 'The person with dementia is an individual with feelings – treat them with respect and dignity.' It goes on to say:

- remember that the person you care for is still an individual with feelings; dementia affects people in different ways – in the early stages of the disease, the person may be aware that they are struggling with everyday tasks they once found easy
- what you and others say and do can be disturbing – avoid discussing the person's condition in their presence.

The advice also presents guidance on various aspects of care that will help to promote the dignity of people with dementia, such as:

- establishing routines
- supporting independence
- avoiding confrontation
- simplifying tasks
- improving safety
- keeping active
- communicating
- using memory aids.

As you can imagine, and may even have experienced if you have cared for someone with dementia, the condition can leave the person in a very vulnerable position. Legislation exists to protect the interests and dignity of people who are vulnerable due to a mental health problem, including dementia. It is important to have a basic understanding of these laws, because they affect what you can do as a carer to support people with dementia and their families. Again, no one would expect

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you to know every sentence and clause of the law that relates to your country, but a basic understanding will help you provide care that is in the person's best interests and, importantly, within the law.

M.2.3.4 Avoiding shame and revulsion when dealing with continence issues

People of all ages suffer from bladder and bowel problems, often described as continence problems. If you ask them how they feel about their problem, they'll almost invariably tell you that the hardest part is the humiliation they feel about the loss of dignity it brings.

Bladder and bowel problems can be caused by many things, such as infections, injuries, immobility, poor diet and sometimes very serious conditions like cancer. People can be supported to manage their problem best by discovering the underlying cause and treating it. Severe cases of dementia can lead the patient to forget or ignore their need to go to the toilet.

Professional carers are often part of a team working to an agreed plan of care that aims to help the person prevent and manage the problem. Ongoing assessment is central to this: assessment starts on first contact with the person and continues thereafter.

In addition, carers help patients to look after their personal hygiene, care for catheters (a tube that is inserted into the person's bladder and which drains urine into a bag that can either be strapped to the person's leg or held on a stand) if being used, and remove and dispose of soiled clothes and continence garments.

As you can imagine, bladder and bowel problems have the potential to be enormously embarrassing for the patient/client. Always, and at all times, carers should act to preserve the person's dignity and supporting him or her through what can be a very devastating experience emotionally, socially and physically. Carers' approach will go a long way to either helping the person to feel at ease or making him or her feel even worse.

Carers should:

- be positive in your approach, showing willingness to help
- never show any signs that you find the task unpleasant
- involve the person in the care: don't just take over and 'get the job done' – remember that the principles discussed in the Person-centred care section apply here just as they do in all other situations
- work speedily and efficiently, but don't try to hurry the person – he or she will decide the pace at which you'll work
- leave the person comfortable and feeling valued, not rejected.

Bladder and bowel problems are very distressing for individuals and their families. You can make the situation better by adopting a positive, professional attitude that maintains the person's dignity and raises his or her self-esteem. You may be able to access a continence or specialist urology nurse through your organisation who will be able to advise you on issues around bladder and bowel problems.

M.2.3.5 Personal portfolios for ensuring quality care

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forget me not

Personal portfolios are the best tool to ensure quality care with the patient in the centre of the care effort. When the patient is not in their home environment, the professional carers need to know them as well as possible by completing and referring to a personal portfolio. A very good example of it would be Alzheimer's society's This is me questionnaire. But a portfolio can of course be adapted in order to fit the care environment and provide the best support for highest quality care.

A typical portfolio would contain the following elements:

Portfolio

Patient

surname _____
first name _____
birth name _____

date of birth _____
nationality _____

Parental family

father _____

mother _____

brother(s) _____
_____
_____

sister(s) _____
_____
_____

Own Family

marital status _____
marriage _____

wife/spouse _____

children _____
_____
grandchildren _____
_____
great-grandchildren _____
_____

Education and Profession

primary education_____
academic studies _____
_____
secondary education _____
_____
further education _____
_____

vocational education _____
_____
academic studies _____
_____
last job/profession _____

personal life events (incidents that had an impact on the patient's life)

_____
_____
_____
_____
_____

deaths and losses (family, friends, pets)

_____
_____
_____
_____
_____

hobbies in the past

_____
_____
_____

hobbies today

_____
_____
_____

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habits in the past

habits today

particular events in recent years

fears and aversions

particular wishes, likes and dislikes (regarding food, sleep, daily routines, care, religion, voice)

Now based on your reading of Module 1 and Module 2, please, read the following case study and reflect on the questions below. This case study is taken from a written final exam in elderly care.

Caring for people suffering from dementia

Mrs. Brown, born in 1937, has been living in an old people's home for about one year now. Lately she's increasingly been showing changes in her behaviour. For example she is always asking: „Nurse, where am I? I have to get home quickly and take care of my children." In addition she tends to get more and more unsettled during the course of the day, wanting to leave the ward. She's also forgetting appointments and agreements. Student nurse Luisa notices, that Mrs. Brown has difficulty naming everyday objects.

With a certain amount of support she is still able to get ready in the mornings by herself, but at the moment she's rigourously refusing oral care. One morning she opens her mouth only after protesting loudly. The student nurse loses her nerve and shouts at Mrs. Brown: „Now open your mouth, or else…It can't be that difficult to brush your teeth. You're acting like my three-year-old daughter."

In the following the students are asked to define Alzheimer type dementia referring to the symptoms shown in the case study, to predict the course of the disease and to comment on the behaviour of the student nurse on the basis of Naomi Feil's validation.

1. Alzheimer's disease, symptoms
   - temporal and spatial disorientation – „Where am I? I need to get home…"
   - amnesia – Mrs. Brown forgets appointments and agreements

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- aphasia – Mrs. Brown has difficulty naming objects
- wandering behaviour – Mrs. Brown wants to leave the ward
- challenging behaviour during oral care

2. Alzheimer's disease, course of disease
   - deterioration is to be expected
   - progressing loss of memory, affecting short term and long term memory
   - increasing difficulties in recognizing objects, persons and faces
   - progressing aphasia to the point of total loss of faculty of speech
   - progressing disorientation, reversion of the day-night-rhythm, not finding the way in the room
   - increasing apraxia, inability to perform daily routines without support
   - increasing agitation, need for movement, repetitive movements, wandering behaviour
   - increasing apathy, withdrawal from social life
   - loss of ability to abstract or follow a (longer) conversation

3. behaviour of the student nurse and validation
   - reaction is not adequate – infantilisation, lack of appreciation and empathy, no consideration of the emotional state of Mrs. Brown
   - validation means appreciation, acceptance, respect and the recognition of the patient's personality
   - validation considers basic needs, emotional states and universal feelings
   - validation is oriented toward the personal reality of the deranged patient in the final phase of life

M.2.3.6 Life Story: Biography work with dementia sufferers

As part of reminiscence therapy carers can work on completing a Life Story – a sort of biography work – with the dementia sufferer. This can be used as a memory support as dementia progresses later in time.

According to Gibson, in Reminiscence and Life Story Work A Practice Guide 4th Edition, (2011) these are the key guidelines to remember when undertaking life story work.

- Remember life story work is meant to be enjoyable – it is neither an exam nor an inquisition.
- It is usually undertaken in a series of spaced joint conversations taking account of a person's health, mood and energy levels which may fluctuate from week to week.
- Informed consent or assent needs to be obtained before the first session, if possible, and it should be made clear that a person may withdraw at any time during the work.
- Completion of written consent towards the end is highly recommended. This may cover issues of who may have access to the book, where it will be kept and who is to become its future custodian.
- Respect that the book belongs to the subject person.
- Explain to family members or next of kin, if appropriate, the purpose of the book.
- Seek their cooperation and allay any anxieties.
- If using a template do not use it as a straitjacket but as a flexible guide.
- Agree mutual roles and responsibilities especially concerning the preparation of written materials.

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- Photographs and documents are better copied rather than including originals.
- Never take over tasks the interviewee might wish to do themselves.
- Whenever possible use the person's own words and capture the emotions attached to the memories.
- Be sensitive to the possibility that significant relationships may be complex.
- Some recollections are bound to be sad and they too will require sensitive empathetic listening.
- Respect any information the person does not wish to have included although they may still have benefited by talking about such recollections.
- Try to go beyond mere facts and encourage reflection on the values that have underpinned the person's life.
- Encourage reflection about how the person sees their whole life and reinforce positive achievements.
- Always seek agreement at the end by working through the book and making any requested alterations or deletions.

Remember that writing is a complex process which includes present circumstances, the passage of time, the intensity of emotion associated with the original memories and their recall, the need to adapt the recalled memories so they fit with the person's present ideas about themselves and how they want to be perceived by others. Teaching people to be responsible for their own writing is a more empowering experience for the story teller.

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