

# RightCare learning disability and aspiration pneumonia scenario

Robert's story: An implementation support tool that highlights the variation between optimal and suboptimal pathways



# » Foreword

**Respiratory disease is one of the biggest causes of death for people with a learning disability in England but many of these deaths are avoidable. In 2021 over 50% of people with a learning disability died before they were 65 years old compared to about 1 in 10 of the general population<sup>1</sup>**

Incidence and mortality rates for those with respiratory disease are higher in disadvantaged groups and areas of social deprivation, and people with a learning disability are no exception to this.

Pneumonia, and particularly aspiration pneumonia, is a prominent cause of death in people with a learning disability. Up to 15% of all respiratory deaths reported to [Learning from Lives and Death review](#) (LeDeR) were caused by aspiration pneumonia in 2021.

Whilst prevention is key to the management of aspiration pneumonia, prompt assessment and diagnosis when symptoms arise is important to ensure patients are cared for in the correct environment and antibiotics are commenced appropriately. NICE guidelines should be followed and particular attention paid to correcting any reversible underlying issues that precipitated the aspiration.

This can be challenging for people with a learning disability because as well as being acutely unwell, they face multiple challenges that result from inequality and discrimination that result in healthcare and patient safety inequalities. These are often created through a lack of reasonable adjustments and appropriate training for clinical staff, and the presence of diagnostic overshadowing.

This scenario shows the difference that can be made to quality of care and outcomes by implementing a consistent approach to good practice when caring for people with a learning disability.

We are pleased that both learning disability and autism and respiratory disease, and more specifically pneumonia, have been recognised as a priority for the NHS and feature in the [NHS Long Term Plan](#).



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1. [LeDeR annual report 2021](#)

\* Please note that Roger Banks was in post April 2020 - March 2023, and Anne Worrall-Davies took up post in May 2023

# » RightCare scenarios

**RightCare scenarios put the person at the centre of the story. They use fictional patients to show the difference between a suboptimal, but realistic, pathway of care compared to an optimal one.**

This learning disability and aspiration pneumonia scenario is part of a series of RightCare scenarios that support local health systems to think strategically about designing optimal care for people (and their carers) with high impact conditions.

They help local systems understand how patient outcomes and quality of life can be improved as a result of shifting the care pathway from a suboptimal journey to one that consistently delivers timely, evidence-based excellence.

The suboptimal story in this scenario deliberately highlights where along the care pathway we know often requires improvement. We invite systems to consider the following questions when using this scenario:

- Do you recognise any elements of the patient journey highlighted in this scenario?
- Which journey best reflects the service within your area?
- What parts of the patient journey and experience can you improve?



This scenario has been developed with expert stakeholders using RightCare methodology. The aim is to help clinicians and commissioners improve value and outcomes for this patient group. To see the full suite of RightCare products please visit the NHS England [website](#).

If you have any questions about this scenario or other RightCare products, please contact us at [rightcare@nhs.net](mailto:rightcare@nhs.net).



## What is a RightCare scenario?

Use fictional patients to show the difference between optimal and suboptimal pathways of care



Put the person at the centre of the story



### Spark strategic questions

- Do you recognise any elements of the patient journey?
- Which journey best reflects the service within your area?
- What parts of the patient experience can you improve?



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# » Clinical introduction

**Aspiration pneumonia is the infectious pulmonary process that occurs after abnormal entry of material into the lower respiratory tract. The aspirated material can be oropharyngeal secretions, particulate matter or gastric content.**

Prevention is a key component of managing aspiration pneumonia. Key indicators that someone has developed it, include:

- Cough and coughing up purulent sputum
- Difficulty breathing and increased respiratory rate
- Pleuritic chest pain
- Fever
- Headache
- Nausea and vomiting
- Reduced appetite and weight loss
- Change in voice quality
- Change in facial expression/colour
- Confusion, agitation change in normal behaviour

The risk of developing aspiration pneumonia in patients hospitalised for community-acquired pneumonia is found to be about 13.8%. The mortality rate from aspiration pneumonia is largely dependent on the volume and content of aspirate and can be up to 70% (['Aspiration Pneumonia'](#), 2022).

A study of death certificates by Glover and Ayub (['How people with learning disabilities die'](#), 2010) found that people with a learning disability are, on average, seven times more likely to die from lung inflammation caused by aspiration than people who do not have learning disabilities. Furthermore, data from the Learning from Lives and Deaths Review (LeDeR) demonstrates that aspiration pneumonia is an important issue for people with a learning disability.

Conditions that may be associated with learning disability such as cerebral palsy, Down's syndrome or dementia, can all make eating, drinking and swallowing more difficult thereby increasing the risk of aspiration, and the subsequent risk of developing aspiration pneumonia.

Aspiration pneumonia can occur with swallowing disorders, during periods of impaired consciousness (e.g. during a seizure), or with other conditions such as gastro-oesophageal reflux or chronic obstructive pulmonary disease (COPD). People receiving nasogastric feeds or with a tracheostomy are at particular risk, as are those with poor mobility or posture problems, frailty, poor oral health, or using certain medications.

People with a learning disability may have a delayed diagnosis and treatment of aspiration pneumonia because of factors such as lack of [reasonable adjustments](#), [diagnostic overshadowing](#), and lack of appropriate training for clinical staff.

Aspiration pneumonia should be treated promptly with antibiotics. A referral to a Speech and Language Therapist (SaLT) should be made to ascertain the cause of the aspiration and to advise on treatment. Primary care clinicians should make an appropriate assessment of all patients living with a learning disability, and, if they are considered to be at risk, they should receive a [one-off pneumococcal vaccination](#) in addition to the childhood vaccination schedule.



## » Introducing Robert

**Robert is in his mid 20s and was born with cerebral palsy and a moderate learning disability. He has an older brother and younger sister, and lives in a residential college 10 miles from his parents.**



Robert is largely non-verbal. His family and his main carer, Lucy, understand his signing and he likes using a combination of vocalisations, Makaton (a unique language programme that uses symbols, signs and speech to enable people to communicate), pictures and a specialist tablet computer to communicate. He is very fond of Lucy who has developed a communication tool with him and his family to support his communication with others. He uses a specialist wheelchair and is independent enough to use the bus with his carer.

He is happy living at the college and has many friends. He particularly enjoys all the activities such as 'Green Fingers Fridays' where, supported by staff, he does the gardening and also regularly visits a local farm to feed the animals.

When he's at the college he loves going through his photo albums, looking at his favourite book, and watching music channels on TV with his friends. Robert enjoys mealtimes and his family take him to the local café regularly.

Although Robert doesn't like needles, he has had the pneumococcal, COVID-19 and flu vaccines which were offered when he attended his annual health check because he understood their benefits. With reasonable adjustments and lots of support from Lucy he tolerated the injections and knew that he could cope with injections and blood tests in the future provided similar reasonable adjustments were made.

**Read on to see how Robert experiences two very different journeys and outcomes. Look out for 'Information points' throughout the suboptimal and optimal journeys; these highlight the key themes of optimal care for pneumonia. More information about these can be found on pages 16 and 17.**

## The start of Robert's suboptimal journey: Robert is 20 years old

Robert, along with a member of his family, attends the local GP surgery for his annual healthcheck. Whilst he has been eligible for these appointments since he was 14 years old, he hasn't been invited to attend every year. During the appointment, the GP speaks to Lucy about the importance of good oral health and when asked, Lucy states Robert has missed his last two dental appointments because he hates going. The last appointment he did attend had to be abandoned part way through as he was so distressed.

The GP suggests to Lucy that she find a local dentist who specialises in providing care for people with a learning disability that can make reasonable adjustments. They didn't provide any advice on how to do this and Lucy is left feeling unsure what to do next.

Back at the college, it's lunchtime and Robert is in the main dining room enjoying lunch with his friends, as usual. Robert coughs a lot after he's finished eating and complains he has stomach ache (that is not due to constipation). This has been happening after most meals lately.

Robert had seen the GP for chest problems and stomach ache before. He was usually prescribed antibiotics and recovered in a few days.

## Day 1: Robert becomes ill and his symptoms deteriorate

One afternoon, Lucy noticed that Robert didn't really seem himself and that he was coughing and running a temperature. He didn't want any dinner or anything to drink which was unusual. Lucy informed Robert's parents and they agreed Lucy should keep an eye on him and update them with any changes.

However, later that evening Robert deteriorated. He wasn't interested in his favourite book, didn't want to listen to any music or look at his tablet.

Lucy knew that this meant he wasn't well as she, along with Robert's parents, had been trained to look out for the soft signs of deterioration using an [identification of deterioration tool](#).



**Information point:**  
Use of soft sign skills and SBARD communication skills

Lucy took Robert's pulse oximeter reading (SpO2) using the small machine they had at the college and it read 92%, a reduction in his normal value of 96%. However, she wasn't sure what to do so she decided she would check again the following morning.

When Lucy called the GP the next morning to arrange a home visit, the GP surgery did not appreciate how unwell Robert was and did not recognise the significance of the soft signs Lucy reported.

As a consequence, the GP didn't attend but from what the care team told them they suspected a chest infection. The GP suggested to Lucy that she and the care team keep an eye on Robert and if he didn't improve in the next few days they would attend, if needed, however they didn't explain what signs she should look out for.

In the meantime, they prescribed a course of amoxicillin capsules but Robert had trouble swallowing them due to their size.

## Day 1: Robert is admitted to hospital

Later that night, Lucy, in agreement with Robert's parents, called NHS 111 as she was concerned about the rattling in Robert's chest. The paramedic who returned Lucy's call advised that she call an ambulance. When the ambulance crew arrived Lucy informed them that she had placed Robert's [hospital passport](#) in his bag. The hospital passport tells the hospital about Robert's healthcare, his learning disability, how he likes to communicate and how to make things easier for him.

Robert was assessed in the emergency department for clinical assessment and diagnostic tests. National Early Warning Score ([NEWS2](#)) and [CRB65](#) scores were taken along with basic bloods. A chest x-ray was attempted but caused Robert too much distress so was abandoned without getting a useable image.

As his SpO2 was 92%, Robert was admitted for the night on a short stay ward and given a different antibiotic. He was very distressed and only settled when Lucy was allowed to join him. Due to his distress, no blood gas analysis was obtained. He was also reluctant to keep the saturation probe on his finger as it was uncomfortable and the reason why it was needed had not been explained. Despite having his hospital passport this was not referred to during his stay.

After Lucy had gone home for the night, Robert became more distressed on the ward. He felt unwell and was in a strange place. He didn't have his wheelchair with him, or support with his posture in bed, which meant he was very uncomfortable because he was in the wrong position. His computer was also attached to the wheelchair so he was unable to communicate with anyone now Lucy had gone.

Robert started shouting for Lucy but when she didn't come he became more upset and kept other people on the ward awake overnight because he was so frightened.

Staff didn't recognise that his behaviour was because he was scared and ill with probable hypoxaemia (low levels of oxygen in his blood). They thought he was being disruptive and not cooperating with treatment.

## Day 2: Robert is discharged

The decision was made to discharge Robert the next day with oral antibiotics and feed thickeners. They had attempted to do a chest x-ray in the morning but again, had to stop due to Robert's distress. No plans were put in place for further follow up.

The pharmacy was very busy when he was discharged so his requirements were not fully considered. This meant his antibiotics weren't dispensed in liquid format meaning Robert would struggle to comply because he found it difficult to swallow pills and capsules.

The pharmacist also dispensed the prescribed feed thickeners but this wasn't explained to his carers. As a result, the carers didn't know how to use feed thickeners and Robert continued to cough and splutter when drinking, getting more short of breath. He started to drink less and less.

As Robert couldn't swallow the medication easily, several doses were missed. Despite not completing the full course of antibiotics, Robert began to feel better.

## Day 6: Robert's symptoms return and an ambulance is called

After a few days his symptoms return but they were much worse than before.

The college called for an ambulance who determined that Robert needed to go to hospital. They lifted him out of his wheelchair and put him onto the ambulance stretcher which made him feel uncomfortable and unsafe.

On the way to the hospital, the ambulance crew measured his oxygen saturation level and noted it was low at 90%. He had a high NEWS2 score of 7 which prompted emergency assessment. Robert was placed on oxygen using a full face mask. He didn't tolerate this and kept pushing it off and, as no carer was allowed to accompany him, he was scared and unable to communicate with the crew.

Robert had his hospital passport in his bag but the ambulance crew were so busy with their treatment and preparations that they didn't think to check his bag or ask for it.

The stress exacerbated Robert's condition and he deteriorated during the ambulance journey.

## Robert arrives at hospital but no reasonable adjustments have been made

When Robert arrived at the hospital the transfer was delayed because there had been no pre-alert. The emergency department (ED) was very busy and he had to wait in the main waiting area for several hours. Although he was allocated an ED nurse, he felt very scared and isolated. Quite a lot of people would stare at him and not speak as they passed which Robert found very upsetting. The fact that there was no pre-alert meant that the learning disability liaison nurse was not available to support him either.

Robert was still feeling distressed as he had no means of communication – his carers hadn't been allowed to travel with him, his hospital passport was still in his bag unread and his computer was attached to his wheelchair back at the residential college.

Once Robert was examined, the emergency department staff tried their best to explain to Robert why they needed to remove his clothes and put a gown on, but as they didn't understand his communication needs, he didn't know what was happening and was frightened.

A nurse brought a needle out before explaining to Robert that he would need a blood test and he became very distressed. Reasonable adjustments were not made to enable the blood to be taken and topical anaesthetic cream wasn't offered. The team tried to support his arm but Robert became very distressed and the procedure was abandoned.

Based on Robert's history and limited clinical examination, he was started on oral antibiotics. Again, these were in capsule form which he found difficult to swallow.



## Day 6: Robert is admitted to a general ward

The hospital staff thought his distress and poor communication was normal for him and they assumed that his breathlessness and coughing was being exacerbated by the fact he was upset.

By now Robert had been propped up in a sitting position in a hospital bed for several hours and his back was very sore.

Robert was admitted to a general ward as he was not considered ill enough for the high dependency unit (HDU). He was assessed by the on-call registrar, who, incorrectly assumed that many of Robert's symptoms were a consequence of his learning disability and him being very upset.

By this point, Robert felt so ill and tired that he didn't try and communicate with anyone. The medical team read the fact that he was a lot calmer as a good sign and he continued the course of oral antibiotics.

## Day 8: Lack of personalised care and dignity in Robert's care

Robert did not respond to the oral antibiotics so this was changed to intravenous (IV) antibiotics. By now Robert was very ill, scared and he expressed this by being more and more upset. His behaviour was perceived as

challenging as he would not co-operate with attempts to insert a cannula to administer IV antibiotics.

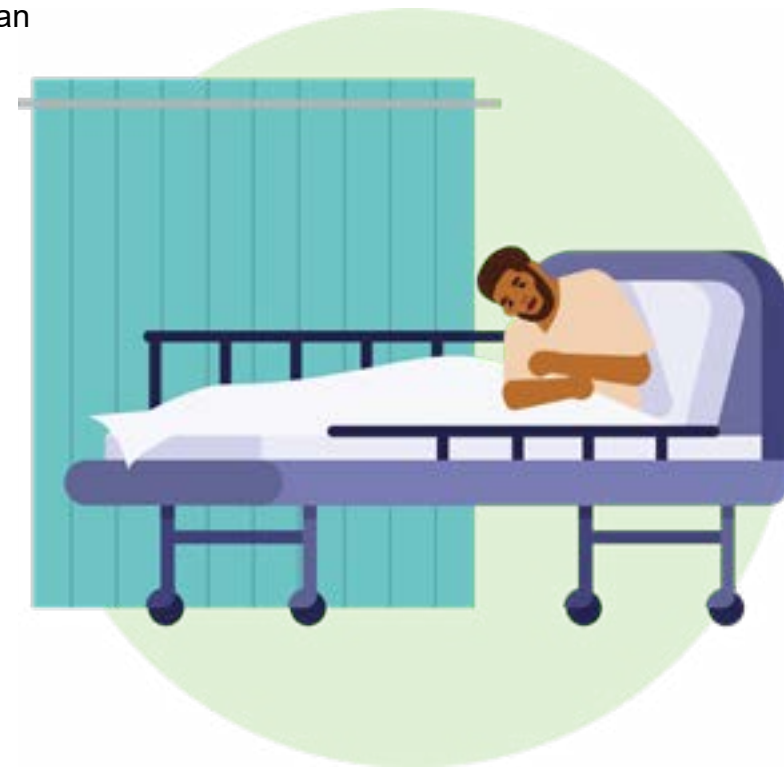
Staff misinterpret this as Robert refusing IV antibiotics when in fact he was expressing that he felt frightened and very ill.

Because the staff on the wards were really busy and didn't really understand the reasons for Robert's behaviour and how ill he was, carers and family were not informed or given the opportunity to help Robert receive IV antibiotics and no reasonable adjustments were made. His family and carers were only allowed in during standard visiting hours rather than when clinical decisions or procedures were being made or undertaken.

**2** Information point:  
Personalised care and dignity

Despite his agitation and not drinking, no fluid balance chart was commenced and his hydration was not considered.

As the staff perceived Robert's behaviour to be part of his disability and thought to be normal for him, no onward referrals were made for SaLT assessment, dietetics or occupational therapy. No [Recommended Summary Plan for Emergency Care and Treatment \(ReSPECT\)](#) conversation took place and it was assumed that his normal quality of life was so poor that this was unnecessary.



## Day 9: Robert has a witnessed aspiration and deteriorates further

Robert doesn't want to eat on the general ward and has trouble swallowing. He is started on thickened fluids but they give him a sore dry mouth. Even though he has a sore mouth, the possibility of thrush, which can be caused by the antibiotics, is not considered. He found eating painful and started to refuse feeds which meant he lost weight very quickly. The inconsistent use of feed thickeners resulted in Robert having a witnessed aspiration and he refused to eat at all. These problems were in part all exacerbated by poor posture as he still didn't have his wheelchair.

Robert wasn't referred to physiotherapy because he was bringing up very little sputum, but no-one had really thought about his posture and how this could exacerbate the problems he faced. He still hadn't received any IV antibiotics due to his distress at having the cannula inserted and continued to take them orally.

Over the next few days, Robert continued to deteriorate and lose weight. He was still on the general ward and the respiratory team were called in to review him. However, they had never seen Robert at his best and were reluctant to refer him to critical care until Robert's mother and Lucy intervened and insisted that "something was done". They knew he was very distressed and unwell and were concerned that diagnostic overshadowing was occurring.

### 3 Information point: Diagnostic overshadowing

Robert was reviewed by the anaesthetic registrar who was not experienced with working with people with a learning disability. They had a phone consultation with the critical care consultant who agreed with the assessment that due to perceived severe cognitive impairment and poor quality of life, critical care would be inappropriate. They agreed that if Robert was intubated, he would unlikely breathe independently, would need a tracheostomy and die anyway so it wasn't an appropriate use of an ITU bed.

## Day 12: Robert dies

Robert was moved to the respiratory ward as he was now critically ill. The staff make a decision not to resuscitate Robert if his heart stops but did not discuss this with his family. Robert was referred to the palliative care pathway and shortly afterwards he has a respiratory arrest followed by a cardiac arrest and dies.

### 4 Information point: Advanced care planning including DNACPR

Robert's family are devastated by his death and do not understand why this has happened. The medical team perceived that the family perhaps had an unrealistic opinion of Robert's condition and that perhaps they ought to have expected him to die. The trust did not notify LeDeR of Robert's death and his family didn't know they could do it.

This misperception of Robert and his family resulted in no support or care for them. They struggled with their loss and the many unanswered questions.

The family lodged a complaint with the patient advice and liaison service (PALS) service.

## Robert's optimal journey starts much earlier. We go back four years to when he was 16 years old.

Robert, along with a member of his family or a trusted carer, has been consistently attending his annual healthcheck at his GP practice since he's been eligible for these appointments at 14 years old. The GP, who knows Robert well, checks his physical health and asks about things that can be much more common in people with a learning disability, such as constipation or problems with swallowing (dysphagia) and reviews his medication.

As part of the healthcheck the practice nurse checks Robert is up-to-date with his pneumonia and flu vaccines (which he is). They talk about staying and living well, including physical activity as this supports respiratory health, and helps Robert with any questions he may have. Robert is also asked whether he needs any community support to assist with his social wellbeing, friendships and hobbies.

Robert goes for a check-up at his local high street dentist twice a year who make the necessary reasonable adjustments for him. He nearly always sees the same dentist and hygienist who know he doesn't like the examination and treatment to take too long.

They always discuss the importance of prevention, fluoride and diet in a supportive manner. Robert understands the benefits of good oral health and is supported to brush his teeth twice a day.

The staff at his college regularly undertake training sessions on identifying the symptoms of aspiration pneumonia and how to reduce the risks of developing it, with particular attention being given to postural support, eating techniques and supporting oral hygiene.

## Start of Robert's symptoms: Robert is 25 years old - GP review

One afternoon, Lucy noticed that Robert didn't really seem himself and that he was coughing and running a temperature. He didn't want any dinner or anything to drink which was unusual. Lucy informed Robert's parents and they agreed Lucy should keep an eye on him and update them with any changes.

However, later that evening Robert deteriorated. He wasn't interested in his favourite book, didn't want to listen to any music or look at his iPad.

Lucy knew that this meant he wasn't well as she, along with Robert's parents, had been trained to look out for the soft signs of deterioration using an [identification of deterioration tool](#). Lucy took Robert's pulse oximeter reading (SpO2) using the small machine they had at the college and it read 92%, a reduction in his normal value of 96%. As he was not drowsy, she decided she would check on him again in the morning.

## Day 1: Robert is examined by the GP at home

The next morning, when Lucy checked Robert's SpO2 it was stable at 92%. She called the GP who visited Robert at the college, concerned that Lucy and his family had picked up on several 'soft signs' of serious illness. The GP was aware of these and could see immediately that Robert was withdrawn and lethargic, which he knew was really unusual for him.

Lucy had assessed Robert and then used the [SBARD](#) communication tool to have a structured conversation with the GP. SBARD is a set of standardised questions that enable staff to share concise information effectively, reducing the need for repetition and the likelihood of errors.

The GP talked to Lucy who, empowered by the SBARD tool, explained that Robert didn't want to eat and was reluctant to drink. She also mentioned that he sometimes got stomach ache and would start coughing just after he had eaten.

On examination, it was clear that Robert had a temperature and his chest was crackly. The GP retook Robert's oxygen saturation levels and also found that it was 92%, far below his normal reading of 96%. They also carried out a CRB65 score which gave a score of 1. Given Robert's CRB65 score and hypoxaemia the GP felt an assessment at the local hospital was warranted as he may have aspiration pneumonia.

## Ambulance crew use Robert's hospital passport to reduce his distress

The GP arranged for an ambulance to transport Robert to hospital. He explained to ambulance control that Robert had complex needs and would have his hospital passport with him which outlined what his preferences for communication were and any reasonable adjustments that were needed.

He also let them know that Robert's hospital passport explains that he would get distressed if he had to wait in a crowded, noisy environment, for long periods of time and asked for reasonable adjustments be made to accommodate this.

When the ambulance crew arrived, they confirmed that he had a high temperature, rigors and had purulent sputum when he coughed.

The paramedic worked with Lucy to explain to Robert why he needed to go to hospital. They also noted from his hospital passport that Robert was less anxious when a trusted carer was with him, so Lucy was also allowed to accompany him in the ambulance to help with communication and to provide a familiar face.

The crew started Robert on oxygen therapy. Whilst it made him feel a bit better, he could not tolerate the mask on his face and kept pushing it off. The paramedic suggested that they try a nasal cannula, and whilst Robert was hesitant, he found this a lot easier.



## Day 1: Robert arrives at hospital and is assessed with support

The ambulance crew phoned ahead to the hospital to alert them to Robert's low saturation on oxygen, imminent arrival and that he needed a quiet area and other reasonable adjustments to help him cope with the admission. They also requested that these be added to his medical record.

Robert's parents met him at hospital and brought his chair.

On arrival at hospital, Robert was immediately triaged in the emergency department and moved in to a side room that contained no other patients and was quieter. The learning disability liaison nurse was informed of Robert's arrival.

### 5 Information point: Reasonable adjustments

After the handover, the medical team did a full ABCDE ([The ABCDE approach, Resuscitation Council UK](#)) assessment. Robert didn't like having his clothes removed but Lucy, along with the learning disability liaison nurse, explained why this was necessary and did everything possible to maintain Robert's dignity and privacy at all times which made the examinations tolerable.

## Robert's timely diagnosis of pneumonia and the start of treatment

The results of the initial examination determined that Robert was tachycardic with a pulse rate of 120bpm and had a respiratory rate of 32. This, combined with a raised temperature, gave a high NEWS2 score of 8.

The medical team calculated Robert's CURB65 score as 1. Although Robert's score was only 1 his assessment of clinical severity suggested his condition needed intensive treatment with a combination of antibiotics by IV (co-amoxiclav) and oral suspension (clarithromycin).

He had a normal consciousness level and his blood pressure was 128/72 mmHg.

On examining Robert's chest, the attending doctor detected bronchial breathing at the base of his right lung, indicative of consolidation that is usually due to pneumonia.

It was decided that he needed some blood tests (including urea and electrolytes) and a chest X-ray. With Lucy's help this was explained to Robert. Initially he was distressed at the idea of blood tests but when the learning disability liaison nurse explained that they could use some local anaesthetic cream to numb the skin and make it less uncomfortable, Robert was able to cooperate. Having his own chair with him was helpful because he was able to maintain a comfortable posture and it meant that he had his computer with him to help him communicate.

After taking the blood, a portable chest x-ray was brought to Robert's bed and a chest x-ray was taken. Again, Lucy and the learning disability liaison nurse explained this to Robert and supported him through the x-ray. After about 40 minutes, the lab results were available and showed a high white cell count with neutrophilia and a high [C-reactive protein](#) (CRP) level of over 200. A few minutes later, hot reporting of the x-ray results showed right lower lobe consolidation which confirmed pneumonia.

### 6 Information point: BTS pneumonia guidelines

Given the history from Lucy that Robert sometimes coughed after eating, consideration was given to aspiration and an urgent referral was placed to the speech and language therapy team. Robert was allowed to eat and drink under supervision in a safe swallowing position, pending review by the speech and language team. The speech and language team later reviewed Robert and devised a plan to help Robert eat and drink safely.

Robert's care was discussed with the on-call respiratory team over the phone, who came and assessed him in the emergency department. They agreed that due to high [FiO2](#) requirement he should be transferred to the High Dependency Unit (HDU) for monitoring.

The HDU team discussed Robert's care with his parents and Lucy who confirmed Robert had a very good quality of life. They showed them a video Robert made as part of his hospital passport, which shows him on his best day. A [Recommended Summary Plan for Emergency Care and Treatment \(ReSPECT\)](#) conversation was also held with Robert, Lucy and family to create a personalised set of recommendations for Robert's care in the case of an emergency situation.



## Day 2: Robert is admitted to critical care

The ReSPECT conversation initiated a prompt joint review between the critical care consultant and the acute medical consultant. A plan was agreed to take Robert to critical care for specialist multidisciplinary care, monitoring and regular chest physiotherapy with cough augmentation for airway clearance.

Although he did not need to be invasively ventilated, the enhanced monitoring and treatment available on critical care was felt to offer significant advantages to Robert. After 24 hours of monitoring, Robert is discharged from critical care to a respiratory ward, with critical care outreach follow-up if needed.

After 72 hours of IV antibiotics, fluids and oxygen, Robert is clinically improving and is switched to oral therapy as a syrup to swallow for another two days. During this time Robert has a personalised care plan written which included regular positional changes, airway clearance, seating plan, pain relief, nutritional targets, twice-daily oral hygiene and health and wellbeing strategies.

By the third day, Robert was starting to eat. He was less keen on the daily chest physiotherapy for secretion clearance but it made him feel so much better afterwards. He was able to tolerate this provided a carer was present who could help him to communicate with the physiotherapist.

The physiotherapy team make a big effort to understand and learn Robert's communication methods which make him feel a lot more secure. To help him with this, the hospital allowed Lucy and his family to be at the hospital for some of his treatments.

Lucy and Robert's family were also able to show some of the staff on the ward how to communicate better with Robert. This made him feel less isolated when he was on his own and could communicate some basic needs like needing a drink or to go to the toilet.

Whilst in the hospital, the social worker reviewed Robert's care plan to ensure that all the changes in his needs were met.

## **Day 10: Robert is discharged from hospital with a clear plan**

On day 10, Robert's doctors were confident that he met the criteria for safe discharge. Robert, his parents and Lucy were advised that on treatment he would steadily improve and the recovery expectations and timescales were clearly explained. A detailed discharge summary was prepared that included MDT input, onward referrals to maximise his recovery and written advice about expected recovery trajectory.

After Robert was discharged from hospital the discharge letter, which was electronically sent to his GP surgery, was passed to the clinical pharmacist who noticed that many of Robert's medications had been changed to include alginate-based syrup to help indigestion and feed thickeners.

## **6-8 weeks later: Robert has a follow-up appointment and clinical review**

The acute learning disability liaison nurse informed the community learning disability teams of Robert's admission and discharge to ensure that his follow-up assessment is planned.

Robert's family found his illness hard to come to terms with. The community learning disability team provided them with details of the local carers network and [NHS Talking Therapies](#), for anxiety and depression service and signposted them to the GP if needed.

Prior to discharge, Robert's medical team arranged for him to have a follow-up chest x-ray and clinical review by the respiratory team in 6-8 weeks' time. An appointment letter was generated from the alert on the system in an accessible format that detailed the appointment, location, date and time.

A week before the appointment a phone call was made to Lucy and Robert by the hospital to discuss the appointment and any reasonable adjustments that may be required. The learning disability liaison nurse arranged to attend the follow-up appointment to support Robert with the discussions taking place.

The x-ray confirmed resolution of the consolidation and the pneumonia had cleared up. The learning disability liaison nurse made the necessary follow-ups in the community by notifying the right teams to ensure that the right information is shared, at the right time.

On discharge, Robert returned to the residential college and, supported by Lucy and the community team, continued with his recovery with a care plan in place to prevent further aspiration.

He enjoyed being back with his friends but he initially wasn't able to get involved in the physical activities such as gardening.

After a few weeks, Robert was starting to feel like his old self and, was gradually able to get more involved in Green Fingers Fridays and started visiting the farm again, which he'd really missed.

His love of food came back and he looked forward to his weekly visit to the local café with his family.

# » Information points

1

## **Information point: Use of soft sign skills and SBARD**

People with a learning disability who are becoming unwell may be unable to tell carers how they feel. In addition, symptoms may present differently. Soft signs are changes in a person's normal behaviour which could include changes in sleeping, eating, drinking and mood. It is important to recognise these signs as early identification of deterioration allows for early intervention and treatment.

There are tools such as [SBARD](#) (situation, background, assessment, recommendation and decision) which can be used by carers and health professionals to spot the soft signs of deterioration and provides a framework for communicating important and relevant information. Further information on soft signs can be found [here](#).

2

## **Information point: Personalised care and dignity**

Personalised care planning is necessary to ensure people with a learning disability are supported to make the lifestyle and behaviour changes needed to achieve and sustain improvements in their physical health. Personalised care planning should address the full needs of the service user, taking steps to combat loneliness and isolation, and promoting wider engagement in selfcare, exercise, healthy eating and lifestyle. Crucially, the process involves shared decision-making between the service user and the professionals supporting them. For more information please see NHS England's [personalised care and support planning handbook: The journey to person-centred care](#).

Key to this is dignity. When present, dignity ensures people feel in control, valued, confident, comfortable and able to make decisions for themselves. When absent, people feel devalued and lacking in control or comfort. They may lack confidence and be unable to make decisions for themselves. They may feel humiliated, embarrassed or ashamed. Dignity applies equally to those who have capacity and those who lack it. Everyone has equal worth as a human being and must be treated as if they are able to feel, think and behave in relation to their own worth or value. (RCN, 2008)

3

## **Information point: Diagnostic overshadowing**

Diagnostic overshadowing occurs when people assume that the behaviour, symptoms or signs of a person with a learning disability is because of their learning disability and they fail to consider whether other factors are causing this. For example, they may be in pain or have a physical health condition. Diagnostic overshadowing could result in key diagnoses being missed, potentially with serious consequences.

For information: <https://leder.nhs.uk/images/resources/Action-From-Learning-Report-2021-22.pdf> (page 10)



# » Information points

## 4 Information point: Advance care planning and DNACPR

Advance care planning is a way for someone to express and document their preferences about how they wish to be cared for as their illness progresses. It includes where they want to be looked after and what treatments they want and don't want. Advance care plans should be followed if someone loses mental capacity to make decisions about their care. Health and social care professionals should be ready to talk to people about their wishes and support them to make an advance care plan.

This should include decisions about DNACPR – do not attempt cardiopulmonary resuscitation. A DNACPR (or a 'DNR' or a 'DNAR') is an advance decision not to attempt cardiopulmonary resuscitation should a person experience cardiac or respiratory arrest. When used appropriately it helps to ensure that a patient's death is as peaceful and dignified as possible. Any decisions made must be with the appropriate involvement of the patient, their relatives or carers. For people with a learning disability, it is evident that sometimes the complex combination of clinical circumstances and a lack of patient, or family and carer, involvement leads to the inappropriate issue of a DNACPR order. Remember that there will be patients over 18 who have a Health and Welfare Lasting Power of Attorney or a Deputyship in place.

For information: [www.england.nhs.uk/publication/universal-principles-for-advance-care-planning/](http://www.england.nhs.uk/publication/universal-principles-for-advance-care-planning/)

## 5 Information point: Reasonable adjustments

The [Equality Act 2010](#) and the [Public Sector Equality Duty](#) require that all publicly funded services make reasonable adjustments to “remove any barriers – physical or otherwise – that could make it difficult for disabled people to use their services or prevent them from using them altogether”, this is a legal requirement. Reasonable adjustments for someone with a learning disability or who is autistic could include longer appointments, providing easy read materials or having the support of a carer. They will vary from person to person.

For more information visit <https://www.england.nhs.uk/learning-disabilities/improving-health/reasonable-adjustments/>

## 6 Information point: BTS pneumonia statements

The British Thoracic Society (BTS) statements provide pragmatic guidance on the management of certain clinical conditions. The recommendations made are based on a review of the published evidence but are predominantly based on expert opinion aimed at providing pragmatic guidance.

There are two that provide advice on aspiration pneumonia and learning disability:

1. The risk assessment, prevention and management of community-acquired pneumonia (CAP) in people with a learning disability.
2. Risk assessment, prevention and management of aspiration pneumonia (AP).

Each section is summarised with key clinical practice points.

For information: <https://www.brit-thoracic.org.uk/quality-improvement/clinical-statements/>

## » The 'cost' of aspiration pneumonia

**As Robert spends a similar total amount of time in hospital in both the suboptimal and optimal journeys the difference in cost is minimal, however, the outcomes for Robert could not be starker or more impactful.**

Sector	Optimal (£)	Suboptimal (£)
Primary care	36	48
Secondary care	3,962	3,698
Ambulance service	357	714
Community pharmacy	0	0
Medicines	96	39
<b>Total (£)</b>	<b>4,451</b>	<b>4,499</b>

*Estimated financial costs for the patient journeys*

In the suboptimal journey the seriousness of Robert's pneumonia is overshadowed by his disability throughout his care journey. His acute symptoms and subsequent behaviour are incorrectly presumed to be signs of his disability and not considered. Because of the delays to recognise the seriousness of Robert's condition and the lack of implementing the right treatment in a timely manner, Robert deteriorated. The ending of the suboptimal journey makes for difficult reading but it's important to recognise that Robert's death was avoidable.

Although prevention is hugely important in aspiration pneumonia, the optimal journey shows the immeasurable impact of adopting a personalised approach that treats Robert as an individual. His disability and symptoms were separated through engagement with Robert's family and carer, and reasonable adjustments are made throughout Robert's care. These adjustments enabled Robert to feel as comfortable as he could be in stressful circumstances, understand what was happening to him and the reasons for the various treatments, and to be part of the decision-making process. This approach enabled the right care to be implemented in the right way at the right time which resulted in Robert making a full recovery.

The table on the left summarises the financial costs calculated for the two pathways by health sector/area. National average costs and similar data sources have been used to calculate the indicative healthcare costs of two hypothetical pathways of care for an individual fictionalised 'typical' person, and therefore do not represent the local cost of service provision.

It is recommended that systems work with local clinical leaders and costing colleagues to map existing pathways, taking into account local circumstances and evidence, and reflecting the make-up of the local population and services already in place.

## » Areas for systems to consider

The following questions are to encourage discussion and investigation within local systems. They are focused on the key optimal themes that can lead to improvement in care for people with a learning disability who develop aspiration pneumonia:



- » How does your local system assure itself that care is continually improved for people with a learning disability?
- » How do you ensure that all healthcare staff are sufficiently trained and made aware of diagnostic overshadowing and are able to identify soft signs of deterioration when treating people with a learning disability?
- » How do you assure yourselves that all reasonable adjustments are made available throughout the pneumonia care pathway for people with a learning disability?
- » Do patients with a learning disability have access to learning disability specialist nurses at emergency departments, and whilst in hospital, to support them in their care? If not, how do you assure yourselves that all reasonable adjustments are put into place and that diagnostic overshadowing does not occur?
- » How do you assure yourselves that there is a culture of personalised care and dignity embedded throughout your system or service? Who has responsibility for this?
- » How do you assure yourselves that appropriate advanced care planning conversations are routinely discussed with patients with a learning disability and their carers, including DNACPR (do not attempt cardiopulmonary resuscitation)?
- » How do you assure yourselves that staff working with people with a learning disability are able to effectively apply the Mental Capacity Act?
- » How do you ensure your teams are prepared to offer treatment to someone with high support needs?
- » What arrangements do you have in place to work in partnership with social care when someone needs support in hospital?
- » How do you assure yourselves that you ask, listen to and involve family and carers at all times (when it is appropriate to do so)?

# » Additional resources, tools and links

## Key resources

- [Learning from Lives and Death Review](#) (LeDeR) is a service improvement programme which aims to improve care, reduce health inequalities and prevent premature mortality of people with a learning disability and autistic people by reviewing information about the health and social care support people received:
  - LeDeR [annual report 2021](#)
  - LeDeR [resources](#)
- [The learning disability improvement standards for NHS trusts](#) have been developed to help NHS trusts measure the quality of care they provide to people with learning disabilities, autism or both.
- RightCare Pneumonia Toolkit: This toolkit supports systems to understand the priorities in pneumonia care and the key actions to take. It contains a comprehensive list of tools, resources and a self-assessment, and can be found on the RightCare [website](#).
- RightCare Pneumonia Scenario: This scenario supports systems to understand how patient outcomes and quality of life can be improved as a result of shifting the care pathway from a suboptimal journey to one that consistently delivers timely, evidence-based excellence, and can be found on the RightCare [website](#).
- Getting It Right First Time (GIRFT) National Respiratory Report: This [report](#) draws on both the data analysis and the discussions with hospital trusts to identify opportunities for improvement across respiratory services.

## National Institute for Health and Care Excellence (NICE)

- Pneumonia in adults: diagnosis and management ([CG191](#)) - at time of publishing this clinical guideline is being updated, please see the [surveillance decision](#) for details
- Pneumonia in adults: Quality standard ([QS110](#))
- Transition between inpatient hospital settings and community or care home settings for adults with social care needs ([NG27](#))
- Care and support of people growing older with learning disabilities ([NG96](#))
- Learning disabilities and behaviour that challenges: service design and delivery ([NG93](#))

## Third sector and national guidelines

- Mencap: [Treat Me Well](#)
- British Thoracic Society (BTS): [Diagnosis and management of aspiration pneumonia](#)
- British Thoracic Society (BTS): [Diagnosis and management of community acquired pneumonia in people with a learning disability](#)
- British Thoracic Society (BTS): [CAP Care Bundle](#)