Open Dementia Programme Printable Notes

Module 6: The emotional impact of dementia

Learning aims

By the end of this module you will:

• be able to describe some of the feelings commonly experienced by people with dementia and their relatives
• recognise responses that can be helpful
• recognise that understanding the perspective of a person with dementia is vital to avoid causing emotional distress
• have a deeper understanding of why our communication must be sensitive to the feelings and needs of people with dementia.

Estimated time required: 20 to 30 minutes

Contents

<table>
<thead>
<tr>
<th></th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Introduction</td>
<td>2</td>
</tr>
<tr>
<td>2 Feelings matter most</td>
<td>3</td>
</tr>
<tr>
<td>3 Responding to feelings</td>
<td>7</td>
</tr>
<tr>
<td>4 How would you feel if...?</td>
<td>11</td>
</tr>
<tr>
<td>5 Self-assessment</td>
<td>17</td>
</tr>
<tr>
<td>6 References</td>
<td>21</td>
</tr>
</tbody>
</table>
Section 1: Introduction

Hello and welcome to this sixth module of the Open Dementia Programme: ‘The emotional impact of dementia’.

It is important to be aware that even though dementia causes many changes in people’s abilities, feelings will be as strong as ever. Indeed, the challenges involved in living with dementia, or with someone who has it, will often cause particularly difficult emotions.

In this module, we will gain a deeper understanding of the feelings that can be involved in living with dementia, and explore ways in which we can support people with these feelings.
Section 2: Feelings matter most

In this section you will:

• learn about some of the common feelings that arise in response to the symptoms of dementia
• gain insights into the emotional reality of relatives and friends of people with dementia
• learn about how, despite the fact that we cannot eliminate the symptoms of dementia, feelings matter most and we can help people experience positive feelings.

Living with dementia can involve many difficult feelings. Frequent experiences of failure can cause frustration and anger. People may feel very anxious if they cannot recognise their surroundings or the people around them. Increasing isolation can result when verbal communication problems impair people’s ability to understand and interact. And some symptoms – such as hallucinations – can be particularly frightening.

While many difficult feelings arise from the experience of the symptoms of dementia, unhelpful responses from other people can make matters a lot worse.

What does it feel like to live with dementia?

Now read these video extracts to hear about some feelings experienced by people with dementia.

David: ‘I make a lot of mistakes, I don't remember things err as I would normally. When I don't sleep enough I can get a bit tetchy. H'mmm, my wife will tell you I get quite annoyed.’

Woman: ‘So what is it that you miss the most since your illness?’
Man: ‘Driving, I miss my driving. I used to really love driving...' Woman: ‘So it’s like, you feel like you've had your independence taken away?’ Man: ‘I feel as if I've had my independence taken away yeh.’

Dr Graham Stokes: ‘A large number of people with dementia are also depressed and so many people think that depression is about crying a lot and looking very upset when that is not severe depression. Severe depression is just sitting in a chair saying nothing, doing nothing. You're so withdrawn and you're now separate from the world around you and sometimes you can just look into a lounge in a care home and you will see 10, 15, 20 people sitting in chairs sitting there saying nothing and doing nothing. That it isn't because their old, that isn't because they have dementia, it's more likely because they are depressed and we just cannot ignore that.’

Please note: any word in blue can be found in the accompanying glossary.
It is common for people living with the difficulties of dementia to experience feelings such as those listed below.

- frustrated
- angry
- anxious
- sad
- depressed
- embarrassed
- frightened
- stupid.

In module 5, you undertook four activities that aimed to help you understand the first-hand experience of some of the common symptoms of dementia.

You may have experienced feelings similar to those often reported by people with dementia themselves, as listed above.

What does it feel like to live with someone who has dementia?

In module 2 we explored the 'whole mess of people' who can be affected by one individual's dementia. Relatives and friends of a person with dementia will often experience difficult feelings too, especially if they are, or have been, involved in caring for the person.

Read each of these video transcripts to hear some of the experiences of people who are close to someone with dementia, then think about the questions below.

Sandra: 'I wouldn't say that I ever felt any guilt about my mother having to go into a home because the situation was one that I couldn't change. It was very difficult to explain to her and I remember I had took her down by car from Cumbria to the home in Hertfordshire and she kept saying, "But Sandra, can't I live with you... but Sandra, I could help to look after the children...", and it was impossible to explain to her that she couldn't even look after herself and her feeling of rejection was very painful.'

Jim: 'Bit by bit everything is stripped away until you have very little of your wife left.'
1. What feelings did you hear these relatives mention?
2. What other feelings do you think relatives of people with dementia can experience?
3. What kinds of support could be most useful to these relatives?

Is it possible to have positive feelings?

While living with dementia is undoubtedly a challenge, it is completely possible for people with dementia to experience positive feelings too. Positive relationships and communication help to enable positive feelings too.

Positive relationships and communication help to enable positive feelings. We can support people to experience a sense of well-being by helping to boost their self-esteem and confidence. This can be done by providing opportunities for people to be occupied in activities that interest them and fuel a sense of purpose.

The two video transcripts that follow provide examples of people with dementia experiencing positive feelings.

Sandra: ‘This is really cheerful isn't it? So that's the prettiest one, do you think that we should take that one?’
Sandra's mum: ‘That's a lovely one!’
Narrator: ‘Sandra regularly takes her mother out to do some of the things that she liked before she developed dementia.’
Sandra: ‘No, that's a brighter colour isn't it?’
Sandra's mum: ‘That difference...’
Sandra: ‘Yes, it's more striking, you're quite right. It's good to get out... really it is quite a small wing and they have to lock it because obviously some of the patients wander. But I think it's very important for her to get some exercise. But, also she needs the stimulation of ordinary life.'
Jerry: ‘But I reckon oddly enough that since we've both been pretty ill we've got a new umm aspect on life.’
John: ‘Understanding of each other…’
Jerry: ‘Well, I've always understood you…’
John: ‘Well, that's true! Yes’ (laughter)
Jerry: ‘Yes, but we've got a new raison d'être (laughter) haven't we?’
John: ‘Yes’
Jerry: ‘And we've got something to fight over and something to fight for... In our support of people with dementia and their carers, we should always bear in mind that although we cannot change many of the difficult realities of people's lives with dementia, we can attend to people's feelings.’

Ultimately, it is the way people feel that governs their quality of life. So we should bear in mind that feelings matter most in our contact with those living with dementia. We can support people to express their difficult feelings and gain relief through doing so. And, very importantly, we can help people to experience positive feelings and achieve a sense of well-being.

For a further exploration, see Sheard (2007).

That brings us to the end of this section. In the next section we will learn more about how we can help people with dementia who are experiencing difficult emotions.
Section 3: Responding to feelings

In this section you will learn:
• how responding to emotions may be more urgent than providing practical assistance
• how listening and empathy are particularly important when problems cannot be 'fixed'
• about responses that can help people who are experiencing feelings of frustration, grief, fear, embarrassment and anxiety.

Since dementia often provokes difficult feelings, it is very important that we respond to them. We may not be able to change the person's situation, but we can help to support them through it.

Even when our role with the person is a practical one, we may find that the person is so upset that they won't accept our assistance unless we first respond to their feelings.

There are sometimes practical solutions to situations that have caused difficult feelings, but many problems cannot be 'fixed' and it will be especially important for the person to feel that someone understands and cares.

‘Please try to make sense of the feelings we are trying to convey... try to understand the meaning of what we intend to say.’
Christine Bryden (2005)

Helpful responses

Now consider the five situations on the following pages and think about the most helpful response that you could give. Different individuals have different needs and preferences so there are no single correct answers, but please read the commentaries that follow.

Situation 1

A person with dementia is frustrated trying to undertake a task that keeps going wrong. Would you:
• take over and do the task for them?
• leave the room?
• ask the person if they would like you to help?
• empathise with the person's frustration?

Please note: any word in blue can be found in the accompanying glossary.
Our commentary
It is important to build up a person's self-esteem by encouraging them to complete a task if they can. However, offering some appropriate assistance with the parts of the task causing most difficulty can help to ease the person's frustration and enable them to complete the task.

It will generally be helpful to express empathy – for example with a phrase like 'It's really annoying, isn't it?' Some people may prefer to be left alone, but this could make a person feel abandoned and people will often feel supported if you stay with them, as long as they feel understood rather than undermined.

Situation 2

A person with dementia is grieving for the loss of her child who died 60 years ago at the age of 2. Would you:

- try to cheer her up and take her mind off it?
- sit with her, listen and offer comfort?
- tell her that she should not be sad as her baby is in heaven?
- explain that this happened 60 years ago and remind her of today's date?

Our commentary
Some painful feelings can last a lifetime and there's no expiry date on grief. Difficult memories can be especially troubling for people with dementia when their past is better remembered and more vivid than the present. People can gain relief from talking about painful memories to someone who listens and shows that they care. Even if the traumatic event happened long ago, the feelings are being experienced now and therefore need to be expressed and acknowledged.

Distraction doesn't make feelings go away and can make people feel isolated. People with a strong faith may gain comfort from this, but our own religious beliefs will not be helpful if the person doesn't share them.

Situation 3

You encounter a person with dementia in the street who appears to be lost, tired and frightened. Would you:

- insist that he accompanies you to the police station?
- keep asking him questions in the hope that he will remember his address?
- ask if you can help and suggest ways of doing this, for example, maybe he has a phone number or address in his pocket, or perhaps he would like you to call the police?
- cross to the other side of the road to avoid him?

Please note: any word in blue can be found in the accompanying glossary.
Our commentary
The experience of getting lost can be a frightening one. When this happens in an environment that the person knows should be familiar to them, they may also feel anxious and angry with themselves.

We will be of most help if we offer assistance in a gentle and calm manner, and try to help the person regain a sense of control. If we help the person feel calmer, they may well be able to think more clearly about possible solutions. On the other hand, pressurising the person with lots of questions may panic them further, and taking over the situation completely can lead to the person feeling disempowered.

Situation 4
A person with dementia has soiled herself and seems very upset and embarrassed. Would you:

• look concerned and say that you're sorry this has happened and you understand she's upset?
• explain that she is dirty and that she must get washed and changed?
• tell her that she should have worn an incontinence pad?
• tell her that there's nothing to worry about and try to coax her into accepting personal care?

Our commentary
When someone has had a continence accident they will have personal care needs with which they may need assistance. However, the person's strong feelings often need to be addressed first, through showing empathy and concern.

Someone who has soiled themselves will often feel embarrassed and upset – these are very understandable emotions and it doesn't help simply to tell the person not to worry, or try to convince them that everything is fine. Moreover, we can make the person feel worse if we feel we are blaming them or treating them as a task rather than as a person with feelings.

Situation 5
A person with early dementia is very aware of his increasing memory problems and is anxious and sad about this. Would you:

• tell him that you know exactly how he feels as your own memory is bad too?
• explain that he shouldn't worry, as things will probably get better?
• listen to him and ask gentle questions to encourage him to express his feelings about his memory problems?
• reassure him that other people have worse problems and at least he is in good physical health?

Please note: any word in blue can be found in the accompanying glossary.
Our commentary

We cannot presume to know exactly how another person feels. Even if we have dementia too, each person's experience is different.

We need to give the person our full attention and try to see things from their point of view, acknowledging their fears and concerns. It is often important for people to feel that they are not alone with their problems, and that someone cares.

We may want to help the person feel better, but telling them not to worry, or to look on the bright side, can often be counter-productive as the person is more likely to feel that you don't understand what they are going through.

The importance of listening well

The exercise you have just undertaken explored a sample of situations causing strong feelings for people with dementia. Each person is an individual and what helps one person will not necessarily help someone else.

We need, therefore, to be guided by the person's responses to our interventions, and learn from them about what they find helpful. It is always important to listen well and try to see things from the person's own point of view. It can be helpful to convey this empathy to the person through voicing our understanding of their feelings (for example, 'I can see you're really upset').

For a further exploration of ways of responding to the feelings of people with dementia see Morton (1999).

That brings us to the end of this section. When you are ready, move to the next section, where we will learn more about our impact on the emotions of people with dementia.
Section 4: How would you feel if…?

In this section you will learn:

- how, in our contact with people with dementia, we can have a major impact on their feelings
- about ways in which we could, without meaning to, cause the person further distress
- about the importance of seeing things from the perspective of the person with dementia
- how we can make our impact a positive one.

In the previous section, we explored some of the ways in which the experience of living with dementia and its symptoms can cause difficult feelings.

But sometimes the difficult feelings that people with dementia experience are responses not to their symptoms but to unhelpful approaches by other people who haven’t taken that person’s difficulties and perspective into account.

Now please move to the next page where you will be asked to consider your own feelings in response to the kinds of situations that can be experienced by people with dementia.

‘Don’t push us into something, because we can't think or speak fast enough to let you know whether we agree. Try to give us time to respond – to let you know whether we really want to do it. Being forced into things makes us upset or aggressive, even fearful.’

Bryden, C (2005)
If it happened to you…

You’re going to be presented with a series of situations. For each try to imagine how you would feel if it happened to you.

**Who the hell are you?**

Picture this: You are asleep in bed at home when suddenly you are woken up by a person you have never seen before, who starts pulling off your nightclothes.

Look at the words below and put a circle around which of these would describe your feelings:

- aroused
- violent
- panicked.

This can be the experience of a person with dementia being given personal care by someone they do not recognise. Perhaps the careworker knows the person, but she has failed to understand that the person with dementia does not remember her. The person may act upon these strong feelings and hit the careworker. This would be an understandable reaction as they attempt to defend themselves from perceived attack.

In order to avoid this kind of situation, it is important to:

- introduce yourself
- explain clearly what you want to do
- ensure that the person understands and agrees to your help before you make any physical contact.

**Failing an exam**

Picture this: you've just learnt that you've failed an important exam.

Look at the words below and put a circle around which of these would describe your feelings if you failed an exam:

- frustrated
- angry
- depressed
- want to leave
- panic
- stupid
- sad
- anxious

Please note: any word in blue can be found in the accompanying glossary.
How might we avoid a person with dementia feeling this way? People with dementia frequently get asked questions they can't answer – questions that test their failing memory and highlight their difficulties.

Asking a person, 'Do you remember what we did yesterday?', 'Do you remember my name', or 'Do you recognise this photo?' can generate the same kind of feelings we would experience in an exam where we were unable to answer any of the questions.

Instead of stressing the person with difficult questions, we need to:
• provide the information that people need
• build conversations that focus on the person's abilities rather than their difficulties.

**How dare you?**

Picture this: You open your front door to someone you know slightly who tells you that it's time you had a bath.

Look at the words below and put a circle around which of these would describe your feelings:
• shocked
• embarrassed
• angry
• outraged
• indignant
• offended
• insulted
• worried.

Care work often involves a number of tasks, but focusing solely on the task and forgetting about the person's need for communication, dignity and privacy can be very undermining.

The person may well act upon these strong feelings by rejecting their carer, which would be another understandable reaction.

We need always to:
• consider the person's psychological needs as well as their care needs
• ensure that our approach is respectful and discreet.
**Everything isn't fine!**

Picture this: You are feeling really angry about something, but nobody around you will take your grievance seriously and they keep telling you that everything is fine.

Look at the words below and put a circle around which of these would describe your feelings:
- more angry
- depressed
- frustrated
- misunderstood
- lonely
- self-doubt
- rejected
- violent.

As we saw in the previous section, there are many reasons why people with dementia experience difficult feelings such as anger.

Although we may wish to give reassurance, it is important that we do not offer platitudes like, 'Don't worry, everything's fine', as these will only serve to make the person feel isolated and perhaps angrier.

The person's verbal communication difficulties might make it hard for them to explain the cause of their feelings, but we should:
- pay close attention to their body language and facial expression
- ensure that we take feelings seriously and act on the person's concerns.

**I don't speak your language**

Someone approaches you in the street and starts speaking rapidly in a foreign language. You tell them that you don't understand, but they keep on repeating themselves, getting louder and louder.

Look at the words below and put a circle around which of these would describe your feelings:
- angry
- confused
- impatient
- worried
- frustrated
- upset
- threatened
- concerned.

Please note: any word in blue can be found in the accompanying glossary.
When verbal communication difficulties are affected by dementia, a person may find it very difficult to understand us. It can seem as if we are speaking a completely different language.

Our own non-verbal communication will be particularly important in helping the person to understand our message.

Often, people still retain some ability to understand and we can help them by:
- speaking clearly, slowly and calmly
- using familiar phrases
- only making one point at a time.

Helpful communication approaches are explored further in the final module, number 7.

None of these situations were everyday experiences for us but, unfortunately, they can be for many people with dementia. The way we interact with people has a major impact and we need to be careful not to cause distress or anger because we haven't understood how things seem from the person's perspective.

If we pay close attention to the person's responses, we can gain insight into their reality and find ways of communicating that address this.

This may involve, for instance, providing explanations; ensuring that people feel in control; focusing on abilities rather than difficulties, and always taking feelings seriously.
Good practice examples

Now read through these two video extracts. Notice how the staff take into account the feelings and needs of each person.

Care home staff worker: ‘Yes, it’s really important that we do get the hearing right on a resident because obviously if we can’t communicate with them they can’t communicate back. Then you get frustration will build up where they’re trying to express what the problem is.’

[Cut away to staff member looking at a patient’s hearing aid.]

‘Right how’s that…? ’

‘If you haven’t got the hearing right, you know, the communication just isn’t good. So it is quite important to get it checked regularly.’

Second care home staff worker: ‘Sometimes residents get upset and when we come along we don’t know what the reason is. The best thing to do is find out what it is that their upset about and have a word with them to comfort them and make them feel comfortable, instead of going against what they believe. When they get upset to them it is always for a good enough reason, to them it is real.’

Older lady in white shirt, pink cardigan: ‘Di di di do do do do di di di do do. It’s wonderful, he, he he , ha ha ha ha. Can we sit down minute please?’

Carer: ‘Yes come on then, you want to go in doors?’

Older lady in white shirt, pink cardigan: ‘It’s cold.’

That brings us to the end of this module. In this module, we have thought about the feelings of people with dementia and their relatives, and our own role in addressing these. We have also considered the emotional impact of some unhelpful communication approaches.

Below is a summary of the key points from the module:

- People with dementia are still capable of experiencing a wide range of feelings.
- Difficult feelings can result from the experience of living with dementia.
- Relatives and friends of people with dementia may also experience difficult emotions.
- Listening and empathy are important for people experiencing strong emotions; some forms of practical support can also help to address emotional needs.
- Unhelpful approaches are those that fail to take the person’s difficulties and perspective into account, such approaches can cause emotional distress.

Before you move on to the seventh module of the programme, where we will look in more detail at communication, why don’t you take our self-assessment quiz, which will allow you to test your understanding of some of the key points?

Please note: any word in blue can be found in the accompanying glossary.
Section 5: Self-assessment

This self-assessment will allow you to test your understanding of some key messages and facts covered in this module. Choose between true and false for each question. You will then see the right answers and some feedback on page 19, and where to look in this module to review.

**Question 1**

<table>
<thead>
<tr>
<th>Dementia causes an inability to experience a full range of feelings.</th>
</tr>
</thead>
<tbody>
<tr>
<td>True</td>
</tr>
<tr>
<td>False</td>
</tr>
</tbody>
</table>

**Question 2**

<table>
<thead>
<tr>
<th>Relatives and friends of a person with dementia can experience feelings of loss.</th>
</tr>
</thead>
<tbody>
<tr>
<td>True</td>
</tr>
<tr>
<td>False</td>
</tr>
</tbody>
</table>

**Question 3**

<table>
<thead>
<tr>
<th>People with dementia will inevitably feel depressed and angry.</th>
</tr>
</thead>
<tbody>
<tr>
<td>True</td>
</tr>
<tr>
<td>False</td>
</tr>
</tbody>
</table>

**Question 4**

<table>
<thead>
<tr>
<th>The emotional needs of a person with dementia are sometimes more important than their practical needs.</th>
</tr>
</thead>
<tbody>
<tr>
<td>True</td>
</tr>
<tr>
<td>False</td>
</tr>
</tbody>
</table>

**Question 5**

<table>
<thead>
<tr>
<th>When we can't find a solution to a problem experienced by a person with dementia, there is nothing we can do to help them.</th>
</tr>
</thead>
<tbody>
<tr>
<td>True</td>
</tr>
<tr>
<td>False</td>
</tr>
</tbody>
</table>

Please note: any word in blue can be found in the accompanying glossary.
### Question 6

When a person with dementia is struggling with a task and getting frustrated, it will generally be best to take over and do the task for them.

<table>
<thead>
<tr>
<th>True</th>
<th>False</th>
</tr>
</thead>
</table>

### Question 7

When a person with dementia is upset we should try to take their mind off it and cheer them up.

<table>
<thead>
<tr>
<th>True</th>
<th>False</th>
</tr>
</thead>
</table>

### Question 8

An insensitive approach can often cause further distress to a person with dementia.

<table>
<thead>
<tr>
<th>True</th>
<th>False</th>
</tr>
</thead>
</table>

### Question 9

To avoid causing a person with dementia to experience difficult feelings we need to see things from their perspective.

<table>
<thead>
<tr>
<th>True</th>
<th>False</th>
</tr>
</thead>
</table>

### Question 10

Aggressive responses from a person with dementia can often result from a lack of clear explanations.

<table>
<thead>
<tr>
<th>True</th>
<th>False</th>
</tr>
</thead>
</table>

Please note: any word in blue can be found in the accompanying glossary.
Answers

1. The correct answer is ‘false’. Dementia does not affect a person's capacity to experience a full range of feelings. In fact, the experience of living with dementia often causes many strong feelings.

2. The correct answer is ‘true’. Many relatives and friends of people with dementia feel a sense of loss for the person's previous abilities and the aspects of the relationship that have changed because of the decline in that person's abilities.

3. The correct answer is ‘false’. Many factors influence the way people feel, and when people with dementia have good relationships and stimulating ways of spending their time, they will often experience positive feelings.

4. The correct answer is ‘true’. People's emotional needs are often urgent and these may need to be addressed before the person will be able to accept practical assistance.

5. The correct answer is ‘false’. Many problems can't be solved, but we can be of great help by showing the person that we understand and care about what they are going through. You can review this in Section 3, 'Responding to feelings', where we cover this point.

6. The correct answer is ‘false’. We may be able to ease the person's frustration by providing some assistance and showing empathy, but if we take over the task completely we can cause damage to the person's self-esteem. You can review this in Section 3, 'Responding to feelings', where we cover this point.

7. The correct answer is ‘false’. If a person with dementia does not feel that we empathise with their feelings, they will often feel more upset and isolated. You can review this in Section 3, 'Responding to feelings', where we cover this point.

8. The correct answer is ‘true’. The way we communicate with a person with dementia has a major impact on their feelings. You can review this in Section 3, 'Responding to feelings', where we cover this point.

9. The correct answer is ‘true’. If we understand how things seem from the person's perspective we can often adapt our approach to avoid causing difficult feelings. You can review this in Section 4, 'How would you feel if...?’, where we cover this point.

Please note: any word in blue can be found in the accompanying glossary.
10. The correct answer is ‘true’. The memory and comprehension problems experienced in dementia mean that people can easily misunderstand our intentions and actions, feel threatened, and therefore respond aggressively in self-defence. Giving clear explanations, and repeating information as necessary, helps to avoid a person feeling threatened by our interventions. You can review this in Section 4, 'How would you feel if...?', where we cover this point.
Section 6: References

