Open Dementia Programme Printable Notes

Module 7: Positive communication

Learning aims

By the end of this module you will:
• recognise factors that can impact on successful communication
• have learnt some new communication techniques that you can use to help people with dementia to express themselves and understand what we are saying
• have a better understanding of how to respond when a person with dementia is expressing a different reality
• understand how to avoid causing distressing situations by recognising and responding to clues about the needs of the person with dementia.

Estimated time required: 20 to 30 minutes

Contents

| 1 Introduction                                      | 2 |
| 2 Communication: a two-way process part 1         | 3 |
| 3 Communication: a two-way process part 2         | 8 |
| 4 Understanding and responding to a different reality | 12 |
| 5 Detective work                                    | 22 |
| 6 Self-assessment                                   | 28 |
| 7 References                                        | 32 |
Section 1: Introduction

Hello and welcome to the seventh and final module of the Open Dementia Programme.

In whatever context you come into contact with people with dementia, you will be communicating with them. In this module, we look at some of the difficulties that can arise, and how to overcome them.

We also consider the importance of looking beneath the surface to identify the person’s needs, particularly when their communication is challenging for us.
Section 2: Communication – a two-way process part 1

In this section you will:

- assess the way we express ourselves and how this can be a help or hindrance to positive communication with people with dementia
- learn how the dementia itself can affect a person’s understanding of our message
- look at how much or how little of our message might be understood by a person with dementia
- consider how other factors can impede communication with some people with dementia
- acquire some basic tips to help a person with dementia to understand your message.

Communication is essential for all human beings. Connecting with other people helps to maintain our quality of life and even our own sense of identity.

But as dementia progresses, verbal communication abilities will often be affected. This can cause isolation, misunderstandings and a great deal of frustration.

If you saw two people arguing and looking frustrated, how could you tell if either one suffered from dementia? Actually, either one of the two could have dementia. Not being able to understand someone else is a frustrating experience, whether or not you have dementia. And not being able to make yourself understood is equally frustrating.

Now we will look at some of the factors that can get in the way when a person with dementia tries to understand what others are saying. The first thing we need to consider is our own communication approach.

Have we been as clear as possible?

Is our attitude friendly and helpful?

It’s very important to think about how we communicate with people with dementia to ensure we do not create any additional problems.
Different communication styles

Imagine you are lost and approach various people for directions.

Read how each person below responds and rate their communication on a scale from one to five: give ‘five’ if you think they’re helpful, clear, friendly and supportive down to ‘one’ if they sound unhelpful, patronising, overbearing and unclear.

First person: ‘You wanna go kitty-corner from the Carphone Warehouse, left after All Saints, follow Cedars Avenue down to the far end and then hang a right.’

How do you rate this communication style?

Second person: ‘Oh no, are you lost again? Don’t you know where you are?’

How do you rate this communication style?

Third person: ‘Turn left at the church. Go down to the end of that road and then turn right.’

How do you rate this communication style?

Fourth person: ‘What you want to do is go right down to the church and then go left, or is it right ... wait a minute, no it’s left, and by the way, have you met the vicar? He’s my wife’s second cousin. Anyway ...’

How do you rate this communication style?

Fifth person: ‘No, don’t go there! You have to come with me ...’

How do you rate this communication style?

Over to you!

1. What was the most helpful response, and why?
2. What did you find unhelpful about other responses?
3. How did you feel when you were asked whether you were ‘lost again’?
4. Would you have been prepared to cooperate with the stranger who told you to ‘come with me’?

Please note: any word in blue can be found in the accompanying glossary.
How things sound to a person with dementia

The examples above illustrated that sometimes it is the way others communicate that makes it difficult for a person with dementia to understand. But, of course, dementia itself can also cause problems with understanding.

Even when our own communication is clear and helpful, a person with dementia might still struggle to understand us (receptive communication difficulties). This is because dementia can affect the areas of the brain that deal with understanding words.

You probably found some of these characters’ responses unhelpful before, but read how all of them might come across to a person with dementia.

<table>
<thead>
<tr>
<th>First person</th>
<th>What they said: ‘You wanna go kitty-corner from the Carphone Warehouse, left after All Saints, follow Cedars Avenue down to the far end and then hang a right.’</th>
<th>How it sounded: ‘You bleah blah bleah blah from duhh duhh drmm follow dwbb dwbb hang ... hanging ... swinging.’</th>
</tr>
</thead>
<tbody>
<tr>
<td>Second person</td>
<td>What they said: ‘Oh no, are you lost again? Don’t you know where you are?’</td>
<td>How it sounded: &quot;Lost ... lost ... lost ...&quot;</td>
</tr>
<tr>
<td>Third person</td>
<td>What they said: ‘Turn left at the church. Go down to the end of that road and then turn right.’</td>
<td>How it sounded: ‘Turn ... The church ... turn right.’</td>
</tr>
<tr>
<td>Fourth person</td>
<td>What they said: ‘What you want to do is go right down to the church and then go left, or is it right ... wait a minute, no it’s left, and by the way, have you met the vicar? He’s my wife’s second cousin. Anyway ...’</td>
<td>How it sounded: ‘Right down, left down, right, left, right left rightleftleftleftleft, vicar ...’</td>
</tr>
<tr>
<td>Fifth person</td>
<td>What they said: ‘No, don’t go there! You have to come with me...’</td>
<td>How it sounded: ‘This stranger’s trying to take me, this stranger’s trying to take me...’</td>
</tr>
</tbody>
</table>

Please note: any word in blue can be found in the accompanying glossary.
A person with dementia might not understand the meaning of our words. Sometimes it can seem as if we are speaking in an unintelligible language.

Unfamiliar accents and/or words can be particularly hard to understand. Memory and attention problems may cause parts of our communication to be lost, and people may forget the beginning of our sentence by the time we reach the end.

Background noise and other distractions will cause further problems, and if a person is unsure of who we are, or whether they can trust us, they are unlikely to comprehend what we are saying.

In communicating with people with dementia it is also important to be aware of any other factors that might block their ability to understand.

For example, imagine the frustration of people with dementia who have hearing impairments too, which prevent them from understanding what others are saying.

**Positive communication tips**

Since people with dementia may struggle to understand, we need to be particularly careful about how we communicate. We should:

- demonstrate kindness and respect through our non-verbal communication
- use gestures and visual prompts wherever possible
- take our time, speaking clearly and slowly
- try to make only one point at a time; pay attention to the person’s responses and simplify things further if we need to
- do what we can to address any sensory impairments, such as checking that a hearing aid is working properly, or that glasses are clean
- be at the same physical level as the person with dementia, using eye contact and touch if appropriate to the individual
- use language and phrases that are familiar to the individual
- repeat and/or rephrase as necessary and ensure that the person has enough time to process what we’ve said.

When we communicate well with a person with dementia we give the person the best chance of understanding us, despite their disability.
Good practice example

Read the scenario below for an example of positive communication. Here, the staff member is taking her time, making use of visual prompts, paying attention to the responses from the person with dementia and simplifying her communication accordingly.

Carer: 'Would you like orange juice or would you like cranberry or water?'
Narrator: 'George has been offered a choice of three drinks.'
Carer: 'That’s a good song, would you like orange juice George or would you like cranberry?'
Narrator: 'Lucy narrows it down to a choice of two, perhaps this will be easier for George.'
Carer: 'Would you like orange juice George?'
Narrator: 'Lucy makes it more simple and shows George the jug.'
Carer: 'Would you like orange juice George?'
George: 'Yes.'
Lucy: 'Okay.'

This brings us to the end of this section where we have considered how to help people with dementia to understand us. In the next section we will focus on how to help people with dementia make themselves understood.
Section 3: Communication – a two-way process part 2

In this section you will:

• explore the challenges faced by a person with dementia trying to make their own message understood
• look at, and listen to, some of the language people with dementia might use
• learn how the dementia itself can affect the way people express themselves
• be aware of the importance of non-verbal clues in comprehending the message of a person with dementia
• acquire some key tips that will enable you to better understand what a person with dementia may be trying to say to you.

As we saw in the previous section, trying to understand other people can be a problem for people with dementia. But often it is an even greater challenge for the person with dementia to get their own message across in a way that others can understand (expressive communication difficulties).

Explaining communication difficulties

Look at the boxes below: each one has examples of communication problems that can occur and explanations of why this can happen.

In each example, a man with dementia is trying to explain that he has bad pains in his chest and feels short of breath.

‘Spnnn, isstra ... mmnmnmn insstra ...’

Explanation
When the temporal and frontal lobes of the brain are badly damaged through dementia, a person can eventually lose all verbal language, though it is important to be aware that their non-verbal communication abilities remain intact.

‘I have a bad pint ... it’s a bad pint – here.’

Explanation
When the correct word is not immediately accessible, a person may inadvertently select the wrong word (often one that is similar in sound to the word that is needed). Here, the person has substituted ‘pint’ for ‘pain’.

Please note: any word in blue can be found in the accompanying glossary.
‘It hurts in my chest and I can’t ... I can’t ... properly.’

*Explanation*
People with dementia can struggle to find the word they need to express their meaning. In this example, the person cannot access the word for ‘breathe’.

‘Man skauda mano krūtin÷s ir jausti trumpas kv÷pavimas’

*Explanation*
People with dementia who learnt English as a second language might lose much of it and begin to communicate again in the language of their country of origin. In this example, the person has reverted to Lithuanian.

‘It really hurts here and ... there was ... two people arguing ...’

*Explanation*
A person with dementia may struggle to remember what they are trying to say – in this example, the person has become distracted by something that’s going on nearby, maybe on the TV.

‘It hurts in my chest, in my chest, in my chest, in my chest ...’

*Explanation*
Dementia can cause a symptom known as ‘perseveration’. This involves the person getting ‘stuck’ on what they are saying or doing. In this example, the person is unable to control his repetition of the phrase ‘in my chest’.

‘It’s burning, bursting into flames, I’m stuck on one side and I can’t pull the air through.’

*Explanation*
When a person with dementia cannot access the usual words to express their message, they will often seek to express their meaning through more descriptive language. In this example, the person has found a unique way of describing the sensations he is experiencing, with highly vivid and meaningful language.

Verbal communication can become increasingly difficult for people with dementia. But through our own careful listening, observation and knowledge of the individual, it is often possible to grasp the person’s meaning.
Over to you!

1. How much of each speech attempt would you have understood?
2. How would you feel on hearing each of these attempts at communication?
3. What would help you better understand each communication attempt?
When verbal communication is difficult

As dementia progresses, a person with dementia may have increasing difficulties expressing themselves in words. Here are some examples of things a person with dementia who has problems with verbal communication might say:

| Person 1: ‘Knock an knock an knock a bag out and Oooo Oooooo’ |
| Person 2: ‘Arrrrrah arrrrrah Arrrrrah arrrrrah Arrrrrah arrrrrah’ |

How can we make sense of these pieces of communication? Knowing the person as an individual will help greatly – for instance, we can build up knowledge of the phrases a person uses to indicate particular meanings (as in the way that the phrase ‘spend a penny’ used above means ‘use the toilet’).

Despite the fact that it is hard to understand the precise meaning of many of the words and sounds that are used, there are many clues – including facial expression, tone of voice, key phrases and gestures – that indicate vital information about the person’s feelings and needs.

Since communication is so important to human beings, we need to be aware that the person with dementia is doing their best to get their message across. We cannot take away the difficulties caused by dementia, but we can help people to express themselves by:

- listening very carefully and showing the person, through our verbal and non-verbal responses, that we are listening and we have time for them
- observing everything the person is communicating non-verbally
- avoiding assumptions but asking the person to confirm if we’re right about any guesses we make about what they are trying to say
- knowing the person as an individual, including what’s important to them and key phrases that they use to indicate particular meanings
- encouraging the person to take their time, to show us what they mean if they can’t find the words (e.g. through pointing), and to express themselves in their own way.

For some useful further reading on communication, see *Communication and the care of people with dementia* (Killick and Allen, 2001).

That brings us to the end of this section. In the first two sections we have looked at the two way nature of communication. When you are ready, move to the next section where we look at communicating with people experiencing a different reality.

Please note: any word in blue can be found in the accompanying glossary.
Section 4: Understanding and responding to a different reality

In this section you will:
- realise that ‘reality’ to a person with dementia might be different to our own reality
- recognise that we often need to enter the reality of the person with dementia
- understand that what a person with dementia expresses about their reality will often indicate key feelings and needs
- understand that it is to these feelings and needs that we should respond
- realise that telling the truth and lying are often unhelpful responses that fail to address the needs of a person with dementia who is experiencing a different reality.

‘For people with dementia our behaviour is normal, considering what is happening inside our heads. Try to enter our distorted reality, because if you make us fit in with your reality, it will cause us extra stress.’

In Module 5, we saw that people with dementia will often retain memories of the past, even though they may not be able to hold on to information relating to the present day. This means that the past will often be much more vivid than the present, and so will often seem more real.

Emily and Steve: choosing better ways of communicating

In this exercise that follows we look at Emily and Steve and the communication styles they use. Picture Emily and Steve: an elderly couple, sitting together in the same room, yet separated by decades. In order to reach Emily, Steve will need to be prepared to travel in time to understand Emily’s reality.

The story begins with Emily saying: ‘I’m frightened. I’m sure there’s going to be another air raid and Mum isn’t here to keep me safe. Dad seems really annoyed with me.’

Meanwhile, Steve says: ‘I’m shattered. She keeps asking for her mum. What can I tell her? I wish she’d settle down. I just want to relax and watch Match of the Day.’
Memories of past times that involved strong emotions (such as Emily’s love for her mother, or her wartime experiences) are often the strongest memories, and so are most vivid in the present time.

It can be difficult to know how to respond to a person with dementia when they believe that something from long ago is happening now, or that someone who has died is still alive. But, as we mentioned in Module 6, it is feelings that matter most. Rather than trying to correct a mistaken ‘reality’, it is often more helpful to recognise and respond to these feelings.

It is important to understand that the things that people with dementia say and do give us lots of information about their needs. In a way, there is a coded message conveyed through a person’s mistaken beliefs about reality. It’s up to us to work out what the message is. The better we know the person, the easier it is to understand their message.

We may be tempted to confront the person with the truth, or to lie to them, but such responses can do more harm than good.

Our commentary:
If someone asks for their mum, they probably need something that a mum used to provide. It might be that they are feeling unwell and their mum used to look after them. It might be that they are feeling lonely and unloved. And, of course, their mum used to address those needs when they were younger. So it’s often more helpful if we go beneath the surface of what the person is literally saying and think not ‘Do I tell the truth or do I tell a lie?’ but what’s more important here, the facts or the feelings?

Please note: any word in blue can be found in the accompanying glossary.
Emily and Steve’s conversation continues: part 1

In the next exercise, you will guide Steve to address the feelings and needs that Emily is conveying through her ‘reality’. Emily is feeling frightened and is asking for her mum because she needs someone to help her feel safe.

How do you think Steve could respond best to Emily, bearing in mind that she is feeling frightened and in need of comfort? We give you three choices: select which one you think provides the best response.

Remember, our story begins with Emily saying: ‘I’m frightened – I’m sure there’s going to be another air raid and Mum isn’t here to keep me safe. Dad seems very annoyed with me.’

Now, what do you think is the best way for Steve to respond …?

1. ‘Your mum’s been dead for more than 30 years.’
   
or

2. ‘It’s OK Emily, I’m here, I’ll keep you safe.’
   
or

3. ‘Don’t worry – she’ll be home soon.’

On the next page, you will see our commentary on each of these responses, and our suggestion as to which is the best.

Please note: any word in blue can be found in the accompanying glossary.
1. ‘Your mum’s been dead for more than 30 years.’

Our commentary:
Confronting Emily with the truth is unlikely to bring any benefits. It may seem to Emily that this is the first time she has heard her that mum has died and she will be plunged into intense feelings of grief. Alternatively, Emily may vehemently deny the possibility that her mum has died, and become angry with Steve.

2. ‘It’s OK Emily – I’m here – I’ll keep you safe.’

Our commentary:
This is the best response. Steve is showing empathy with Emily’s feelings, and this will help her feel that she is understood and is not alone. Emily might gain sufficient comfort from Steve offering the safety that she needs.

3. ‘Don’t worry – she’ll be home soon.’

Our commentary:
Lying to Emily may bring her temporary relief. If she believes that her mum will be home soon, she will look forward to the comfort she will get then. But Emily’s expectations will not be fulfilled. Although she may feel better for a short while, Emily is likely to feel more distressed later when her mum doesn’t return. Even though she may not remember Steve’s lie, her feelings of longing for her mum will have been heightened. And if she does remember that Steve has lied to her, she may feel that he has betrayed her.

On the next page, you’ll see how the conversation between Emily and Steve continues.
Emily and Steve’s conversation continues, part 2

But maybe there is a more specific reason why she is asking for her mum, which Steve has not yet addressed?

Emily says next: ‘But will Mum be coming soon?’

Again, we give you three choices: select which one you think provides the best response.

1. ‘Come on Emily, you’re 89 years old ... how old would your mum be if she were still alive?’

or

2. ‘Yes, she’ll be here soon.’

or

3. ‘What would Mum do, Emily? What do you need from Mum?’

On the next page, you will see our commentary on each of these responses, and our suggestion as to which is the best.
1. ‘Come on Emily, you’re 89 years old ... how old would your mum be if she were still alive?’

Our commentary: Even if Emily is able to work out for herself that her mum is dead, this will not help – she is asking for her mum for a reason, and the information that her mum is dead will cause further distress, rather than meeting her current needs. Moreover, the nature of the short-term memory problems occurring in dementia mean that however many times Emily discovers the truth, she will not be able to retain it. She may remember the distress she has felt, but not the information about her mum’s death that caused her to feel this way.

2. ‘Yes, she’ll be here soon.’

Our commentary:
Emily has strong feelings that have led her to ask for her mum. Crucially, she feels frightened and needs comfort. Steve is denying her this comfort by fobbing her off with a lie. Her needs will go unmet. And because her needs will not be met, Emily is likely to carry on asking when her mum will be home.

3. ‘What would Mum do, Emily? What do you need from Mum?’

Our commentary:
Yes this would be the best response.

On the next page, you’ll see how the conversation between Emily and Steve continues.
Emily and Steve’s conversation continues: part 3

Emily says next: ‘She’ll pull the curtains … the blackout curtains …’

Steve has helped Emily express the specific need that led her to ask for her mum. Now he can try to meet this need.

Again, we give you three choices: select which one you think provides the best response for Steve to give.

1. ‘This is the 21st century – we don’t need blackout curtains!’
   or

2. ‘I’ll pull the curtains – we won’t even let a crack of light escape.’
   or

3. ‘OK, Mum can draw the curtains. There are lots of bombers out tonight.’

Look on the next page to see our commentary on each of these responses, and our suggestion as to which is the best.
1. Steve’s response: ‘This is the 21st century – we don’t need blackout curtains!’

Our commentary:
Emily’s reality feels just as real to her as Steve’s reality is to him. It serves no purpose to try to convince Emily that she is wrong. Emily is unlikely to be able to ‘time-travel’ into the present day, since her dementia has caused disorientation in time. If Steve does manage to persuade Emily that she is wrong, she could experience feelings of humiliation and failure. It will be much easier, and more helpful, for Steve to understand and enter Emily’s reality.

2. ‘OK, Mum can draw the curtains. There are lots of bombers out tonight.’

Our commentary:
Steve has understood that Emily believes it to be wartime. But by adding to her reality (‘there are lots of bombers out tonight’) he could cause her further, unnecessary fear. It is important to acknowledge what the person with dementia believes to be real, but it is not helpful to add a new dimension to it. Even though Emily’s facts may be incorrect, her feelings are completely real and true, and it is these feelings that need a response.

3. Steve’s best response: ‘I’ll pull the curtains – we won’t even let a crack of light escape.’

Our commentary:
‘I’ll pull the curtains – I’ll make sure that we don’t even let a crack of light escape.’

By avoiding confronting Emily with the truth, or telling her lies, Steve has addressed the feelings and needs that led Emily to ask for her mum in the first place. He offered tenderness and comfort to ease Emily’s fears.

He took her concerns seriously and recognised that he needed to pay attention to Emily’s reality, since he would not have succeeded in convincing her of his own reality. Now that Emily is feeling better, Steve will probably be able to watch that football match!

Over to you!

1. Why do you think that Steve’s responses helped Emily to feel better?
2. What problems could Steve have created if he had insisted on telling Emily the truth?
3. What problems could Steve have created if he had lied to Emily?

Please note: any word in blue can be found in the accompanying glossary.
There is no single response that will help a person who is experiencing a different reality. It depends on the individual, the situation, and your own role in relation to the person with dementia.

The important thing is to recognise that the person’s ‘reality’ provides important information about their feelings and needs. It may be that you can do something to meet these needs – as Steve did for Emily.

Your discoveries about the person’s needs will also help you identify longer-term strategies for ongoing work with the person.
When words disguise needs

The boxes below reveal the fundamental emotional and psychological needs that may lie behind some of the words often expressed by people with dementia.

<table>
<thead>
<tr>
<th>When a person with dementia says...</th>
<th>They may be expressing...</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘I want my mother.’</td>
<td>…a need for love and comfort, like that received from a mother or someone else with whom the person felt safe.</td>
</tr>
<tr>
<td>‘I’ve got to go to work.’</td>
<td>…the need for a purpose and fulfilment of a person who still wishes to have an impact on the world around them.</td>
</tr>
<tr>
<td>‘I want to go home.’</td>
<td>…a need for privacy, security and comfort.</td>
</tr>
</tbody>
</table>

If your role involves caring or supporting the person with dementia, addressing feelings and needs is a key part of this. The person’s mistaken beliefs about reality can give you vital information about their feelings and needs, which will help you do your job well.

If you are only with the person for a short time and your role does not involve providing care, it is still very important that you respect their reality, respond with empathy, and ensure that you don’t make matters worse. Let the person take the lead and ask them what you can do to help.

That brings us to the end of this section. When you are ready, move to the next section where we will see how people with dementia also communicate through their behaviour.

Please note: any word in blue can be found in the accompanying glossary.
Section 5: Detective work

In this section you will learn how:

- recognise the importance of understanding and responding to non-verbal communication
- examine the importance of gathering, sharing and using information about people with dementia to better engage with them
- learn that so-called aggressive or challenging behaviour is usually an attempt to communicate
- give further consideration to the feelings of people with dementia in situations that are challenging to them
- learn that, often, the biggest problem for people with dementia is other people.

As you have seen there can be many barriers to good communication. To prevent problems occurring, we often have to do a lot of detective work.

The exercise that follows recreates an event that really happened.

Bob’s story

Bob is a 75-year-old gentleman with dementia who is recovering from a recent urine infection. He is also quite hard of hearing. He has been in St Welstaft Hospital for a week. He is keen to go home, as he feels much better.

What follows is a description of a real event that involved Bob. Follow the story and think about how Bob is feeling as the situation escalates. Also, think about how you feel as you witness this.

Scene 1: Bob is sitting on his hospital bed, fully dressed. His bag is packed, and he appears to be ready to go home.

Are there any clues to indicate how Bob is feeling?

What do you think Bob might want to do?

Scene 2: A nurse approaches Bob and says, ‘No Bob, stop. You’ve got to go back to bed.’

Bob is sure he can go home today. He feels fit and well and has decided he’ll walk himself. Imagine his surprise and shock that someone is trying to physically prevent him from getting out of this place.

Please note: any word in blue can be found in the accompanying glossary.
How do you think Bob is feeling?
How do you think he will react?

Scene 3: Bob takes a swipe at the nurse who is trying to prevent him from leaving. Fortunately he misses, but she is quite shaken. The staff immediately follow the policy for dealing with this and call security. Bob is now running down the stairs to find the exit.

What do you think caused this reaction from Bob?
What do you think could have been done differently?

Scene 4: As Bob is on his way out of the hospital, a security guard tries to grab him. Bob strikes out at the guard. The police are then called and Bob is chased over a busy road to a field where he is now cornered.

How is Bob feeling now?
What do you think of the reaction to Bob leaving the hospital?

Scene 5: Having been captured, Bob is now back at the hospital entrance. Bob cannot hear what the police are trying to say to him.

How do you think Bob is feeling at this point?
How well do you think the situation was handled?

Clues for the observant detective

To understand a person’s communication we need to consider the whole picture:
• What’s been happening?
• What do we know about the person’s health and any sensory impairments?
• What are the person’s lifestyle and habits?
• What’s going on in the environment?

We need to be a detective.

There’s often enough information available if we look hard enough. Let’s go back to the start of this story. In the hospital environment there are several key clues for you to pick up on as a dementia detective. Imagine exploring the scene with a magnifying glass and learn more about Bob.

Please note: any word in blue can be found in the accompanying glossary.
Think about why he is there, how he is feeling, how he might act upon those feelings, the communication difficulties he may have, and Bob's own ‘reality’. Learn what the nurse says while handing over some information to her colleague. You may begin to discover some ways to avoid the situation escalating into the scene you witnessed.

**Six key clues**

**Clue 1**
A nurse talks to her colleague and says, ‘I have explained to Bob about the transport and that his son coming tomorrow. He was really disappointed that he can't go today. He will need reminding, though and, because he’s so hard of hearing, you have to write it all down.’

**Clue 2**
Bob’s hospital notes say: ‘Admitted for infection. Had gone out for a daily walk and not found his way home. Picked up by police. Has mild dementia. Son reports he is a very fit man who was in parachute regiment and always enjoyed regular hikes of several miles. Treated for a urine infection and slight dehydration but now fit for discharge.’

**Clue 3**
Bob’s personal items: Bob is packed and ready to go home.

**Clue 4**
Bob’s behaviour: Bob is twitching his thumbs and may be getting a little restless.

**Clue 5**
Notepad on side table says: ‘Bob, unfortunately, they can't get the transport arranged for you today so your son is coming tomorrow to take you home.’

**Clue 6**
Hearing aid is sitting on side table: Bob has hearing problems but his son reports that he hardly ever wears the hearing aid.

Please note: any word in blue can be found in the accompanying glossary.
Now, we will take you through how the story could have gone if all the clues were followed.

**Bob’s story: with a better outcome**

Bob is feeling fit and well enough to go home. As he is on his way out, he is pleasantly surprised to see the nurse who always greets him with a smile. Understanding what a fit and active person Bob is and realising he is feeling restless, she knows she should not try to stop him, but rather should accompany him.

Knowing that Bob likes to go out walking, the nurse engages in non-threatening small talk about getting out for a stroll to stretch the legs. As Bob mentions he is going to buy a paper like he always does, the nurse is immediately able to help guide him to the paper shop.

The nurse is now inviting Bob back up to the ward for a cup of tea and to read the paper together. Knowing that Bob also has hearing problems and is not wearing his aid, she is talking face to face and using clear gestures to make sure he understands. Bob is happy to accept the invitation and they return to the ward.

Back on the ward, the nurse has spent a little time looking at the news headlines with Bob. He is in a very relaxed mood now that he has had a walk. The nurse is now able to remind Bob about the delay in his discharge. She uses the notepad to show him the important message that was previously written down for him. Bob reads the message: ‘Bob, unfortunately, they can’t get the transport arranged for you today so your son is coming tomorrow to take you home.’ Bob nods his understanding that his son will be coming tomorrow.

Now that you have worked through both scenarios, think about the questions below.

<table>
<thead>
<tr>
<th>Over to you!</th>
</tr>
</thead>
</table>
| 1. What specific factors made a difference to the outcome of each scenario?  
2. How do you think Bob felt in the second scenario compared to the first one?  
3. Thinking about the handling of both situations, how much staff time was taken up by each?  
4. What do you feel you can take from this real life example? |

It is always important to be aware of non-verbal communication, which will give us crucial information about the feelings of a person with dementia. We can cause problems if we fail to understand important messages.

Please note: any word in blue can be found in the accompanying glossary.
In fact, what gets labelled as ‘problem behaviour’ is nearly always the person’s attempt to communicate something important about their feelings and needs. The main problem is our own lack of understanding.

For a more in-depth look at communication and detective work, see And still the music plays, by Graham Stokes (2008).

‘My biggest complaint about dementia is other people.’
Richard Pryce, retired teacher and younger person living with dementia.

We have now come to the end of this module. It is not only the dementia that can cause problems with communication, but also the way we engage with people with dementia – what we say, how we say it, and how we can interpret meaning and non-verbal clues.

We have again stressed the importance of tuning into a person’s feelings rather than the factual content of their speech. Finally, Bob’s true story (both events happened within hours of each other) revealed the potentially disastrous consequences of not picking up on key clues and also the benefits of taking them into account.

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

- A range of factors can make it difficult for people with dementia to understand what others are saying.
- Dementia itself can cause problems in communicating and understanding.
- We can use particular techniques to help people with dementia understand and be understood.
- A person with dementia may indicate that their ‘reality’ is different to ours, and we should seek to understand the feelings and needs that they are communicating.
- People with dementia may communicate their feelings and needs through actions.
- ‘Challenging behaviour’ is usually the result of a multitude of contributory factors that can be addressed or avoided.
We have now also almost come to the end of the Open Dementia Programme. Have a think about the questions below.

Over to you!

1. How do you feel having completed the Open Dementia Programme?
2. What use will you make of the agencies and literature referenced in the programme?
3. What do you feel you have learnt from the programme?
4. In what way will you change the way you interact with, or perceive people with dementia

You’ve reached the end of the Open Dementia Programme! It is fitting to finish on the topic of positive communication, as it has been a recurrent theme throughout the programme.

We have tried to help you acquire a clearer understanding of the needs, strengths and experiences of individuals with dementia, and to signpost other sources of support and information.

We hope you have benefited from and enjoyed this learning experience and that you can now continue to help people live with dementia rather than suffer from it.

Before you finish, 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 6: 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 30.

**Question 1**

If people with dementia cannot understand to them, it is just because their brain is too damaged.

True
False

**Question 2**

Using gestures and prompts can help a person with dementia understand what we are trying to say to them.

True
False

**Question 3**

Noise from a television or radio can contribute to a person with dementia struggling to remember what they’re trying to say.

True
False

**Question 4**

People with dementia may often express a simple message in a highly poetic way.

True
False

**Question 5**

As dementia progresses, it is impossible to get the meaning of what a person with dementia is trying to say.

True
False

Please note: any word in blue can be found in the accompanying glossary.
### Question 6
Telling a person to ‘hurry up and spit it out’ is often the best way to encourage a person with dementia to express themselves more coherantly.

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

### Question 7
If someone is saying something that is clearly not true, you should tell them a lie to humour them or make them face up to the truth.

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

### Question 8
If someone were to ask for their mother, you should quiz them to work out how old their mother would be now so they can work out for themselves that she must be dead by now.

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

### Question 9
It is often possible to guess how a person with dementia might react in a given situation.

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

### Question 10
What gets labelled as ‘problem behaviour’ is nearly always a person’s attempt to communicate.

<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’. Although damage to the brain does affect how messages are received, successful communication also depends on how well the message is put across, the environment, and on any other sensory impairments.

2. The correct answer is ‘true’. The use of visual prompts or pointing to objects as a back-up to the spoken word can help a person with dementia whose understanding of spoken words may be impaired.

3. The correct answer is ‘true’. A noisy environment can be a real hindrance to a person with dementia in their efforts to maintain their train of thought.

4. The correct answer is ‘true’. When a person with dementia cannot access the usual words to express their message, they will often seek to express their meaning through more descriptive language.

5. The correct answer is ‘false’. Through careful listening and observation and a greater knowledge of an individual, it is often possible to make sense of a seemingly scrambled collection of words and noises.

6. The correct answer is ‘false’. It is vitally important to give a person with dementia time to express themselves and let them know that you are listening, so that they do not feel pressured or hurried.

7. The correct answer is ‘false’. What is more important than lies or the truth is to respond to the feelings behind what the person with dementia is saying. It is important to take any concerns seriously and try to find a way of addressing them.

8. The correct answer is ‘false’. It is much more important to recognise the person’s deeper expressed need for love, comfort and reassurance than to convince them that their mother is dead.

9. The correct answer is ‘true’. If we take notice of the many clues in a person’s language, expression, and their life history, as well as the clues in the immediate environment and situation, it should be easier to predict how they might react in certain situations.

Please note: any word in blue can be found in the accompanying glossary.
10. The correct answer is ‘true’. Everyone communicates through actions as well as words, so ‘behaviour’ should be seen as communication. When a person with dementia is experiencing strong feelings or unmet needs, and cannot find words to explain this, their behaviour may be experienced as challenging or problematic. But the challenge is for us: to understand and respond to the message being communicated.
Section 7: References

