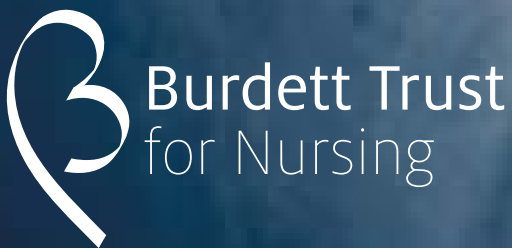




# Barbara's Story

Her whole journey



Guy's and St Thomas'   
NHS Foundation Trust

At Guy's and St Thomas' NHS Foundation Trust we have been running an awareness programme on the needs of dementia patients when they are in hospital. Entitled 'Barbara's Story', the programme has been hugely successful in turning around the attitudes and understanding shown by all staff to our most vulnerable patients.

Thanks to the Burdett Trust and Guy's and Thomas' Charity, we have developed five further episodes of Barbara's Story and can now make this part of the programme available to other trusts.

Included with this training pack are the resources you will need to run this programme yourselves: Episodes 1 - 6 of Barbara's Story along with the relevant training scripts.

I strongly recommend that all senior leaders should support the project to ensure 'Barbara's Story' is made part of mandatory training. If everyone attends the training and makes one small change, the impact can be amazing.

This of course would not be possible without the support and funding received. I would like to say a huge thank you to all those who took part in the production and distribution of Barbara's story from the film crew and actors, the Guy's and St Thomas' Charity, The Burdett Trust and all the Trust staff who have worked so hard to make this become what it is today.

The Trust is available to assist and support you if you want any further advice or support.

**Eileen Sills CBE**

Chief Nurse & Director of Patient Experience



# Tips for trainers

- ▶ Explain why dementia is important for everyone. Some people may think these sessions are not relevant for them if they are working in departments with no older patients - midwifery, for example. But the principles of caring, compassion, good communication, competence and commitment apply to all patients.
- ▶ You are not trying to tell staff what to do but asking them to take away with them a sense of the things that they could do.
- ▶ Try running the programme for a limited period of time as attendance improves when staff realise they are running out of time to attend.
- ▶ Do not be afraid of holding the silence for a few seconds to let people think about what they have seen. Count to 10. This is not as long as it seems - it is easy to jump in and answer your own question, but try not to.
- ▶ These episodes are not always appropriate for people recently bereaved or who are carers, so managers need to be sensitive to this.
- ▶ It is important to ask the audience to turn off their phones, beepers (if they are able) and not to eat or be otherwise distracted. Ask them for feedback if their attention is wandering.
- ▶ Make the point that although in most episodes it is a nurse who shows caring and compassion, it could be any member of staff who shows these values - such as the hospitality lady in episode 3.
- ▶ Make sure people arrive on time or before the start of the video.
- ▶ Dementia is not everyone's chosen speciality and we must accept that not everyone feels that it is important. But Barbara does have the potential to influence change even to those seemingly resistant in the beginning.

“ You have started a chain, a caring chain of events that will ease many lives. Knowledge is far better than fear with all forms of dementia. We cannot prevent ageing but we can be sensitive to the quality of the journey... this is a wonderful legacy. ”

**Member of staff**

Guy's & St Thomas' Hospital



More copies of Barbara's Story pack can be obtained from:

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# Barbara's Story

# training briefing

## Welcome to **episode one** of Barbara's Story

**BEFORE YOU PLAY EPISODE ONE:** Barbara's Story is a training programme launched by Guy's and St Thomas' NHS Foundation Trust in September 2012 to raise awareness of how it feels to be a patient with dementia.

The training programme follows the journey of an older woman called Barbara through her healthcare journey as her dementia gradually advances.

Each film focuses on different aspects of her care and in turn supports our aim to provide these films to continue their dementia training.

Some of you may find this film very emotional so, if you need to leave, please don't hesitate - someone will be on hand to support you at the end of the session.

This episode is in two parts. We will show part one, which is about 10 minutes long, then discuss what we have learned. We will then show you part two and discuss this as well.



### **WHEN THE FILM HAS FINISHED**

Pause for a moment and ask the audience to reflect on the film and the impact it has had. Ask the audience to share their immediate impressions and the key messages from the film - it is advised to take no more than five minutes on this section.

## what's inside

- ▶ **PART ONE, SCENE 1:** Barbara is anxiously waiting at home for transport to take her to hospital. She is worried the taxi may not have her correct home address or may forget to collect her. She is also worried that she may have mixed up her appointment dates. She has a letter from the hospital on which is written an appointment time and basic information about the clinic she is to attend. The taxi arrives and takes her to the hospital's outpatient department.
- ▶ **SCENE 2:** Barbara arrives in the outpatient department and has to wait a long time before seeing a doctor. She tries to find out information from the receptionist who is indifferent towards Barbara. No one offers to help when she gets lost in the corridor trying to find the toilet.
- ▶ **SCENE 3:** Barbara is in the doctor's consulting room. There is a nurse and a medical student in the room. She is asked to remove her blouse before being examined by the doctor.
- ▶ **SCENE 4:** When Barbara arrives on the ward she is not welcomed. The nurse relies on her piece of paper, describing Barbara as "in for heart tests" and points to the bed to which she should be taken.
- ▶ **PART TWO, SCENE 1:** Barbara is visited at home by the district nurse and is asked how she felt about her hospital visit and what could be done to make patients feel happier when visiting hospital departments.

# PART ONE

## SCENE 1

Barbara is anxiously waiting at home for the transport, arranged by the hospital, to take her to hospital. She is worried the taxi may not have her correct home address or may forget to collect her. She is also worried that she may have mixed up her appointment dates. She has a letter from the hospital on which is written an appointment time and basic information about the clinic she is to attend. The taxi arrives and takes her to the hospital's outpatient department. Whilst in the taxi, Barbara sees a photograph of the driver's family which triggers a flashback of her daughter Anna.

### Teaching points

#### Communication

- Appointment letters are generic and can be confusing for everyone, especially an older person.
- Try and write outpatient appointment letters in simple, easy to understand language. Include a telephone number for the department.
- Consider ringing or texting patients the day before their appointment to remind them.
- Barbara reminiscing about her daughter whilst in the taxi reminds her of a time when she felt safe.
- The taxi driver was dismissive towards Barbara - when they arrived at the hospital he simply said, "We're here". How could he have communicated better with her?

## SCENE 2

Barbara arrives in the outpatient department and has to wait a long time before being seen by a doctor. She tries to find out information from the receptionist who is indifferent towards Barbara. No one offers to help Barbara when she gets lost in the corridor trying to find the toilet.

### Teaching points

#### Communication

- People are anxious when they come to hospital and are afraid of getting lost. Hospital staff are busy but take time to ask anyone you see looking lost or anxious whether they need help.
- The receptionist is efficient but very offhand towards Barbara - she does not smile or greet Barbara when she arrives in the outpatient department. Barbara asks the receptionist why she is at the hospital but the receptionist ignores her question.
- What could the receptionist have done differently? She could have taken the time to reassure Barbara and to explain exactly why she had been asked to come to the outpatient department.
- When the receptionist calls her name, Barbara corrects her - asks her to use her full name "Mrs Barbara Reece".
- All patients should be asked their preferred method of being addressed.
- Barbara has to wait a long time to be seen by the doctor. No one comes to tell her that her appointment has been delayed. This makes her very anxious. If the receptionist had kept Barbara informed, it would have helped alleviate her anxiety.
- Barbara wants to go to the toilet, which makes her even more anxious. She is afraid of leaving her seat because she does not know when she will be called to see the doctor. If she had been kept informed about the delays to her appointment, it would have helped allay her anxiety.
- Barbara gets up and walks hesitantly down the corridor to look for the toilet. Nurse Jane notices Barbara looks agitated and lost. She approaches Barbara and using a calm tone of voice enquires whether she can help Barbara.

- Barbara is reassured and comforted by a caring and compassionate approach. Nurse Jane validates her anxiety which in turn helps to reduce it.
- Nurse Jane maintains eye contact, smiles, uses a soft tone of voice and takes Barbara to the toilet.
- On returning to the waiting area after nurse Jane has taken her to the toilet, Barbara's anxiety has disappeared and she is in a more relaxed frame of mind. A simple act of kindness or alleviating a cause of stress can rapidly make a person feel valued.

### **Signage**

- Barbara starts to walk down the corridor and several members of staff walk straight past Barbara even though she clearly looks confused and lost. No one offers to help her until nurse Jane stops to talk to her.
- There is a noticeable lack of signs to help guide Barbara to the toilets. Hospitals need to be aware that people find hospitals very confusing and need clear signposting to find departments.
- Bad signage can often be missed by those who are anxious.

### **SCENE 3**

Barbara is in the doctor's consulting room. There is a nurse and a medical student in the room with Barbara and the doctor. She is asked to remove her blouse before being examined by the doctor.

### **Teaching points**

#### **Anxiety**

- None of the healthcare professionals introduce themselves when Barbara walks into the consulting room, making her feel vulnerable and anxious. Neither do they seek permission for a student to be present during the consultation.
- The examining doctor calls Barbara by her first name - he does not ask her how she would like to be addressed. However, he addresses her GP as "doctor", implying the doctor commands more respect than Barbara.
- Barbara is asked to remove her blouse for an examination. She has never removed her blouse in front of strangers before - only her husband Len. This will be the case for many older people. Removing her blouse in front of all these strangers embarrasses Barbara and makes her feel vulnerable and anxious.
- The doctor tells Barbara she has to stay in hospital for further tests. However, neither the doctor or nurse explain which tests are going to be carried out and they are very dismissive towards Barbara when she asks for an explanation. Taking time to explain procedures to patients helps alleviate anxiety and fears.
- The sudden decision to admit Barbara to hospital increases her anxiety and confusion. Minimal reassurance is given and minimal empathy shown. This would be very frightening for any patient.

## SCENE 4

The porter arrives and pulls Barbara backwards on the wheelchair whilst taking her to the ward. When Barbara arrives on the ward she is not welcomed. The nurse relies on her piece of paper, describing Barbara as “in for heart tests” and points to the bed to which she should be taken. The porter and nurse talk over Barbara’s head discussing the nurse’s recent wedding. Barbara is not included in the conversation. Barbara has missed lunch and is treated as if this is her fault. Nurse Jane visits Barbara on the ward.

### Teaching points

#### Respect

- It is very disorientating being pulled backwards in a wheelchair, especially for a patient with minor cognitive impairment. The porter should have made the effort to push Barbara forwards.
- The porter and ward nurse talk over Barbara’s head discussing the nurse’s wedding and in doing so treat Barbara with disrespect. They do not include Barbara in the conversation.
- The nurse does not introduce herself or meet and greet Barbara when she arrives on the ward.
- The nurse does not show Barbara the call bell or how to use it, leaving Barbara bewildered and confused. She assumes that Barbara already knows how to use the bell.
- Good practice was shown by nurse Jane who, when arriving on the ward to see Barbara, showed respect by asking Barbara whether she could sit down. Barbara was comforted by a caring and compassionate approach.

#### Nutrition

- When Barbara asks for some lunch, the ward nurse tells her she has “missed lunch” and offers her tea and biscuits instead.
- How else can food be offered? Are tea and biscuits adequate?
- On waking from her tests, Barbara is given lunch. She is not offered a choice of food and the nurse does not ask whether Barbara has dietary or religious requirements.
- Barbara falls asleep whilst eating - whilst she is asleep, her lunch is removed.
- What could have been done better? The nursing staff should have asked Barbara before removing her tray containing uneaten food, and supported her to eat her lunch.
- The food was served on a red tray. What does this highlight? It flags up to staff that food and fluid intake should be monitored and that patients may need help with eating or drinking.
- When nurse Jane arrives on the ward, she asks Barbara whether she has eaten lunch. This was kind of nurse Jane.
- When she hears that Barbara’s lunch has been removed nurse Jane offers three choices of sandwiches.
- For people with a dementia or minor cognitive impairment it may be necessary to use closed questions to help patients make a decision.
- It might have been better for nurse Jane to ask Barbara what she would have liked in her sandwich rather than offering three different sandwich fillings.

#### Empathy

- Nurse Jane spoke to Barbara about her previous job as a headmistress.
- This demonstrated nurse Jane’s knowledge of Barbara as a person and helped reduce Barbara’s anxiety. It also assisted building rapport and trust between them.
- Good communication: try to sit at the patient’s eye level, use the patient’s preferred name and observe all non-visual cues. Use all the principles of good communication such as asking closed questions, maintaining eye contact and speaking calmly and slowly.
- Nurse Jane treats Barbara with respect: she asks whether she can help Barbara. Barbara is reassured and comforted by a caring and compassionate approach.

Thank you for watching **part one** of Barbara’s Story.  
We will now watch **part two**.



# PART TWO

## SCENE 1

Barbara is visited at home by the district nurse and is asked how she felt about her hospital visit and what could be done to make patients feel happier when visiting hospital departments. It is noticeable Barbara does not appear agitated or confused in the familiar surroundings of her own home.

### Teaching points

#### Respecting patient's wishes

- Barbara says that everyone in the hospital called her a different name.
- Ask patients how they would like to be addressed - Mrs Reece or Barbara.

#### Communication

- Introduce yourself when first meeting a patient.
- Barbara tells the district nurse she didn't know why she had to go to hospital and when she was at the hospital, no one asked her opinion. Decisions were made on her behalf without consulting her.
- Make time to explain procedures to patients and ensure they understand your explanation.
- Use hospital communication books or interpreters if needed.
- Smile, make eye contact and speak clearly asking one question at a time, in a calm environment.
- Draw the curtains around the bed if necessary to ensure a calm environment when asking questions or explaining procedures. Make sure the curtains are opened once the discussion has finished.

#### Treating patients with kindness and respect

- Barbara said she felt anxious and apprehensive on the way to hospital, whilst she was waiting for her appointment in the outpatient department and when in the doctor's consulting room. She said she wanted to see a "friendly face". She did not feel welcome at the hospital and felt she was "just an old woman".
- Introduce yourself when you meet a patient for the first time. Be welcoming.
- If you see anyone in the hospital who looks lost ask them whether you can help.
- Smile!
- Be mindful everyone feels slightly apprehensive when not in a familiar environment - treat everyone as if they really matter and treat them as if they are special.
- People wish to be seen as individuals - be mindful of not talking over patients as the ward nurse and the porter did when Barbara arrived on the ward. What is routine for us is not routine for our patients.
- All patients like to be included in making decisions about their own treatment - even older patients.

#### Follow your trust values - go out of your way to help anyone who looks lost, confused or anxious

- Put patients first
- Respect others
- Strive to do your best
- Have pride in what you do
- Act with integrity

**Above all, be calm.**

Thank you for watching **episode one** of Barbara's Story.

Although we have focused on the care of older people and those who are confused, the principles of caring, compassion, respecting others and acting with integrity apply to all our patients.

# Barbara's Story

# training briefing

## Welcome to **episode two** of Barbara's Story

Episode one of Barbara's Story touched the hearts of staff at Guy's and St Thomas' NHS Foundation Trust, inspiring them to make changes to the care they provide to patients.

With the generous support of the Burdett Trust, five further episodes have been developed focusing on Barbara's healthcare journey and experiences as her dementia advances.

Each film reflects on different aspects of Barbara's care and supports our aim to provide patients with the highest standards of care across all areas of the Trust. Over the next five episodes staff will have the opportunity to use information from these films to continue their dementia training.

Like episode one, some of you may find this episode very emotional. If you need to leave, please don't hesitate - someone will be on hand to support you at the end of the session.

**EPISODE TWO** is about 10 minutes long. We will follow the viewing with a learning discussion.

### **i** WHEN THE FILM HAS FINISHED

Pause for a moment and ask the audience to reflect on the film and the impact it has had. Ask the audience to share their immediate impressions and the key messages from the film - it is advised to take no more than five minutes on this section.

## what's inside

- ▶ **SCENE 1:** We see Barbara at home. She stops and catches a glimpse of herself in the hallway mirror, but does not recognise herself.
- ▶ **SCENE 2:** Barbara's daughter is concerned about her mother and calls the GP who agrees to make a home visit. We see the GP gain access to Barbara's home.
- ▶ **SCENE 3:** The GP calls the hospital based on her assessment of Barbara. She is worried Barbara has a chest infection and does not seem to be her usual self.
- ▶ **SCENE 4:** Barbara arrives in A&E. The nurse forgets to introduce herself and asks a lot of questions in quick succession which adds to Barbara's confusion.
- ▶ **SCENE 5:** Barbara is left alone to put on the hospital gown. She gets down from the bed to explore her surroundings and falls to the floor, injuring herself.
- ▶ **SCENE 6:** Barbara is still showing signs of being confused and agitated when she is moved to the orthopaedic ward. She is not able to hear Anna talking to her on the telephone.

## SCENE 1

We see Barbara at home. She stops and catches a glimpse of herself in the hallway mirror, but does not recognise herself.

### Teaching points

#### Recognition

- ▶ Barbara's lack of self-recognition highlights a common difficulty for people diagnosed with a dementia as their ability to recognise objects, themselves and others can become impaired.
- ▶ People with a dementia may think someone else is in the room instead of recognising themselves. Many nursing homes have removed mirrors from bedrooms and bathrooms due to the distress this can cause.
- ▶ Reflective, shiny surfaces can alter perception and cause distress for some people with a dementia. For example, a shiny, polished floor may look like water and therefore patients may feel anxious or confused when walking over it. Or a dark rug may look like a hole in the floor.

#### Delirium

- ▶ This is a medical emergency.
- ▶ Barbara's difficulty recognising her own face may be a symptom of delirium or a dementia.
- ▶ Patients with delirium can experience auditory and visual distortions, or have hallucinations. When Barbara's GP takes her temperature and blood pressure she hears distorted sounds. Her behaviour and appearance may also indicate delirium.
- ▶ The NICE definition of delirium: 'Delirium is when someone becomes acutely confused because of a physical problem or a change in environment.'
- ▶ There are many causes of delirium, but some of the most common include infections, constipation and pain.
- ▶ Delirium is usually what brings people to hospital. They may be acutely confused as a result of an infection, which can be exacerbated by being brought into an unfamiliar, confusing or frightening environment. Always consider that a patient will not be at their baseline level of functioning when they are in hospital.
- ▶ Delirium should be assessed using the **C**onfusion **A**ssessment **M**ethod or **CAM** score.
- ▶ A patient is CAM positive if their confusion has an:
  - 1) Acute onset and fluctuating course, and
  - 2) They are inattentive and either
  - 3) They show evidence of disorganised thinking or
  - 4) They have an altered level of consciousness, either hypo or hyper alert.

#### The signs that Barbara may have delirium are:

- ▶ She is more confused than normal (1. acute change).
- ▶ She is distracted and impatient when the GP talks to her (2. inattentive).
- ▶ She is fidgety and twitchy (4. hyperactivity).
- ▶ She is also more irritable than normal: a change in mood or 'emotional lability' can be a feature of delirium.

Delirium is very serious and it is important to identify the cause as soon as possible. There are delirium bundles available for health professionals to use that guide you through the exact steps of how to investigate and manage a delirium.

Your trust's delirium guidelines will detail best practice treatment and management of delirium.

## SCENE 2

Barbara's daughter has called the GP as she is concerned about her mother. We see the GP, who has agreed to do a home visit, gain access to Barbara's home.

### Teaching points

#### No access policy

- ▶ The GP gains access to Barbara's house using a key kept by the neighbour, which Barbara has given her consent to use.
- ▶ When discharging patients or referring to community services, always make sure a range of access options to the home are available. For example, key safes, keys with neighbours or keys held by community nurses. Even if a person is not going to have onward professional input it is a good idea to suggest keeping spare keys with friends and family.

#### Communication

- ▶ The GP asks a lot of questions in quick succession causing Barbara to become more anxious and defensive. She also questions Barbara when she says that she has not called her daughter, saying: "Are you sure Barbara?"
- ▶ When speaking with people who are confused, questions need to be asked one topic at a time, leaving plenty of time for the person to respond.
- ▶ Many people feel overwhelmed if too many questions are asked at once or if complex language is used. Use the 10 second rule, maintain eye contact and keep your voice calm and soft.
- ▶ Consider using closed questions and always observe facial expression and tone of voice. Always check if you have understood what the patient has said.
- ▶ Consider using pictorial cues and gestures as supplements to what you are saying.
- ▶ Do not contradict or challenge what the patient tells you, because, as we see in the film, this can upset the patient and damage the rapport you are trying to build with them. Engage with the patient's reality even if it does not fit in with your own.

## SCENE 3

The GP calls the hospital based on her assessment of Barbara. She is worried that Barbara has a chest infection and does not seem to be her usual self.

### Teaching point

#### Consent and capacity

- ▶ The GP is calling the ambulance as she is concerned about Barbara. The GP could possibly have considered a less restrictive option such as rapid response or contacting the home ward team.
- ▶ The GP could have spent a little more time explaining the situation to Barbara and attempted to gain her consent.
- ▶ Patients with delirium can and often will consent and agree to care if a softer approach is used and they are given time to process the information.

## SCENE 4

Barbara arrives in A&E. The nurse forgets to introduce herself and asks a lot of questions in quick succession whilst doing her observations. She also phrases the same question in different ways, which can add to confusion.

### Teaching point

#### Busy environments

- ▶ Although we would not usually pull the curtains round a bed to complete a routine set of observations, consider doing this with a confused patient as it will help minimise distractions, both visual and auditory.
- ▶ When assessing confused patients do one thing at a time. Look at the patient when asking a question. This will help them concentrate on what is happening and they may not feel so overwhelmed.
- ▶ Try to sit at eye level, use the patient's preferred name and observe all non-visual cues.
- ▶ Use all the principles of good communication such as asking closed questions, maintaining eye contact and speaking calmly and slowly.
- ▶ Do not look away when asking a question to a patient with a dementia or delirium as they may think that the question is being directed at someone else.

## SCENE 5

Barbara is left alone to put on the hospital gown, which she 'agrees' to do. She gets down from the bed to explore her surroundings and falls to the floor, injuring herself.

### Teaching point

#### Falls

- ▶ Could Barbara's fall have been avoided?
- ▶ The A&E bed was too high - Barbara's feet were dangling off the bed and she was only wearing stockings: a slip hazard.
- ▶ Assumptions were made about 1) her physical ability to put the gown on and 2) her understanding of what a call bell was and how to use it.
- ▶ The curtains were pulled around the A&E bed so Barbara could get changed in privacy. However, Barbara is left unattended. If you leave a curtain closed it is natural for a patient to get up to see what is going on - to seek familiarity and reassurance. This is especially true for confused patients to whom a few minutes may seem much longer.
- ▶ Barbara does not ask the nurse for help to put on her gown. Older people often do not want to trouble staff whom they think are too busy to be disturbed.
- ▶ The majority of patients over the age of 65 who have a fall that results in harm have delirium.
- ▶ Patients with delirium are often below their baseline level of functioning and require extra help. A delirious patient may not realise they are unable to do the things they usually can and therefore will not ask for assistance.
- ▶ Your trust may have a policy to assess all adult patients on admittance for risk of falls. One such assessment tool is the STRATIFY risk assessment tool.

## SCENE 6

Barbara is still showing signs of being confused and agitated when she is moved to the orthopaedic ward. She is unable to hear Anna on the phone which may be due to perceptual disturbances caused by her delirium or due to background noise from the ward.

### Teaching point

#### Empathy

- ▶ Nurse Mwamba treated Barbara with respect: he did not challenge her when she asked for Len. He sought clarification of the situation from her daughter Anna.
- ▶ Barbara's concerns were validated; she was reassured and comforted by a caring and compassionate approach.
- ▶ Nurse Mwamba sat down, maintained eye contact and used a soft tone of voice.
- ▶ He used the distraction of talking about Barbara's grandchildren to take her mind off worrying about Len. This reduced Barbara's anxiety and helped build rapport and trust between them. He also held her hand. This simple gesture speaks volumes. It is caring, reassuring and comforting. We all seek reassurance when we are frightened.

Thank you for watching **episode two** of Barbara's Story.

Although we have focused on the care of older people and those who are confused, the principles of caring, compassion, respecting others and acting with integrity apply to all our patients.

# Barbara's Story

# training briefing

## Welcome to **episode three** of Barbara's Story

Barbara's Story continues to touch the hearts of staff at Guy's and St Thomas' NHS Foundation Trust, inspiring them to make changes to the care they provide to patients.

Like the first two films, some of you may find this one very emotional so if you need to leave please do not hesitate - someone will be on hand to support you at the end of the session.

Before we show **EPISODE THREE**, we will have a quick recap of the previous episode. Barbara appeared unwell and was admitted to A&E with a suspected chest infection. She had a fall whilst in A&E, fractured her femur and was subsequently admitted to the orthopaedic ward. Whilst on the orthopaedic ward, Barbara appeared confused and disorientated.

Barbara does not have a diagnosis of delirium or a dementia yet.

We will now show you episode three, which is about 12 minutes long, and then discuss what we have seen.

### **i** WHEN THE FILM HAS FINISHED

Pause for a moment and ask the audience to reflect on the film and the impact it has had. Ask the audience to share their immediate impressions and the key messages from the film - it is advised to take no more than five minutes on this section.

## what's inside

▶ **SCENE 1:** We see Barbara on the orthopaedic ward pre-operatively. She has a flashback to when she was a teacher and pregnant. She appears confused, distracted and inattentive.

▶ **SCENE 2:** Barbara wakes up on the orthopaedic ward post-operatively. She has had a repair of her fractured neck of femur. Barbara is distressed, disorientated and the rails of her bed are raised which is making her anxious.

▶ **SCENE 3:** Barbara asks the nurse the whereabouts of her husband. The nurse initially tries to avoid the question but eventually tells Barbara that Len is dead.

▶ **SCENE 4:** The hospitality lady offers Barbara a cup of tea in a china cup and saucer. She is smiling and maintains good eye contact with Barbara.



## SCENE 1

We see Barbara on the orthopaedic ward pre-operatively. She has a flashback to the time when she was a teacher and pregnant. She appears confused, distracted and inattentive.

### Teaching points

#### Consent

- ▶ The doctor and nurse seem to realise that Barbara is confused but do not appear to identify she has delirium. It appears they want her to consent to her operation. Does she have the capacity to do so?
- ▶ Having delirium does not automatically mean a patient does not have capacity to make a decision.
- ▶ How do you assess capacity?

#### Capacity: Two-stage test

- ▶ Stage 1 of the capacity test: In Barbara's case, the doctor needs to be aware that Barbara's confusion is likely to be attributable to her delirium as she is presenting with inattentiveness, altered consciousness and disorganised thinking which appears to be fluctuating and acute in onset.

This then tells us she may have an impairment and/or disturbance of the mind, which is probably temporary and is affecting her ability to give informed consent.

- ▶ Stage 2 of the capacity test: The doctor needs to test Barbara's ability to give informed consent by going through the following criteria. To have capacity, the patient must be able to:
  - **Understand** the information relevant to the decision - information must have been communicated to that person in a way appropriate to their circumstances.
  - **Retain** this information for long enough to...
  - **Use and weigh up** the information to arrive at a choice (which requires an understanding of the consequences of making a decision one way or the other, or of failing to make a decision) and
  - **Communicate** the decision.

**REMEMBER: Capacity is time and decision specific. It can also fluctuate. We always use all practicable steps to support the patient as much as possible.**

#### Best-interest decisions

- ▶ Weigh up all circumstances: eg co-morbidities, impact of the intervention on the person, rehab implications.
- ▶ Consultation with next of kin ie a consultation with Anna (her daughter) should be carried out to ascertain Barbara's values and beliefs.
- ▶ Consideration should also be given to whether the same result could be achieved in a less restrictive manner.

## SCENE 2

Barbara wakes up on the orthopaedic ward post-operatively. She has had a repair of her fractured neck of femur. Barbara is distressed, disorientated and the rails of her bed are raised which is making her anxious.

### Teaching points

#### Pain

- ▶ The nurse observes Barbara is in pain and offers her pain relief - which is good practice. However, Barbara does not answer the nurse - did she receive any pain relief?
- ▶ The nurse does not assess Barbara's level of pain - she might have used a hospital communication book to explain to Barbara she had just had an operation.
- ▶ The Abbey pain scale can be used to assess pain.

- ▶ When the doctor asks whether Barbara is in pain she replies that “her books are fine.” She is confused and illogical. Does the doctor pick this up?
- ▶ The doctor says: “Let’s get her something for the pain and something to calm her down.” Does he recognise she has signs of delirium? Is he prescribing antipsychotics appropriately or inappropriately?
- ▶ He then says to the nurse: “Are you alright to deal with this? I will write it up this afternoon.” Is this appropriate?

### Delirium

- ▶ This is a medical emergency.
- ▶ Can you define delirium? The NICE definition of delirium: ‘Delirium is when someone becomes acutely confused because of a physical problem or a change in environment.’
- ▶ There are many causes of delirium, but some of the most common include infections, constipation, pain and change of environment.
- ▶ Delirium is usually what brings people to hospital. They may be acutely confused as a result of an infection, which can be exacerbated by being brought into an unfamiliar, confusing or frightening environment.
- ▶ Always consider that a patient will not be at their normal level of functioning when they are in hospital.
- ▶ We assess delirium in this Trust using the **Confusion Assessment Method or CAM** score.
- ▶ A patient is **CAM** positive if their confusion has:
  - 1) Acute onset and fluctuating course, and
  - 2) They are inattentive and either
  - 3) Show evidence of disorganised thinking or
  - 4) Have an altered level of consciousness either hypo or hyper alert

### The signs that Barbara may have delirium are:

- ▶ She is more confused than normal, believing her husband Len is still alive (1. acute change).
- ▶ She is distracted when both doctors and the nurse talk to her (2. inattentive).
- ▶ She is fidgety and twitchy (4. hyperactivity).
- ▶ She is more irritable than normal - change in mood or ‘emotional lability’ can be a feature of delirium.

### Causes of delirium

- ▶ In Barbara’s case this could be due to her hip fracture, having surgery, being in pain, or due to the suspected chest infection with which she was originally admitted.
- ▶ Other causes of delirium include polypharmacy, post-operative sedation and urinary retention.
- ▶ If a patient has delirium they may be inattentive to the pain - so ask and look for non-verbal cues. Patients with dementia receive 50% less analgesia than other patients.
- ▶ Delirium is very serious and it is important to identify the cause as soon as possible.
- ▶ If you would like to learn more about delirium, then book yourself on to a dementia study day or speak to your local delirium and dementia team about organising a CAM teaching session in your clinical area.
- ▶ Your trust is likely to have a delirium protocol providing guidance on best practice treatments and management of delirium.

### Risk assessment for falls

- ▶ The ward is noisy with many health professionals talking to one another.
- ▶ Barbara’s movement is limited with raised bed rails to which she is objecting.
- ▶ Has a risk assessment for the use of bed rails or one-to-one nursing been carried out?
- ▶ Bed rails may be used in acute care as a falls prevention strategy. However, they should not be used when looking after confused, agitated patients. Avoid bed rails if a patient is able and likely to climb over them.
- ▶ See your trust’s policy on the use of bed rails.
- ▶ Strategies to be used instead of using bed rails include: considering using a low bed with crash mats; using a crash mat on its own; putting one-to-one nursing in place; moving the patient’s bed into an observable area in a bay; using Wanderguard and/or chair and bed sensors.



### SCENE 3

Barbara asks the nurse the whereabouts of her husband. The nurse initially tries to avoid the question but eventually tells Barbara that Len is dead.

#### Teaching points

##### Differing realities/validation

- ▶ Telling Barbara that Len has died causes Barbara enormous distress. Dementia is associated with short-term memory loss and therefore every time Barbara is told Len has died it will be as if she has been told for the first time and she will repeatedly grieve.
- ▶ The nurse should have engaged with Barbara's reality about Len.
- ▶ **Telling the truth** - if we tell the truth and try to orientate Barbara by telling her Len has died, she will grieve again and become more distressed. This may lead to her becoming more confused.
- ▶ **Giving misleading information** - if we respond with something like: "Len has popped out and will be back in a minute" it will raise Barbara's expectations which will not be met, leading to a breakdown of trust and a cycle of confusion and anxiety.
- ▶ **Validating the patient's reality** - "Len is not here at the moment, how can I help? Tell me about Len - where did you meet?"
- ▶ Reminisce with Barbara rather than creating stories about Len.

##### VERA: Validate; Empathise; Reassure; Activity

- ▶ Do not argue with or contradict Barbara. Do not give misleading information or be scared of talking to a patient about his or her life experiences.
- ▶ **Validate:** "I can see you are upset/frightened. I'm sorry Len's not here. How can I help you?"
- ▶ **Empathise:** "You look upset - is there anything I can do to help?"
- ▶ **Reassure:** "My name is XXXX - I am here to help you."
- ▶ **Activity:** Distract: "Where did you meet Len? Where did you get married?" Use pictures, photographs or cards if possible. Try to persuade patients to talk to you about their spouses or next of kin.
- ▶ Patients will not always talk about their spouses, but may talk about their parents.
- ▶ A patient's reality is based in a different time to the present. They may think they are only thirty years old and so their partners and children will be younger too.

### SCENE 4

The hospitality lady offers Barbara a cup of tea in a china cup and saucer. She is smiling and maintains good eye contact with Barbara.

#### Teaching points

##### Positive engagement

- ▶ Small acts of kindness go a long way.
- ▶ Rapport can be built through kindness and compassion and fostering feelings of being special.
- ▶ Visual clues can help to calm patients with delirium, for example, use a china cup and saucer rather than a paper cup and plastic holder.
- ▶ Sometimes using a teapot, milk jug and sugar bowl also helps, as does sitting down and having a drink with the patient.

Thank you for watching **episode three** of Barbara's Story.

Although we have focused on the care of older people and those who are confused, the principles of caring, compassion, respecting others and acting with integrity apply to all our patients.

# Barbara's Story

# training briefing

## Welcome to **episode four** of Barbara's Story

Barbara's story continues to touch the hearts of staff at Guy's and St Thomas' NHS Foundation Trust, inspiring them to make changes to the care they provide to patients.

Like the first three films, some of you may find this one very emotional so if you need to leave please do not hesitate - someone will be on hand to support you at the end of the session.

Before we show episode four we will have a quick recap of the previous two episodes: Barbara appeared unwell and was admitted to A&E with a suspected chest infection. She had a fall whilst in A&E, fractured her neck or femur, and was subsequently admitted to the orthopaedic ward.

Prior to and on waking from her operation, Barbara appeared extremely confused, disorientated and distressed. However, she was calmed by the kind words and action of the hospitality lady who offered her a cup of tea in a china cup and saucer.

Barbara still does not have a diagnosis of delirium or a dementia.

We will now show you **EPISODE FOUR**, which is about 17 minutes long, and then discuss what we have seen.

### **i** WHEN THE FILM HAS FINISHED

Pause for a moment and ask the audience to reflect on the film and the impact it has had. Ask the audience to share their immediate impressions and the key messages from the film - it is advised to take no more than five minutes on this section.

## what's inside

- ▶ **SCENE 1:** Barbara has flashbacks of her husband Len and daughter Anna while she is being transferred to another ward post-operatively.
- ▶ **SCENE 2:** We see the nurse smiling and talking gently to Barbara. However, she is sitting on Barbara's bed.
- ▶ **SCENE 3:** Barbara's daughter Anna comes to visit, but Barbara does not recognise her. This upsets Anna. The senior nursing assistant asks Anna if she is OK, which is good practice.
- ▶ **SCENE 4:** We see Anna talking to the nurse. Anna tells her that Barbara 'doesn't go out and seems to have lost her confidence'. The nurse suggests a referral to the inpatient memory team, but does not have the time to talk to Anna in detail.
- ▶ **SCENE 5:** Barbara is being looked after by nurse Mira - a senior nursing assistant providing special one-to-one nursing care and surveillance for patients.
- ▶ **SCENE 6:** We see the doctor complete a dementia and delirium review (DAD review) with Barbara.
- ▶ **SCENE 7:** The occupational therapist speaks to Anna and Barbara about the support the OT department can provide for Barbara on her discharge.

## SCENE 1

We see Barbara having flashbacks of her husband Len and daughter Anna while she is being transferred to another ward post-operatively.

### Teaching point

#### Transferring confused patients

- ▶ Transferring confused patients from ward to ward can add to their confusion, therefore it is best to minimise moves and transfers.
- ▶ You may find therefore you are caring for patients who would not normally be on your ward. It is right for them to be there.
- ▶ Transferring confused patients at night should only be carried out in exceptional circumstances.

## SCENE 2

The nurse is seen smiling and talking gently to Barbara. However, she is sitting on Barbara's bed.

### Teaching point

#### Reassurance

- ▶ The nurse is trying to calm and reassure Barbara by smiling, maintaining eye contact and talking gently.
- ▶ The nurse is communicating with Barbara and shows care and compassion.
- ▶ Discuss: infection control vs. comforting patient.

## SCENE 3

Barbara's daughter Anna comes to visit but Barbara does not recognise her. This upsets Anna. The senior nursing assistant asks Anna if she is OK, which is good practice. She also suggests Anna helps her mother to eat because Barbara has forgotten how to use her knife and fork. Barbara is still very confused and thinks her husband Len is alive; however, she recognises Anna once she starts to eat with her knife and fork.

### Teaching points

#### Motor memory

- ▶ We all have inherent motor memory. Feeding ourselves is something we have done three times a day since we were very young. The actions of eating are deeply ingrained in our memories.
- ▶ Using gesturing and hand-over-hand movements when feeding patients can trigger motor memory and will also send an early signal to the brain to tell the patient he/she will soon need to swallow.

#### Recognition

- ▶ Sometimes people need a little extra time to recognise familiar faces - Barbara does not recognise Anna straight away but once she starts using her cutlery she recognises Anna.
- ▶ Smell is one of the most powerful, memory-evoking senses and sitting close to a person so they can smell you, hear the sound of your voice and the way you speak can help. Even if they do not remember your name or remember exactly who you are, they will know you are a familiar person.

#### Supporting carers

- ▶ Carers often feel powerless and excluded from care when their relative is admitted to hospital.
- ▶ Encouraging carers to engage with the patient can help them to cope with what is happening. This may include helping with eating and drinking, giving hand and foot massages, brushing hair etc.
- ▶ This must be carefully balanced by not overburdening carers, as some carers will use a hospital admission as respite.
- ▶ Carers are equally as important as patients. They need your support to maintain their physical and mental resilience.

## SCENE 4

We see Anna talking to the nurse. Anna tells her that Barbara 'doesn't go out and seems to have lost her confidence'. The nurse suggests a referral to the inpatient memory team, but does not have the time to talk to Anna in detail. Anna is left in the corridor feeling distressed.

### Teaching points

#### Referral to memory team

- ▶ This is prompted by Barbara's delirium AND the fact there is evidence of personality change and she has had memory problems for some time.
- ▶ Changes in a person's cognition, function and personality for 12 months or more should prompt a visit to the GP.
- ▶ People with a dementia are five times more likely to develop delirium in response to a medical problem. Repeated episodes of delirium may indicate an underlying cognitive impairment.

#### Supporting carers

- ▶ The nurse does not have time to spend with Anna, who is clearly distressed.
- ▶ Carers often need as much care and attention as our patients; they also hold valuable information about a patient's usual day-to-day abilities which can help us when we are making assessments.
- ▶ Ask another member of staff to take the carer to the staff room/relatives' room and offer them a cup of tea. Tell them you will speak to them after you have finished your current task. In the meantime give the carer a delirium and/or dementia patient information booklet. This may help prompt a greater conversation when you are free to talk.

## SCENE 5

Barbara is being looked after by nurse Mira - a senior nursing assistant providing special one-to-one nursing care and surveillance for patients. She accompanies Barbara for walks around the ward, sits with her, helps her do the crossword and helps her to mobilise safely. She helps Barbara to go to the lavatory but Barbara does not want the Wanderguard monitor attached to her.

### Teaching points

#### One-to-one nursing

- ▶ One-to-one nursing should demonstrate best practice and should keep the patient stimulated, engaged and interactive with their care. At Guy's and St Thomas' NHS Foundation Trust we have a dedicated team of senior nursing assistants available to provide one-to-one care to confused patients.
- ▶ The 'heightened surveillance' policy advises staff to use someone familiar from the ward in this role. Using a different bank/agency nurse each day will add to a patient's confusion.

#### Wanderguard

- ▶ This is a small device that can be attached to the nightgown/clothes of a patient and will emit a noise if the patient moves.
- ▶ It can be used if there is a possibility a patient who has a high risk of falls is likely to attempt to walk on their own.

#### Privacy

- ▶ How do we balance a patient's right to privacy with risk of falling?
- ▶ In this scenario it was correct for the nurse to wait outside the door of the lavatory. Each case should be judged on its individual merit.

## SCENE 6

We see the doctor complete a dementia and delirium review (DAD review) with Barbara.

### Teaching points

#### Delirium and dementia review

- ▶ Initially a CAM and a 4AT are carried out to assess whether a patient is delirious or not.
- ▶ When a patient is admitted with an episode of delirium, they are not at their baseline level of functioning. Therefore undertaking a very detailed memory test will be meaningless.
- ▶ If, after assessment, the patient is found not to have a delirium a MoCA (Montreal Cognitive Assessment) is carried out. This can be downloaded from the internet and is available in many different languages.
- ▶ Non-confrontational - Barbara becomes upset when she cannot verbalise the months of the year backwards. The doctor sees this and does not proceed to ask any further questions.

#### Diagnosis of a dementia

- ▶ We do not routinely diagnose a dementia in hospital as it is likely the person has been admitted to hospital because they are unwell and therefore unlikely to be able to perform to the best of their abilities.
- ▶ The community is therefore the usual environment in which diagnosis of a dementia is carried out.
- ▶ Although the hospital is not the right environment for the kind of detailed testing required for diagnosis, some investigations can be carried out such as dementia bloods (routine haematology and biochemistry, thyroid function, serum B12 and folate, HIV and syphilis) and a brain scan (CT and MRI) if appropriate, as all other possible causes of confusion need to be excluded.

## SCENE 7

The occupational therapist speaks to Anna and Barbara about the support the OT department can provide for Barbara on her discharge. We then see that Barbara is ready to go home and she appears back to her normal self. However, her medicines are not ready to be collected.

### Teaching point

#### Discharge planning and TTOs

- ▶ Barbara's medication should have been ready for her on discharge. Maybe the hospital should have couriered them to her home?
- ▶ It is often in the patient's best interests to discharge them home to a familiar environment, even if they have a delirium, as they recover better in recognisable surroundings.

Thank you for watching **episode four** of Barbara's Story.

Although we have focused on the care of older people and those who are confused, the principles of caring, compassion, respecting others and acting with integrity apply to all our patients.

# Barbara's Story

# training briefing

## Welcome to **episode five** of Barbara's Story

Barbara's story continues to touch the hearts of staff at Guy's and St Thomas' NHS Foundation Trust, inspiring them to make changes to the care they provide to patients.

Like the first four films, some of you may find this one very emotional so if you need to leave please do not hesitate - someone will be on hand to support you at the end of the session.

Before we show episode five we will have a quick recap of the previous episodes: Barbara appeared unwell and was admitted to A&E with a suspected chest infection. She had a fall whilst in A&E, fractured her neck of femur and was then admitted to the orthopaedic ward. Whilst on the orthopaedic ward, Barbara appeared confused and disorientated. On waking from her operation she was confused and distressed but was calmed by the kind words and actions of the hospitality lady.

In the last episode Barbara was given a diagnosis of delirium and was seen by the delirium and dementia team (DAD team) who referred her to the community-based memory clinic. Whilst in hospital she was supported by senior nursing assistant Mira who delivered one-to-one safe and supportive care.

Barbara has not been diagnosed with a dementia yet.

We will now show you **EPISODE FIVE**, which is about 15 minutes long, and then discuss what we have seen.

### **i** WHEN THE FILM HAS FINISHED

Pause for a moment and ask the audience to reflect on the film and the impact it has had. Ask the audience to share their immediate impressions and the key messages from the film - it is advised to take no more than five minutes on this section.

## what's inside

► **SCENE 1:** We hear Barbara calling her daughter Anna on the telephone. Anna is not at home - Barbara just hears a message on the answerphone.

► **SCENE 2:** Barbara is seen talking to Len and pouring her orange juice into a jam jar instead of a glass. She is visited by the district nurse who talks to Barbara about how she feels.

► **SCENE 3:** Several weeks after the last visit by the district nurse, Barbara's neighbour Betty calls the district nurse and asks her to make a home visit. Betty is concerned about Barbara who is acutely confused, not dressed in her usual tidy fashion and whose house is far more untidy than normal.

► **SCENE 4:** Later the same day we see the home ward team arrive at Barbara's home to assess her condition. Unlike her earlier presentation, Barbara is now hypo-delirious. The home ward team assess Barbara and decide that it is in her best interest to be taken to hospital and they call for an ambulance.



## SCENE 1

We hear Barbara calling her daughter Anna on the telephone.

Anna is not at home - Barbara just hears a message on the answerphone.

### Teaching point

#### Depression, loneliness and bereavement

- ▶ Barbara telephoning her daughter may indicate she is lonely, anxious or distressed and needs to call close family for reassurance.
- ▶ Alternatively her short-term memory may be failing and she may not remember that she might have already called her daughter several times that morning.
- ▶ Maybe she does not understand how the answerphone works?
- ▶ Low mood may cause memory problems and a depression screen will be part of a memory assessment.
- ▶ Many carers report they find support networks very useful when caring for a loved one with delirium or dementia.

## SCENE 2

Barbara is seen talking to Len and pouring her orange juice into a jam jar instead of a glass. She is visited by the district nurse who talks to Barbara about how she feels.

### Teaching points

#### Emotional responses

- ▶ We all do unexpected things when not concentrating properly, but visual perceptions can shift when viewing objects for those with a dementia and/or delirium - hence Barbara pours the orange juice into a jar instead of her usual glass.
- ▶ Barbara sees Len and talks to him: it is common for patients to have hallucinations if they have delirium. However, in this situation it is more likely that she may also be grieving for Len, making her feel lonely and depressed.
- ▶ Past memories that have involved strong emotions are often the most vivid in the present time.
- ▶ The district nurse shows best practice by discretely observing, but not questioning her, which could cause embarrassment or defensive behaviour.
- ▶ The district nurse is empathetic - she understands that Barbara feels lonely and is missing Len and does not feel embarrassed or nervous by talking to Barbara about her feelings.
- ▶ It is important to have familiar faces around someone with a dementia and wherever possible the same group of nurses need to be involved in their care. Sending someone new to work with Barbara, who is becoming agitated, would not have the desired outcome.

#### Community support

- ▶ District nurse and care worker (nursing assistant) support is arranged in the community as per the needs of the patient. It is goal oriented and is reviewed regularly. Once the goals are achieved or the patient's condition improves, a decision is made as to whether this support needs to continue.
- ▶ Barbara has always been very independent. She tells the district nurse she has been coping well without recent community nursing and nursing assistant support. She also informs the district nurse she has been given a diagnosis of Alzheimer's disease by her GP.
- ▶ It would appear this visit by the district nurse is a review of goals achieved.
- ▶ As Barbara appears very capable, has capacity to make her own decisions and clearly wishes to remain independent, the district nurse suggests Barbara continues to attend her GP and hospital appointments. She implies if Barbara feels she cannot manage, she would be able to ask for help when visiting the hospital or GP.
- ▶ Care worker support in the community is arranged after assessment by the local authority social services department.
- ▶ After assessment, social services appoint a care agency or a care home to provide the relevant care, which is reviewed regularly.
- ▶ If the care needs are high then a long-term care package is deployed with support from other health professionals. The local authority is responsible for all care support needs and is accessed directly through them.

### **Diagnosis of a dementia**

- ▶ Diagnosis of a dementia is made through working in partnership between the hospital, the GP and memory clinic.
- ▶ Barbara's GP was contacted by the hospital dementia and delirium team (DAD team) and she responded by referring Barbara to the community memory clinic.
- ▶ For diagnosis of a dementia to be made, there needs to be a history - over several months - of changes in the patient's functioning, cognition, mood and personality.
- ▶ A brain scan and full blood work up needs to be carried out (along NICE guidelines) to rule out other causes of cognitive changes.

### **'This is Me' document**

- ▶ This is a very useful reference tool that can be used to help communicate with a confused patient.
- ▶ A template can be downloaded from the Alzheimer's Society website.
- ▶ It can be completed by the patient in the early stages of a dementia or by anyone who knows the patient well ie next of kin, healthcare workers, best friend or a neighbour.
- ▶ The 'This is Me' document becomes a patient's life story, and in the community may be referred to as a person's 'Life History'.
- ▶ It is a live working document and can be added to at any time. It remains the patient's property and can be scanned or photocopied and included in a patient's notes in hospital.
- ▶ Healthcare professionals need to remember that as well as being able to complete the document, they also need to share the information with other professionals.
- ▶ Does the district nurse ask Barbara whether she has shared the information of her diagnosis of a dementia with her daughter?
- ▶ Show examples to the audience of a 'This is Me' document.

## **SCENE 3**

Several weeks after the last visit by the district nurse, Barbara's neighbour Betty calls the district nurse and asks her to make a home visit. Betty is concerned about Barbara who is acutely confused, not dressed in her usual tidy fashion and whose house is far more untidy than normal.

## **Teaching points**

### **Hyper-delirium**

- ▶ This scene highlights hyper-delirium. Barbara has had a marked acute change in presentation: she is agitated, confused and restless and does not recognise her neighbour Betty or the district nurse.
- ▶ She has difficulty focusing and sustaining attention.
- ▶ Although dressed, she is wearing her cardigan inside out.
- ▶ The kitchen is very untidy and dirty with mouldy food lying around. This scene illustrates how delirium can impact on functioning.
- ▶ Barbara gestures to her chest: she may be in pain or is having difficulty breathing.
- ▶ It is important to observe cues such as this rather than relying strictly on verbal reporting.
- ▶ The district nurse establishes that Barbara does not wish to be admitted to hospital so she calls the home ward team and asks them to make a home visit later the same day.

### **Home ward team**

- ▶ The best outcome for a patient is to be treated professionally and quickly at home, without the need for an unnecessary stay in hospital.
- ▶ The home ward team includes a matron, specialist community nurses, GPs, pharmacists, rehabilitation support workers and administrators who all provide intensive support to meet patient needs, seven-days-a-week.

### **Decision making and capacity**

- ▶ Barbara is hyper-delirious and does not have the capacity to make a decision, so the district nurse, knowing that Barbara previously requested to be treated at home wherever possible, and acting in Barbara's best interest, makes the decision to call in the home ward team.



## SCENE 4

Later the same day we see the home ward team arrive at Barbara's home to assess her condition. Unlike her earlier presentation Barbara is now hypo-delirious. The home ward team assess Barbara and decide that it is in her best interest to be taken to hospital and they call for an ambulance.

### Teaching point

#### Hypo-delirium

- ▶ This scene shows it is possible for people to change from hyper to hypo-delirium over a relatively short period of time. We see Barbara is very sleepy and difficult to rouse.
- ▶ If left alone and hypo-delirious, patients may not eat or drink enough and may also forget to take their medication.
- ▶ Barbara is very confused and cannot engage with the home ward team due to her altered level of consciousness.
- ▶ Once urgent treatment is given and Barbara regains some consciousness, the ambulance crew use Barbara's 'This is Me' document to communicate and reassure Barbara, reducing her anxiety on the way to hospital.

Thank you for watching **episode five** of Barbara's Story.

Although we have focused on the care of older people and those who are confused, the principles of caring, compassion, respecting others and acting with integrity apply to all our patients.

# Barbara's Story

# training briefing

Welcome to the **final episode** of Barbara's Story

Barbara's Story continues to touch the hearts of staff at Guy's and St Thomas' NHS Foundation Trust, inspiring them to make changes to the care they provide to patients.

This has been a thought-provoking, emotional journey and for those of you who have watched the previous five episodes - thank you for joining us.

Barbara's Story will have made an impact on you and will therefore be making a difference to the way you care and interact with patients who have a dementia.

This last episode is arguably one of the most emotional films in the Barbara's Story series and, as always, it is difficult to watch. Please do not hesitate to leave if you need to - someone will be on hand to support you.

In the previous episode, the community based memory clinic assessed Barbara and she was given a diagnosis of Alzheimer's disease. For a while, Barbara appeared to be coping well at home with the support of carers and the district nursing team, but she subsequently became very confused and agitated again.

She was visited at home by the district nurse and home ward team and an ambulance was called to take her to hospital.

We join her now as she is readmitted to hospital.

This episode is slightly longer than previous episodes.

## what's inside

► **SCENE 1:** Barbara arrives at the A&E department. It is noisy and Barbara is very agitated and confused.

► **SCENE 2:** Barbara is seen confused and wandering in the ward by herself during the early hours of the morning. She is having visual hallucinations and thinks she sees her husband Len on the ward. She is comforted and reassured by nurse Fatima.

► **SCENE 3:** We see Barbara and her daughter at home. She is very agitated and confused. The district nurse and palliative care nurse arrive, calming her down and subsequently explaining the care that can be offered in the community.

## **i** WHEN THE FILM HAS FINISHED

Pause for a moment and ask the audience to reflect on the film and the impact it has had.

Throughout Barbara's journey we have been continuously reminded that Barbara is a person and every episode has made us look beyond the dementia and to focus on Barbara and her needs, and this last episode is no different.

There was an inevitable outcome when we set out on Barbara's Story that she would die. What this episode tries to emphasis is right up to the end dignity, respect and understanding the patient and their care wishes, are critical.

We recognise training after viewing this episode may be difficult. You may therefore choose to go straight to the concluding points on the back page giving staff time to reflect on the journey they have been on.

## **SCENE 1**

Barbara arrives at the A&E department.

It is noisy and Barbara is very agitated and confused.

## **Teaching points**

### **Communication and busy environments:**

- ▶ Transferring confused patients from home to hospital and from ward to ward can add to their confusion, therefore it is best to minimise moves and transfers.
- ▶ When assessing confused patients do one thing at a time. This will help patients to concentrate on what is happening and they may not feel so overwhelmed.
- ▶ When speaking with people who are confused, questions need to be asked one topic at a time leaving plenty of time for the person to respond.
- ▶ Many people feel overwhelmed by being asked too many questions at once or if complex language is used.
- ▶ Try to sit at eye level, use the patient's preferred name, and observe all non-visual cues. Use all the principles of good communication such as asking closed questions, maintaining eye contact, speaking calmly and slowly and observing the 10 second rule.
- ▶ Always observe facial expression and tone of voice. Always check if you have understood what the patient has said.
- ▶ Consider using pictorial cues and gestures as supplements to what you are saying.
- ▶ Do not contradict or challenge what the patient tells you, because this can be upsetting and damage the rapport you are trying to build with them. Engage with the patient's reality even it does not fit in with your own.
- ▶ Although we would not usually pull the curtains round a bed to complete a routine set of observations, consider doing this with a confused patient as it will help minimise distractions, both visual and auditory.

### **The diagnosis of a dementia**

- ▶ For the diagnosis of a dementia to be made there needs to be a history - over several months - of changes in the patient's functioning, cognition, mood and personality.
- ▶ The diagnosis of a dementia is made through working in partnership with the hospital, the GP and memory clinic.
- ▶ A dementia is not routinely diagnosed in hospital as it is likely that the person has been admitted to hospital because they are unwell and therefore unlikely to be able to perform to the best of their abilities. The community is therefore the usual environment in which a diagnosis of a dementia is carried out.
- ▶ Although the hospital is not the right environment for the kind of detailed testing that is required for diagnosis, some investigations can be carried out such as dementia bloods (routine haematology and biochemistry, thyroid function, serum B12 and folate, HIV and syphilis) and a brain scan (CT and MRI) if appropriate, as all other possible causes of confusion need to be excluded.

### 'This is Me' document

- ▶ This is a very useful reference tool that can be used to help communicate with a confused patient. A template can be downloaded from the Alzheimer's Society website.
- ▶ It can be completed by the patient in the early stages of a dementia or by anyone who knows the patient well ie next of kin, health care workers, best friend or a neighbour.
- ▶ The 'This is Me' document becomes a patient's life story, and in the community may be referred to as a person's 'Life History'.
- ▶ It is a live working document and can be added to at any time. It remains the patient's property and can be scanned or photocopied and included in the patient's notes in hospital.
- ▶ Healthcare professionals need to remember that as well as being able to complete the document, they also need to share the information with other professionals.

## SCENE 2

Barbara is seen confused and wandering in the ward by herself during the early hours of the morning. She is having visual hallucinations and thinks she sees her husband Len on the ward. She is comforted and reassured by nurse Fatima.

### Teaching points

#### Empathy

- ▶ Nurse Fatima treats Barbara with respect: she does not challenge her when Barbara thinks she sees Len in the corridor.
- ▶ Barbara is reassured and comforted by a caring and compassionate approach. Nurse Fatima maintains eye contact and uses a soft tone of voice.
- ▶ Later the same morning nurse Fatima uses the same techniques to persuade Barbara to take her paracetamol tablets. When Barbara initially refuses to take her tablets nurse Fatima asks Barbara whether she is feeling hot and then suggests taking her medication may make Barbara feel better.
- ▶ Nurse Fatima's calm and caring approach reduces Barbara's anxiety and helps build rapport and trust between them.

#### Differing realities/validation

- ▶ If nurse Fatima had told Barbara that Len had died and was not really in the corridor, it would have caused Barbara enormous distress.
- ▶ A dementia is associated with short term memory loss and therefore every time Barbara is told that Len has died it would be as if she has been told for the first time and she would grieve repeatedly.
- ▶ The nurse engages with Barbara's reality about Len.

#### VERA: Validate; Empathise; Reassure; Activity

- ▶ Do not argue with or contradict or give misleading information to a patient with a dementia or delirium.
- ▶ Do not be scared of talking to a patient about their life experiences.
- ▶ **Validate:** "I can see you are upset/frightened. I'm sorry Len's not here. How can I help you?"
- ▶ **Empathise:** "You look upset - is there anything I can do to help?"
- ▶ **Reassure:** "My name is XXXX - I am here to help you."
- ▶ **Activity:** Distract: 'Where did you meet Len? Where did you get married?' Use pictures, photographs or cards if possible. Try and persuade patients to talk to you about their spouses or next of kin.
- ▶ Patients will not always talk about their spouses, but may talk about their parents.
- ▶ A patient's reality is based in a different time to the present. They may think they are only thirty years old and so their partners and children will be younger too.

## SCENE 3

We see Barbara and her daughter at home. She is very agitated and confused. The district nurse and palliative care nurse arrive, calming her down and subsequently explaining the care that can be offered in the community.

### Teaching point

#### Community palliative care teams:

- ▶ Community palliative care teams play an important part - involve them.

#### Care of the family

- ▶ Healthcare professionals should remember a patient's family may wish to be closely involved in the patient's care, and this should be respected. In many cases this will help bring closure for the family.
- ▶ Family members may have concerns they need to discuss and this should be addressed by all the healthcare professionals involved in the care of the patient.
- ▶ Families will want to be kept informed. It is good practice to offer a point of contact for them so they do not have to make numerous telephone calls to find out information or talk through their concerns.

## CONCLUDING POINTS

#### With Barbara in mind please always remember:

- ▶ See the person - not the dementia
- ▶ Kindness, patience and a smile go a long way
- ▶ Patients with a dementia need to be cared for in a calm, safe environment
- ▶ Patients with a dementia need time - make time to listen
- ▶ Carers are just as important as the patient - please do not ignore them
- ▶ The way we communicate and share information will need to be adapted
- ▶ Look at your environment - is it dementia friendly?
- ▶ Timely assessment: (FAIR) FIND, ASSESS, INVESTIGATE, REFER
- ▶ Remember acute delirium - identify and treat as a medical emergency

Throughout the series we have tried to show that when all staff, whether clinical or non clinical, are committed to caring for patients in the most compassionate way possible and to the best of their abilities, it makes a real difference to the way patients are treated.

Thank you for taking time out of your busy day to watch this final episode and to follow Barbara through her healthcare journey.

Above all, thank you for caring.