Module 4

Meeting the needs of the person with dementia who is distressed

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Introduction

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

Learning Outcomes

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

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

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

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

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

- Is it best to leave you alone?
- Can you think of someone you know who needs to talk it out, or even seeks out other people to make them feel better about something that is bothering them?

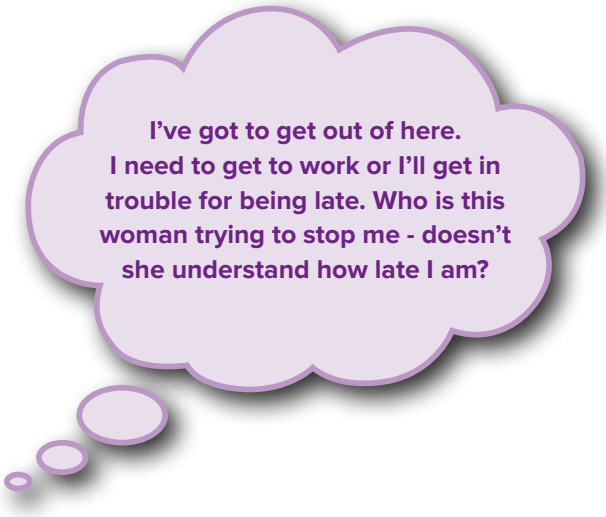
Every person is different in how they respond to experiencing strong emotions.

Now consider someone who has dementia who feels distressed, agitated, angry, or anxious. In Module 1 we explored the difficulties that people with dementia have in communicating and we developed this more in Modules 2 and 3. People with dementia can have difficulties in communicating what has caused their emotions. The way they may act when feeling distressed may be viewed as 'challenging' by other people, including families and carers. It is important for us to understand the causes, triggers, and ways of responding to stress and distress in a person with dementia, as dealing with this poorly can cause further emotional distress for the person and/or cause significant distress for families and carers.

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

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

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



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

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

Using the 'Unmet Need Model' developed by Cohen-Mansfield

Who is Molly?

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

What are Molly's mental or physical health issues?

Alzheimer's disease, depressed, communication difficulties.

What need of Molly's is her behaviour fulfilling?

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

What does Molly need/want?

Meaningful and purposeful activity

What is Molly's environment?

Very sheltered accommodation.

Lives alone in contained flat with carer input.

How does Molly communicate her frustration/concern?

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

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

Tearful/withdrawn/agitated.

Activity

Think of a person with dementia whom you support.

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

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

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

Please ensure that you anonymise any information

Record your answers here:

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

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

People with dementia can express stress and distress in many ways and this can vary between individuals. For one person it may be simply shouting at other people, while for another it may be that they become withdrawn and unresponsive to those around them. For example, Alec who recently moved into a nursing home frequently paces the floor, follows staff around the care home and appears generally agitated.

This can be viewed as Alec experiencing stress or distress, as he only started behaving this way a few weeks ago. When he first moved into the home he was someone who would happily talk to other residents.

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

Activity

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

Please ensure that you anonymise any information

Record you answers here:

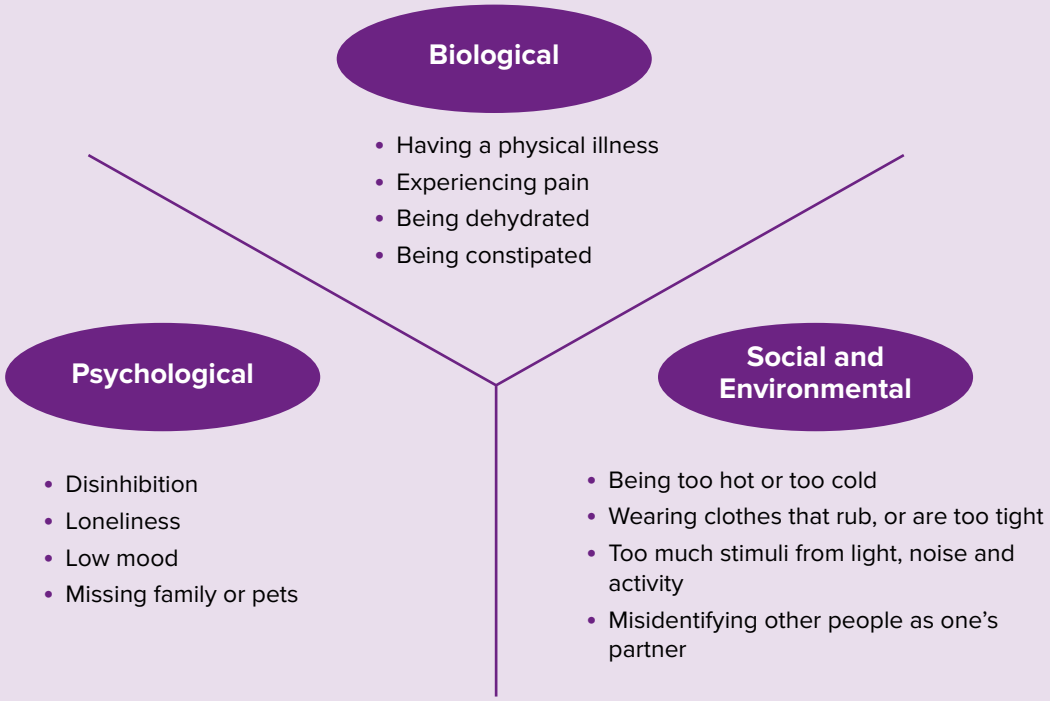
Often there can be more than one behaviour present at any one time.

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

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

Triggers and causes of distressed behaviour

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



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

Remember

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

Sudden onset of distress

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

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

Ellen's Story

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

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

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

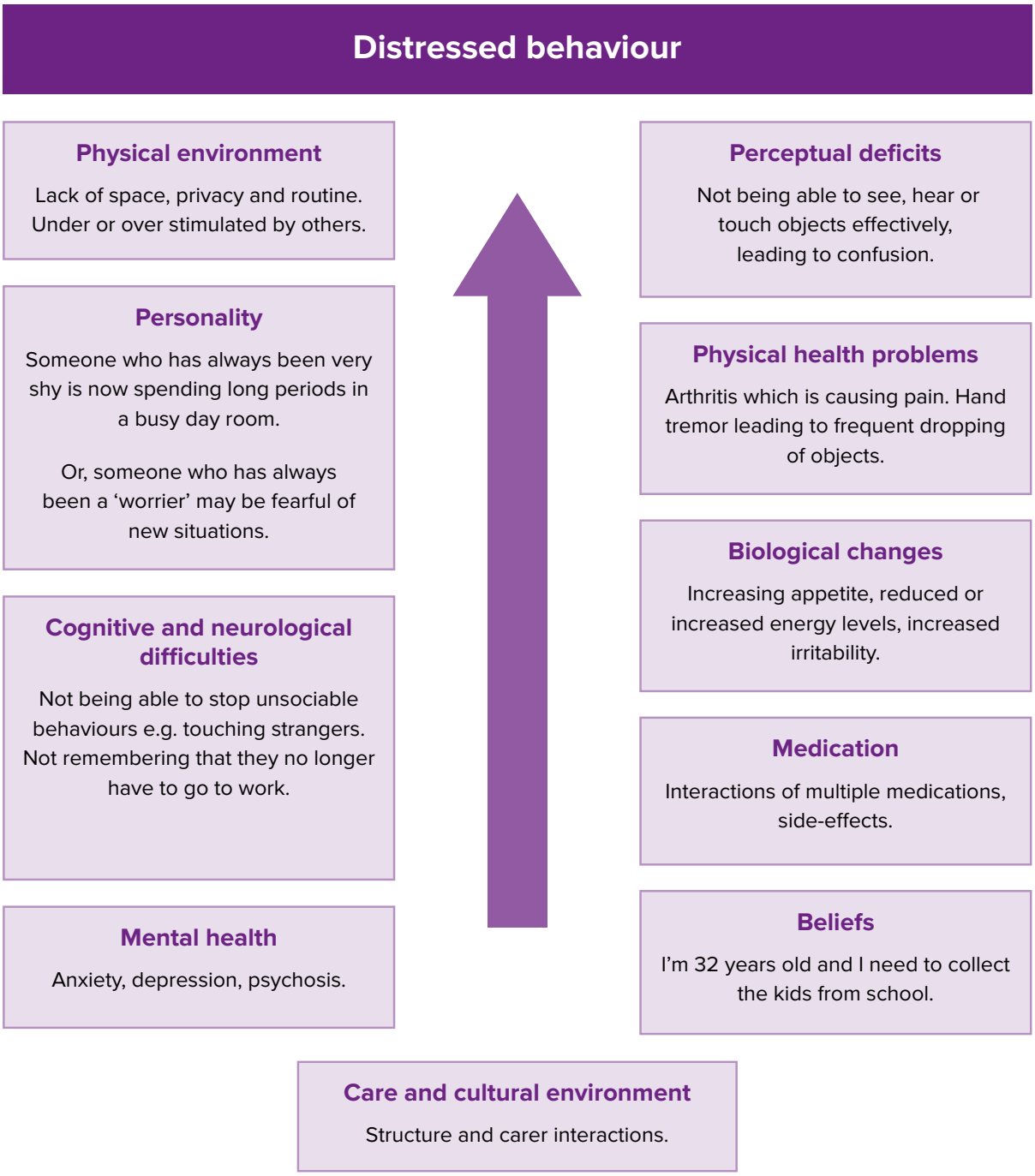
Activity

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

Record your answer here:

Possible causes of distressed behaviour

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



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

Biological

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

Psychological

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

Social and Environmental

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

Activity

Now that you have looked at the previous table answer these questions:

- Do you think any of these factors could be related to Ellen's situation?
- Which factors do you think they could be?
- Can you think of anything that could help Ellen's situation?

Record your answers here:

Reflection

- Have you ever had an experience where you felt that someone was 'being difficult'?
- What are your thoughts about this, having read the information above?
- What impact will this have on your practice?

Please ensure that you anonymise any information

Record your answers here:

Approaches to understanding distressed behaviour

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

What are ABC charts?

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

The ABC chart:

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

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

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

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

Adapted from James, I A (2011)

1. Distressed Behaviour: .....

2. Date and Time	**3. Where was the distress observed?**	**4. Who was there at the time?**
5. What was going on for the person prior to the incident? (A – antecedent)		
6. What did you observe the person do? (B – actual behaviour)		
7. Record what the person said during the incident.		
8. What made the situation better? (C - consequences)		

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

ABC stands for:

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

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

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

How to complete ABC charts

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

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

Consider these questions when completing ABC charts:

1. What is the specific behaviour you are analysing?
   Example answer: Repetitive shouting "Help me! Help me!"

2. What is the date and time?
   Example answer: Monday at 8pm.

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

4. Who was present in the environment? Remember to include yourself.
   - Were there other people before this who had just left?
   - Was the person alone prior to your arrival?

   Example answer: Penny, Iain, and myself.

5. **Completing the As:** How noisy was the environment? Was the temperature hot/cold? How was the lighting? Who else was there? Was someone else distressed? What just happened?
   Example answer: Penny was sitting in the day room watching the television. Iain walked behind her and touched her head. It was warm and quiet in the day room.

6. **Completing the Bs:** What happened? How did the person behave? How often did it occur and how long did it last?
   Example answer: Penny screamed after Iain touched her head and shouted "Help me! Help me!" for approximately 30 minutes.

7. What did the person say at the time of the incident?
   Example answer: "Help me!. Help me!".

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

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

9. How did the person look before the incident in terms of the emotions being experienced? (there are tick boxes in the chart for you to use).
   Example answer: Penny looked frightened, worried, and anxious.

10. How did the person look during the incident in terms of the emotions being experienced? (there are tick boxes in the chart for you to use).
    Example answer: Penny looked frightened, worried and anxious.

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

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

1. Distressed Behaviour: Shouting "Help me, Help me".					
2. Date and Time Monday 12th June at 8pm		**3. Where was the distress observed** In the day room		**4. Who was there at the time?** Iain (resident), Penny, myself (nursing assistant)	
5. What was going on for the person prior to the incident? (A – antecedent) Penny was sitting in the corner of the day room watching television. Iain walked behind her and touched her head. It was warm and quiet in the day room.					
6. What did you observe the person do? (B – actual behaviour) Penny screamed after Iain touched her head and shouted "Help me! Help me!" for approximately 30 minutes.					
7. Record what the person said during the incident. "Help me! Help Me!"					
8. What made the situation better? (C - consequences) Two other staff came to assist, but Penny increased her shouting. Staff left the day room and re-directed Iain away from Penny. I tried to reassure Penny by saying "you're OK now Penny, you're safe" in a soft tone while stroking her hand. I started to talk about the dog she had when she was younger.					
9. What emotion were they expressing before the incident?				**10. What emotion were they expressing during the incident?**	
Angry	☐	Frustrated	☐	Angry	☐	Frustrated	☐
Anxious	☒	Happy	☐	Anxious	☒	Happy	☐
Bored	☐	Irritable	☐	Bored	☐	Irritable	☐
Content	☐	Physically Unwell	☐	Content	☐	Physically Unwell	☐
Depressed	☐	Restless	☐	Depressed	☐	Restless	☐
Despairing	☐	Sad	☐	Despairing	☐	Sad	☐
Frightened	☐	Worried	☒	Frightened	☒	Worried	☒

Why do we have to fill in ABC charts?

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

Activity

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

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

What happens after the ABC charts are completed?

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

Remember

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

Frequency charts

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

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

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

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

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

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

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

Remember

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

Preventing distress

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

Some key issues you should consider are summarised below and you may want to revisit previous modules where many of these issues are explored in more depth.

Always use helpful communication approaches

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

In previous modules we have spent a lot of time exploring communication issues and 'tips'. Remember these simple 'tips' for communicating with people with dementia to reduce the potential that they may experience confusion resulting in distress:

- Avoid jargon.
- Speak calmly using gentle tones.

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

Encourage people's choice and independence and make sure their fundamental care needs are being met

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

These are explained in more detail in earlier modules.

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

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

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

- Always take the time to explain what you are trying to do before beginning a care task. You wouldn't assume you can walk into your friend's house and start moving things about. Treat people with dementia as you would anyone else. Ask them if you can come in, or ask 'is it ok if I help you with that?'
- Ask permission to carry out tasks or to enter their personal space such as a bedroom and give an explanation of what you would like to do. Be prepared to repeat instructions, calmly and clearly. It is also important to make sure people have had time to fully waken up before beginning with tasks such as personal care or medication regimes. Startling someone can lead to a frightened or defensive response.
- Providing appropriate stimulation can be both a preventative measure and a response to distressed behaviour. If someone appears withdrawn, depressed, bored or lonely, why not ask if you can provide personalised activity such as listening to a genre of music they have liked in the past or looking at old photographs they have (stopping if they appear at all distressed).

Remember

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

Standards of Care for Dementia in Scotland (2011)

Responding positively to people with dementia who are communicating distress

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

An example – A person communicating distress by shouting and searching

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

Points to consider:

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

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

How could you best respond?

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

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

An example – A person communicating distress by verbal aggression

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

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

Activity

Now put yourself in a similar situation to Penny.

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

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

Record your answers here:

How could you best respond?

Use good **verbal communication:** Tell the person who you are e.g. "I am Angela, Penny. I come in the mornings to see if you need any help with anything. How are you today?"

- Communicate that you actually know the person and you are not a complete stranger.

- Use their preferred name. Talk to them about their personal interests or experiences, for example Penny may feel more orientated if you said "I saw a painting you might have liked yesterday" or "Tell me about your dogs?", if she is known to have had dogs throughout her life or enjoyed art. If you do not know about the person's interests make this your task!

  Talking about familiar things to the person works by providing a pleasurable distraction and reducing their anxiety by allowing them to relate to something familiar.

- **Use non verbal communication**, for example, direct the person to a photograph with you both in it – by showing a photograph of you both together, this will be a memory prompt or reminder that the person has spent time with you before. It is important to make sure that the person recognises him or herself in the photo in order to avoid increasing or triggering distress.

An example – A person communicating distress by physical aggression

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

Jeannie's thoughts:

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

Points to consider:

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

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

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

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

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

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

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

Points to consider:

- Is Iain trying to leave because he does not recognise this as his home?
- If so, could you place more familiar objects around for him such as pictures of himself with staff and other residents?
- Does this behaviour occur at certain times such as meal times? Is the environment too noisy or overwhelming for him at these times?
- Would he benefit from time in a quiet room for his meals?

How could you best respond?

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

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

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

Peter lives in a care home and tends to touch staff and other residents. He has also been touching his genitals in public areas.

Points to consider:

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

How could you best respond?

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

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

- Are the female residents wearing similar clothes to Peter's wife?
- Do they have similar glasses or hairstyles?
- Does Peter believe he is a young man and is he misinterpreting approaches from staff?
- Would this behaviour reduce if his most frequent contact is with a male staff member?
- If this is an unmet sexual need, can he be directed to a quiet private area where he can fulfil this without upsetting other residents?

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

Other ways that people may communicate distress

Repetitive questioning

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

Distraction

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

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

Repetitive phrases or movements

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

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

Suspicion

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

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

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

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

Pharmacological approaches to distressed behaviour

Medications

A number of medications are prescribed to try to manage distressed behaviours expressed by people with dementia. This is because health professionals are trying to treat what they believe to be the cause of the person's distress. For example, if a person is shouting or screaming at others that only they can see and they are very distressed by this, it is reasonable to think that they are experiencing hallucinations. Therefore, treating the psychosis or hallucination would be desirable, to reduce the distress. Sometimes other behaviours such as aggression, agitation, or mood problems such as anxiety and depression are also treated with prescribed medications, with the aim of reducing the distress associated with these.

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

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

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

Possible side effects of medication

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

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

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

Remember

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

For more detailed information on medications used for treating symptoms of distress, please read **The Pharmaceutical Care of People with Dementia** available on the NES website.

Accessing professional support and interventions to alleviate stress and distress

Remember

Prevention is best!

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

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

If you find that you are at all unsure you should communicate your concerns to your manager or, if you do not have one, approach a relevant professional. The person with dementia may already have a Community Mental Health Nurse, Psychiatrist, or other mental health professional who can assess and intervene, if you need additional support. We all have a responsibility to contribute to prevention of distress in people with dementia.

Remember

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

Standards of Care for Dementia in Scotland (2011)

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

Remember

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

It is important to prevent distress in people with dementia not just for the person in distress, but for their families and carers. Observing someone in distress can result in the carer experiencing stress or distress too. It is important to discuss difficulties managing or coping with stress and distress in people with dementia, for all parties involved.

Carers can be signposted to Alzheimer Scotland and health and social care services for information help and support.

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

Module summary

In this module we have we have explored:

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

Reflective Account

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

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

Please ensure that you anonymise any information

What happened?

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

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

Describe what you did or how you responded.

Describe the outcome of your actions or response.

So what does this mean?

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

Now what will you do in the future

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

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

Action into practice

From your learning in this module

- make a note of 3 new things you have learned about supporting people with dementia who are experiencing stress and distress.
- have a look around your place of work and see if there are any environmental or social issues that could cause people with dementia to experience distress.
- make a note of 3 changes you could make that you feel could enhance your practice.

Make notes of your responses below:

Appendix I

Adapted from James, I A (2011)

1. Distressed Behaviour: Pushing/General Agitation.

2. Date and Time	**3. Where was the distress observed?**	**4. Who was there at the time?**
Friday 11:30am	Ellen's lounge	Daughter Caroline and Lunch Club support worker Leanne

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

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

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

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

7. Record what the person said during the incident.

Ellen shouted "I need to take my tablets".

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

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

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