



DEATHS DUE TO PNEUMONIA IN PEOPLE WITH A LEARNING DISABILITY

LeDeR 2024

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Deaths due to pneumonia in people with a
learning disability

A LeDeR Deep Dive report

Learning from Lives and Deaths -
People with a learning disability and autistic people
(LeDeR) report for 2022
(LeDeR 2022)

Autism and learning disability partnership

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KEY MESSAGES

- Appropriate training and knowledge for carers in the signs and symptoms of pneumonia is essential to ensure deterioration is identified quickly.
- Increased awareness of the risk factors for pneumonia is needed to avoid people with a learning disability contracting the illness. Risk factors include advancing age, poor mobility, postural problems, impaired airway clearance, comorbidities such as dysphagia and cardiovascular conditions, and genetic conditions such as Down syndrome. Those with such conditions should be monitored closely for signs and symptoms of respiratory illness, and for signs of deterioration when they do develop a respiratory infection.
- Vaccination programs for respiratory conditions (such as age thresholds for pneumococcal vaccines) need to be reviewed for those at high risk such as people with Down syndrome and certain other genetic conditions to ensure optimal coverage.
- Continued focus on the importance of person-centred care with clear communication for all those involved.
- Continued focus on the importance of timely referrals, investigations, treatment, and efforts to reduce delays in care.

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Background

Pneumonia refers to infection of the lung, usually caused by bacteria or viruses, which results in alveoli becoming inflamed or filled with fluid, leading to difficulty breathing and other symptoms such as a cough and chest pain ([Mackenzie, 2016](#)). Pneumonia can cause mild to life-threatening illness at any age. Short-course antibiotics have been found to effectively treat bacterial pneumonia in many cases, however the severity of the infection can mean that this is not always sufficient ([Tansarli & Mylonakis, 2018](#)). Pneumonia can affect anyone, however, certain groups may have a higher than average risk and be prone to poor outcomes. Pneumonia is often categorised by the setting in which it is acquired, as either community-acquired pneumonia (CAP) or healthcare-associated pneumonia ([Franquet, 2017](#); [Ottosen & Evans, 2014](#)). In this deep dive, we will investigate pneumonia in people with a learning disability using data collected from mortality reviews completed as part of LeDeR (Learning from Lives and Deaths – people with a learning disability and autistic people), which reviews the lives and deaths of people with a learning disability and autistic people including their health and social care.

It is well established that people with a learning disability (also known as intellectual disability[1]) are more likely to die from respiratory conditions compared to the general population ([Heslop et al, 2014](#); [White et al, 2022](#); [White et al, 2023](#)). The LeDeR 2021 annual report showed that pneumonia is one of the leading causes of death for people with a learning disability, accounting for more than one-fifth of all respiratory deaths in this group[2] ([White et al., 2022](#)). The LeDeR 2022 annual report found that, for people who died in 2021, pneumonia accounted for 35% of all respiratory deaths ([White et al., 2023](#)).

As a prominent and potentially preventable cause of death in people with a learning disability, pneumonia has been the focus of attention in the academic literature. A recent systematic review of 17 papers, all from more economically developed countries, confirmed that pneumonia was the primary cause of death from respiratory diseases for adults with a learning disability between 1985 and 2020 ([Truesdale et al., 2021](#)). In England, [Tyrer et al., \(2022\)](#) found that, of the 33,844 deaths of patients with a learning disability compared to 980,586 people from the general population without a learning disability between 2000 and 2019 in England, excess mortality was markedly high for people with a learning disability who had pneumonia and aspiration pneumonia. [Tyrer and McGrother \(2009\)](#) noted that death from bronchopneumonia was six times more likely in people with a learning disability compared to the general population.

High rates of death due to pneumonia in people with a learning disability have been demonstrated across the globe, with studies from the US ([Landes et al., 2021](#)), Japan ([Motegi et al., 2022](#)) and Australia ([Trollor et al., 2019](#)). A Dutch study by [Oppewal et al. \(2018\)](#) noted that, in a cohort of 1,050 older adults with a learning disability, 32.1% of the 207 participants who died in the study's 5 year follow-up died from respiratory diseases (mean age of death 68.2 ± 9.8 years), of which 80.4% were due to pneumonia. For comparison, 14.7% of recorded deaths were pneumonia related in the general population in England in 2021, with the average age of death being 79.3 years for males and 83.1 years for females between 2018-2020 (ONS, 2024). In addition to increased deaths due to pneumonia, there are indications that other poor outcomes of pneumonia occur more frequently in people with a learning disability.

1. For the purposes of this report both terms are interchangeable.

2. For the COVID-19 pandemic years of 2020 and 2021, pneumonia was not the most commonly occurring cause of respiratory death, as COVID-19 itself was. In years outside of the pandemic however, pneumonia was shown to be the most common cause of respiratory death.

For example, Chang et al., (2017) showed that hospitalisation for respiratory diseases, including pneumonia, is more frequent, of longer duration, and has a higher likelihood of recurring in people with a learning disability compared to those without a learning disability.

Determining the risk factors associated with poor outcomes of pneumonia in people with a learning disability could inform targeted prevention and early treatment to help to reduce the number of deaths from pneumonia (Santoro et al., 2020). Previous studies have typically used large, register-based cohorts (Oppewal et al., 2018) to describe the percentage of deaths accounted for by pneumonia, without investigating the contributory factors.

In this report, we first conduct a literature review focused on risk factors for poor outcomes of community-acquired pneumonia in adults with a learning disability. We then investigate the presence of these and other risk factors for pneumonia in a sample of 100 people with a learning disability who died from pneumonia. Finally, we review the quality of care that people who died from pneumonia received before their death to highlight areas for potential improvement.

Objectives of this report

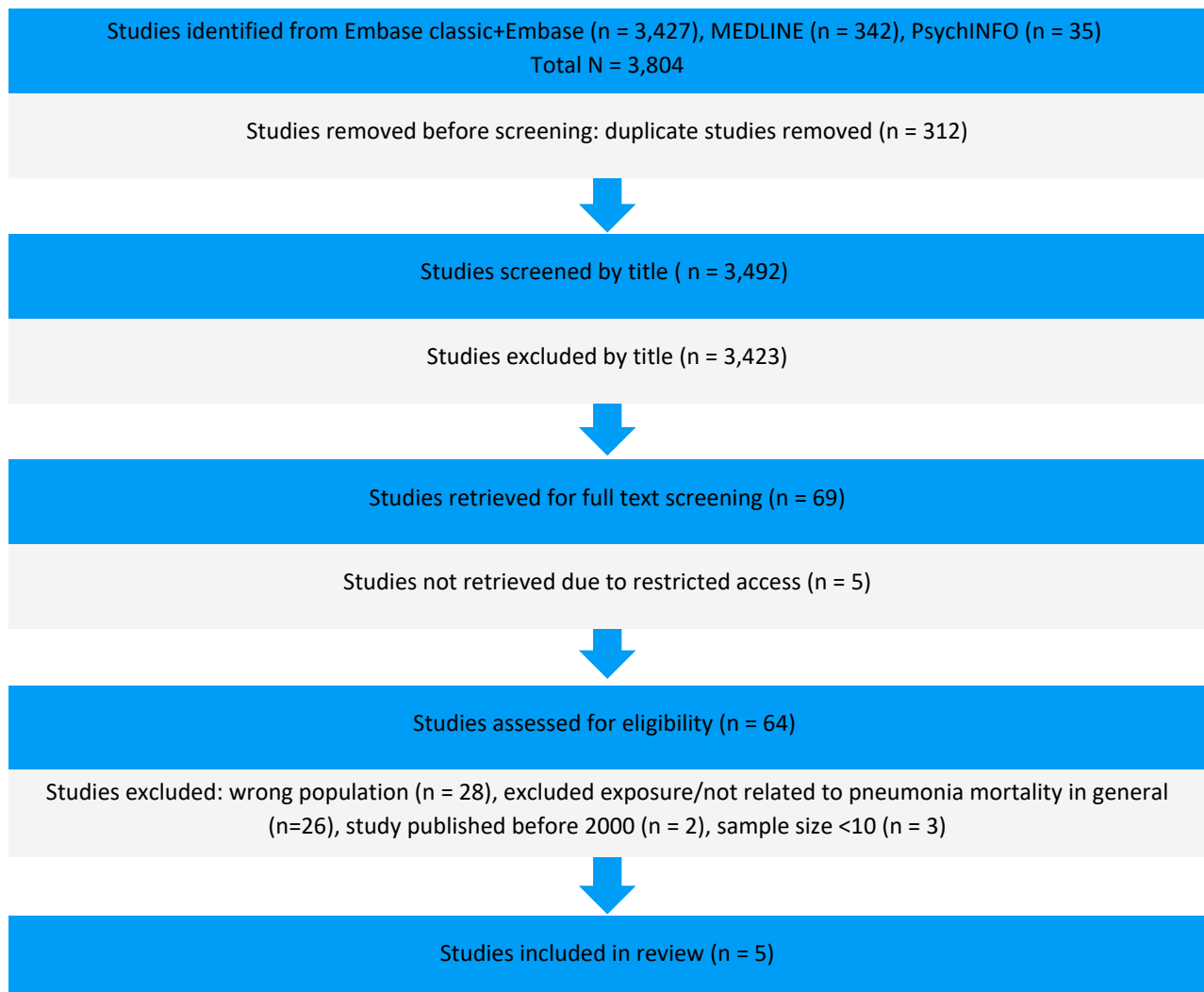
1. To conduct a systematic literature review to establish risk factors for poor outcomes of community-acquired pneumonia in adults with a learning disability to establish high-risk groups.
2. To undertake an in-depth review of a subset of LeDeR reviews where the person died from pneumonia to determine the presence of risk factors and areas where care can be improved.
3. To explore the evidence for aspiration pneumonia as a cause of death of people with a learning disability.

Systematic literature review

Method

We conducted a focused literature review by searching three electronic databases (EMBASE+Embase Classic, MEDLINE, and PsychINFO) for studies that included terms related to “learning disability[3]”, “community-acquired pneumonia”, and “poor outcomes”. Poor outcomes were defined as, admission to hospital, admission to an intensive care unit, and death (Appendix 1). The initial search strategy was supplemented with targeted searches and expert knowledge of the literature. Articles were included if they presented original data on people (of any age) with a learning disability (of any aetiology, defined according to standard classification systems). The paper must have reported outcomes of CAP and have been published in a peer-reviewed academic journal between January 2000 and May 2022, when the search was conducted. Reviews, single case studies, studies with small samples (<10 participants), and studies reporting types of pneumonia or respiratory illness other than CAP (including COVID-19 infection) were excluded. The database searches identified 3,492 unique studies which were individually screened for eligibility. Five studies met inclusion criteria and were included in the review (see Figure 1).

Figure 1: study selection flow chat



3. As noted earlier, whilst the term “learning disability” is more commonly used in the UK. The term “intellectual disability” is used as a descriptor in the international literature and so was used in this systematic review to broaden the scope of potential research.

Results

The small number of papers that met inclusion criteria highlights the limited literature that explores risk factors for poor outcomes of CAP in people with a learning disability. In this section, we first discuss the findings of the systematic review, and then set this in a broader context.

Table 1: Summary of findings of the 5 studies included in the systematic literature review

Authors	Aim	Sample	Country	Design	Results
Motegi et al., (2022)	To investigate the causes of deaths for people with Down syndrome in Japan.	762 patients with Down syndrome in 2014-16.	Japan	Cross sectional design.	20.5% of deaths were caused by pneumonia/respiratory infections. Aspiration pneumonia accounted for 8.4% of deaths.
Landes et al., (2020)	To investigate cause of death trends for adults, age 18 and over, with Down syndrome.	9,870 adults (18+) with Down syndrome.	USA	Cross sectional design.	Adults with Down syndrome were more likely to die from influenza and pneumonia (AOR 9.34, 10.56, pneumonitis, respiratory failure (AOR 26.16, 29.92), and choking at all ages (AOR 18.84, 24.90) than the general population.
Landes et al., (2021)	To compare specific causes of death in adults with intellectual disability to the general population.	22,512 adults (18+) with a learning disability who died between 2005 and 2017.	USA	Retrospective matched cohorts.	8.71% of all adults with a learning disability died from influenza or pneumonia. This ranged from 3.06% of those who had a mild/moderate disability to 9.85% for those who severe/profound disabilities. Adults with a learning disability were 5.9 times more likely to die from influenza and pneumonia, ranging from 1.8 times more likely for people with a mild/moderate disability to 7.6 times more likely for those with a severe/profound disability.
Blake et al., (2021)	To investigate the rate of pneumonia and respiratory infection for people with Down syndrome.	415 patients with Down syndrome between 2011 and 2020 who received at least one encounter with an emergency department or inpatient admission.	USA	Retrospective chart review.	The most common comorbidities among those aged under 22 years old who died from pneumonia and were associated with poor outcomes were congenital heart disease (84%), dysphagia (49%), and asthma (34%). Among those over 22 years old these were dementia (71%), dysphagia (56%) and congenital heart disease (52%).
Hirose et al., (2022)	To investigate the association between learning disability and the severity of pneumonia infections at the time of hospital admission.	531 patients with a learning disability who were admitted to hospital between 2010 and 2018.	Japan	Matched-pair retrospective cohorts.	24.5% of patients with a learning disability who were admitted to hospital and had severe pneumonia compared to 9.5% of the general population. The researchers found that learning disability was significantly associated with severe pneumonia at hospital admission (OR 3.50; 95% CI; 50.8%-105.0%) and that this was significantly related to a person's level of independence.

Risk factors for poor outcomes of pneumonia in people with a learning disability

The findings of the focused review need to be interpreted with the origin of data in each study borne in mind. Most studies were conducted outside England, in countries with differing population, cultural, and healthcare-related characteristics. It is of note that 2 of the 5 studies included only people with Down syndrome, and the findings may not be generalisable to all people with a learning disability. Nevertheless, the findings may provide some initial insights into those who are most at risk of poor outcomes of pneumonia.

Three papers in the review utilised data from routinely-collected mortality records ([Motegi et al., 2022](#); [Landes et al., 2020](#); [Landes et al., 2021](#)) and one focused on the patient's subsequent medical encounters, including visits to urgent care, emergency departments, or hospital admissions and hospitalisation information following an initial admission for pneumonia ([Blake et al., 2021](#)). The final study examined the associations between pneumonia severity upon admission and in-hospital mortality ([Hirose et al., 2022](#)).

The findings of the studies are grouped into the following three risk factor categories: age, the presence of co-morbidities and genetic conditions, and the individual's level of independence.

Age

Four studies found evidence suggesting that age is a risk factor for poor outcomes of pneumonia in people with a learning disability. [Motegi et al. \(2022\)](#) conducted a cross-sectional study using the Japanese National Death Registry Database to look at the causes of death of patients with Down syndrome between 2014 and 2016. They found that one in four people with Down syndrome died from pneumonia, which was the most common cause of death in this group. The percentage of people with Down syndrome who died from pneumonia was higher in those aged between 20 and 79 years in comparison to the general population (0 year 2.0% vs. 1.9%, 1–9 years 9.3% vs. 8.4%, 10–19 years 0.0% vs. 2.2%, 20–29 years 13.3% vs. 1.2%, 30–39 years 12.5% vs. 1.6%, 40–49 years 25.6% vs. 1.6%, 50–59 years 22.9% vs. 2.3%, 60–69 years 28.1% vs. 3.8%, 70–79 years 37.9% vs. 7.0%, 80–89 years 0.0% vs. 11.5%, and ≥90 years 0.0% vs. 13.3%).

In the United States, [Blake et al., \(2021\)](#) conducted a retrospective chart review of 229 people (all ages) with Down syndrome and found that respiratory infections were a common cause of hospitalisation, particularly in early childhood and older adulthood. While most admissions to hospital for pneumonia were of children under the age of five, most patients admitted to the intensive care unit (ICU) were older adults with longer lengths of stay (an average of 12.5 days). Of the adult patients requiring ICU admission, 50% of those were older than 45 years.

[Landes et al., \(2021\)](#) conducted a cross-sectional study of adults with a learning disability in the United States and also found evidence for age as a significant risk factor for pneumonia in people with a learning disability.

When controlling for the level of learning disability, people of all age groups with a learning disability had a substantially higher risk of death from pneumonia, as well as pneumonitis, influenza and choking than those in the general population. Age-related trends were demonstrated, with a steady increase in risk of death from pneumonia until the age of 60 and then a slight decrease in risk for those aged over 60 years old.

Co-morbidities and Down syndrome

Several studies identified a link between poor outcomes of community-acquired pneumonia and Down syndrome. [Motegi et al., \(2022\)](#) compared the causes of death in patients with Down syndrome to those in the general Japanese population. [Landes et al., \(2020\)](#) compared the causes of death in patients with Down syndrome to those without Down syndrome. Both studies indicated a higher risk of death from pneumonia in people with Down syndrome than comparison groups (the general Japanese population, and American patients with a learning disability other than Down syndrome).

[Blake et al., \(2021\)](#) identified congenital heart disease, dysphagia/feeding difficulties, and asthma/reactive airway disease as the most common co-morbidities in people with Down syndrome who had a clinical encounter due to a respiratory condition. The percentage with co-morbidity was high in the adult population in this study, which is thought to have contributed to the higher rates of hospitalisation and ICU admissions among adults with Down syndrome over the age of 45 years.

Functional independence

A cohort study by [Hirose et al., \(2022\)](#) suggested that people with a learning disability who are less able to undertake activities of daily living (ADL) are at increased risk of worse CAP outcomes. The [Barthel Index](#) was used to assess ADL, which measures independence in bowels, bladder, grooming, toilet use, feeding, transfer, mobility, dressing, stair use and bathing. They found that people with a learning disability had lower functional ability compared to people without a learning disability, as rated by the Barthel index at discharge. While this is in itself not a surprising finding as functional impairment is a diagnostic criterion for learning disability, it is notable that the more severe the impairment the greater risk of death was present. They suggested that a lower ability to undertake ADL may act as a barrier for people with a learning disability in recognising, addressing, and communicating their health needs and may prevent them from accessing timely medical facilities.

Review of systematic review literature: Discussion

Pneumonia is a common cause of death in people with a learning disability and is a condition which may be amenable to early diagnosis and treatment to reduce poor outcomes ([O'Leary et al., 2018](#)). As the main cause of respiratory-related death in people with a learning disability ([White et al., 2023](#)), our work identifying risk factors for poor outcomes of pneumonia may help in identifying people who could benefit from additional input or preventative interventions, such as vaccination. This review of the current literature suggests that there may be value therefore in widening the access of pneumococcal vaccination to people with a learning disability, based on the risk factors that people with a learning disability may have to pneumonia. Improved access to a vaccine with proven efficacy in reducing the risks of illness and death through pneumonia is therefore warranted.

The systematic literature review retrieved only a small number of relevant studies, demonstrating limited literature on the risk factors for poor outcomes of CAP for people with a learning disability. It is notable, and perhaps unsurprising, that many recent studies focused on risk factors for and outcomes of COVID-19 infection, although this was beyond the scope of the current work. However, in bringing the existing data together, we are able to highlight putative risk factors for worse outcomes. From the available evidence, these are:

- Age.
- Down syndrome.
- Lower functional ability or activities of daily living (as rated by the Barthel index).
- Having certain medical co-morbidities, in particular congenital heart disease, asthma, and dysphagia.

Strengths and limitations of the focused review

We used a thorough and systematic method to identify all relevant international literature that explores risk factors for poor outcomes of CAP in people with a learning disability. Identified papers were reviewed independently by at least two members of the research team. A limitation of the review methodology was that adverse outcomes were pre-specified and we may therefore have missed papers that reported a wider range of poor outcomes. Investigating associations with poor outcomes of hospital-associated pneumonia may have yielded additional information, but was beyond the scope of this work.

Other strengths and limitations of the review relate to the primary studies that were eligible. A strength of the literature available is the use of national clinical databases for analysis; all studies included in this review used data from national clinical databases, which increases the representativeness and generalisability of their findings to the population from which the sample is drawn.

Two of the studies reported on people with Down syndrome only and Down syndrome was the only specific learning disability sub-population that had been investigated across studies. People with Down syndrome may have specific health issues (such as congenital heart disease) that make it difficult to extrapolate findings to a wider group of people with a learning disability and further work is needed in this respect.

There are potential limitations to the selected papers in this deep dive as all studies were conducted outside the UK, and none specifically addressed the impact of severity of learning disability (although functional impairment and support needs reported in one paper could be considered a proxy for the degree of learning disability). Considering the severity of learning disability is important as there may be differences in outcomes between people with mild learning disability and those with more severe or profound disability, although primary care learning disability register-based research may be less likely to include people with a mild learning disability as they are underrepresented on learning disability registers ([Tyrer, Smith & McGrother, 2007](#)).

Further evidence from the broader literature

Given the specific nature of the focused review, we also summarised current knowledge (based on the broader literature) on pneumonia and respiratory conditions in people with a learning disability to set this work in context.

Certain conditions (principally Down syndrome), as noted in the focused review, have been shown to be a risk factor for death from pneumonia. A scoping review by [Hayes et al., \(2017\)](#) found that pneumonia accounted for 30% of hospitalisations for people with Down syndrome over the age of 21. Studies by [Jensen et al. \(2015\)](#) and [Medrano et al. \(2007\)](#) found that people with Down syndrome had a greater likelihood of admission for respiratory infections compared to the general population. [Hilton et al., \(1999\)](#) noted an increased likelihood of needing intensive care or mechanically assisted ventilation in those with Down syndrome hospitalised with pneumonia. [Mackay et al. \(2018\)](#) noted that respiratory infections were notable in people with Rett syndrome, and that the mean duration of hospital stay increased over the age of 20 years, suggesting that increasing age is also a risk factor for poor outcomes in this group. To address this, there have been calls for vaccination priority and more extensive pneumococcal vaccination sub-groups at greater risk of developing pneumonia, such as those with Down syndrome (Baksh et al., 2022; Santoro et al., 2021).

The British Thoracic Society clinical statement of the prevention and management of community-acquired pneumonia in people with a learning disability ([Legg et al., 2023](#)) detailed numerous risk factors for CAP in people with a learning disability, including sleep-disordered breathing, reduced mobility, dysphagia, immunodeficiency, poor oral health, nutritional issues, the presence of comorbidities, tracheostomy, poorly controlled epilepsy, and the presence of gastro-oesophageal reflux disease. A systematic review by [Truesdale et al., \(2021\)](#) documented that people with a learning disability experience a significant excess of respiratory-associated deaths, nearing eleven times greater than respiratory deaths in the general population. As noted in other studies in this report, age, gender, and severity of learning disability were found to be risk factors for respiratory mortality common across studies in the review.

Summary of literature

Both the systematic review and the broader literature demonstrate that there is little data on the topic of risk factors for poor outcomes associated with pneumonia in people with a learning disability. The available evidence suggests that various risk factors, including severity of disability, co-morbidity, and Down syndrome seem to be related to poor outcomes, including premature and potentially avoidable death.

In summary, further research is required to better understand the risks of pneumonia for people with a learning disability, in particular those without genetic conditions such as Down syndrome and Rett syndrome. The use of national databases, such as LeDeR, are proving useful in providing accurate data for analysis of population-level trends and in highlighting both strengths and weaknesses in current care provision. Continued investment and development in these databases will provide further evidence to inform targeted improvements efforts.

Analysis of LeDeR reviews

Case selection

The 100 most recent LeDeR focused reviews of adults (≥ 18 years) with a learning disability who died from pneumonia in hospital were extracted from the full LeDeR dataset (Figure 2). By working backwards from the most recently-available data, we aimed to minimise the impact of COVID-19 on our findings. The dates of death of our sample were February 20th 2022 – December 31st 2022. Cause of death was established with reference to part 1 of the Medical Certificate of Cause of Death (MCCD); if an ICD-10 code for pneumonia, aspiration pneumonia or acute lower respiratory tract infection (i.e. J12-J18, J20-J22, or J69) was included in any line in part 1 of the MCCD, this was considered a death due to pneumonia. If these codes were absent from part 1 of the MCCD, the death was considered due to another cause.

The LeDeR focused reviews of 80 people who died in hospital during the same time period with a cause of death other than pneumonia were used as a comparison group, which was the sample size available at the time of data extraction when matched for time frame.

Data collection

A list of variables known to be associated with increased risk of pneumonia and related to best practice in pneumonia assessment, diagnosis, and management in people with a learning disability were identified through i) findings of our review (see above), ii) consultation with a specialist in respiratory medicine and, iii) with reference to the recent British Thoracic Society Clinical Statement for the Diagnosis and Management of Community-Acquired Pneumonia in people with Learning Disability (Legg et al., 2023) and National Institute of Health and Care Excellence guidance (NICE, 2014) (Appendix 1). Each variable was discussed and operationalised using a standard definition to ensure common understanding between members of the research team.

Individual focused review forms and all associated documents uploaded by the reviewer to the LeDeR review platform (<https://leder.nhs.uk/>) were read thoroughly for each case. Example documents may include hospital records, GP notes, and documents related to care planning, but the number and type of available forms differed on a case-by-case basis. Where possible, relevant information (such as socio-demographic variables) was extracted from direct questions included on the standard LeDeR focused review form. The remaining information on risk factors and variables related to care processes was ascertained either through the pen portrait narrative and free-text responses, or by combing through the additional documents uploaded onto the review platform.

To determine the availability and accuracy of extracting data related to the list of variables from the LeDeR focused reviews and associated documents, three researchers independently read through a random sample of 30 reviews and piloted the data collection form. Variables were dropped from further analysis if they were reported in fewer than 30% of reviews, leading to a short-list of 11 clinical and care variables that were used (Appendix 1).

Percentage agreement was used to test inter-rater reliability in assessing the presence or absence of these variables; agreement between researchers across all variables in a subset of 18 reviews was 83%, indicating a high rate of agreement between researchers.

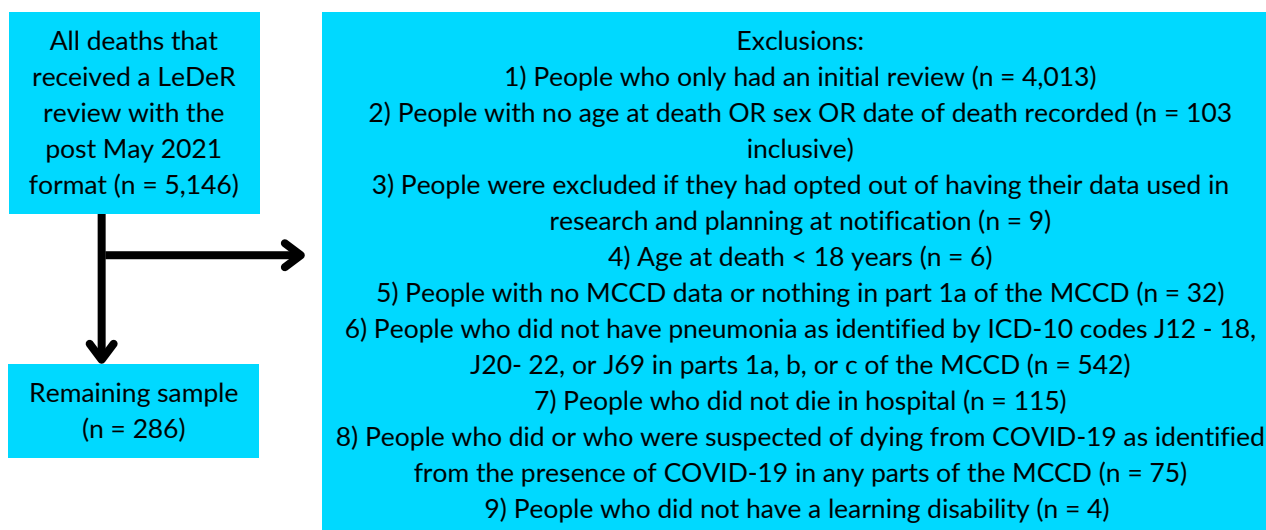
Finally, we investigated aspects of the quality of care received by people with a learning disability who died from pneumonia. We used data from structured questions in the LeDeR focused review, including the reviewer’s overall rating of care completed on a Likert scale, and free text responses provided by the LeDeR reviewers in questions about of positive practice and issues with care. As these questions can relate to all aspects of care that people received, only statements that were considered relevant to assessment or management of pneumonia or the care received whilst in hospital were considered.

Data analysis

We used descriptive statistics to summarise the data and compared the group who died from pneumonia to the group who died from other causes. A regression analysis was completed to investigate differences in risk factor co-morbidities and the individuals’ level of learning disability but further inferential statistics were not performed owing to the limitations of the data (see page 23).

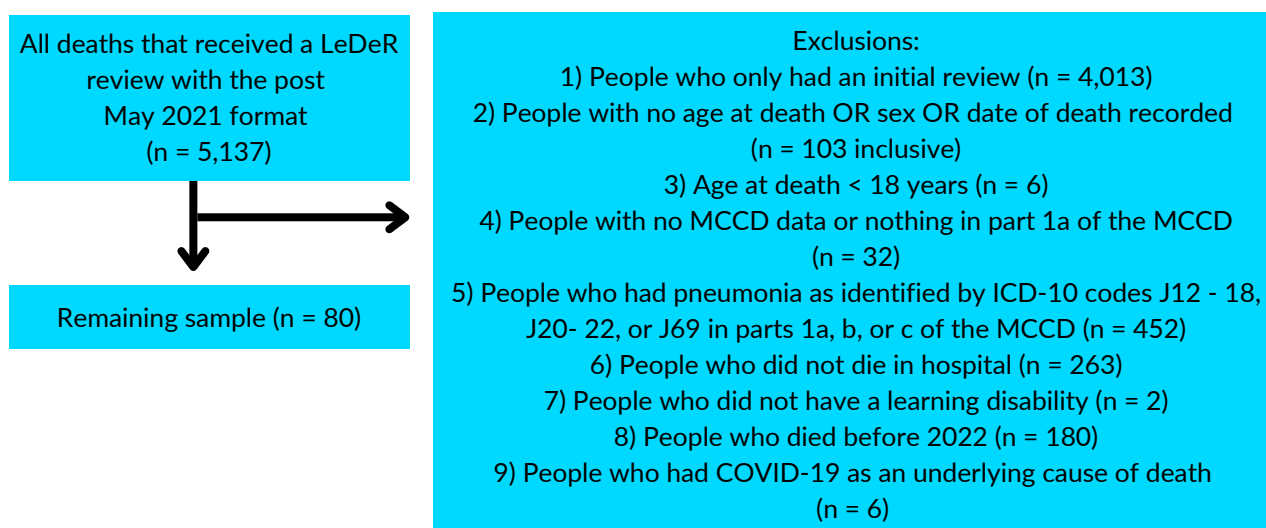
A structured form of thematic analysis was used to analyse reviewers’ comments about positive practices and issues with care related to the diagnosis, management, or treatment of pneumonia and the person’s hospital care. This was achieved first by creating separate spreadsheets for positive practice and issues with care and populating each of these with statements or sentences used by reviewers. The researchers then familiarised themselves with the data by reading and re-reading the comments. Comments were organised into themes, which were named and defined. This analysis was primarily completed by one researcher, who worked collaboratively with the rest of the group to discuss findings and interpretation of the data. Reflective notes were used to guide the process. The qualitative analysis was only completed on those who died from pneumonia and not the comparison group. This is due to the focus in this deep dive report on those who died from pneumonia, and issues with care quality and thematic trends that arose for them.

Figure 2: Selection of LeDeR focused reviews used in the analysis.



100 most recent cases extracted. Date of deaths dates back to 20th February 2022.

Figure 3: Selection of LeDeR focused reviews used in the comparison sample



Cause of death

Table 2 details the causes of the deaths of the people in the pneumonia sample. The causes of death for the comparison group are provided in Table 3, grouped by ICD-10 chapter. The three most common causes of death for the comparison group were: diseases of the nervous system (21%), cancer (20%), and diseases of the circulatory system (14%).

Table 2: Causes of death of the pneumonia sample.

Cause of death	ICD-10 code	Number of times listed in Part 1 of the MCCD, n (%)
Pneumonia	J12-J18	56 (56%)
Aspiration pneumonia	J69	36 (36%)
Other acute respiratory infections	J20-J22	8 (8%)
Total	-	100 (100%)

Table 3: Causes of death of the comparison group.

Cause of death (ICD-10 chapter)*	ICD-10 code	Number of times listed as an underlying cause of death, n (%)
Diseases of the nervous system	G00-G99	17 (21%)
Cancer	C00-C97; D00-D09; D10-D36; D37-D48	16 (20%)
Diseases of the circulatory system	I00-I99	11 (14%)
Diseases of the digestive system	K00-K93	9 (11%)
Certain infectious and parasitic diseases	A00-B99	8 (10%)
Congenital malformations deformations and chromosomal abnormalities	Q00-Q99	7 (9%)

* Endocrine, nutritional and metabolic diseases, diseases of the respiratory system (other than pneumonia), diseases of the genitourinary system, external causes of morbidity and mortality, codes for special services, diseases of the blood and blood forming organs and certain disorders involving the immune mechanism and diseases of the skin and subcutaneous tissue each accounted for fewer than 5 deaths.

Socio-demographic variables

The median age at death of those who died from pneumonia was 54 years (IQR 22.3 years). This was similar to the age of death of those who died from other causes (i.e. not pneumonia), which was 55 years (IQR 23.5 years). Sex, ethnicity, and level of learning disability were similar in both groups, though 11% of people who died from pneumonia had profound/multiple learning disability compared to 6% in the group who died from a cause other than pneumonia (Table 4, overleaf).

Table 4: Demographics of the people who died with from pneumonia and the comparison group of people who died from other causes.

	People with pneumonia in part 1 of their death certificate (n = 100)	People who did not have pneumonia in part 1 of their death certificate (n = 80)
Sex	%	%
Male	56%	48%
Female	44%	50%
Not known	0%	2%
Ethnicity		
White	70%	66%
Black, black British, Caribbean or African	7%	9%
Asian or Asian British	17%	13%
Mixed or Other	6%	8%
Prefer not to say	0%	4%
Level of learning disability		
Not known	21%	10%
Mild	21%	29%
Moderate	19%	25%
Severe	28%	30%
Profound/multiple	11%	6%

Reviews were included of people who had died in all regions of England. There was an uneven distribution of people who died from pneumonia across the regions in England. These may have been because some Integrated Care Boards automatically forward deaths due to pneumonia for a focused review, to learn more about the lives and deaths of people who died from pneumonia. Evidence from the initial reviews in the 2023 LeDeR report suggests this regional difference is not as pronounced as it is in the focused reviews. (White et al., 2023).

Long-term health conditions

The percentage of people with a long-term health condition is shown in table 5. These data were extracted from the LeDeR focused review forms. The list of conditions described here are similar to the conditions described in the annual reports for LeDeR. 21% of people who died from pneumonia had Down syndrome. 10% of people who died from other causes had Down syndrome. 45% of people who died from pneumonia had epilepsy. 41% of the group who died from other causes had epilepsy. The other long-term health condition variables were broadly similar between groups.

Table 5: Long-term health conditions

	People with pneumonia in part 1 of the MCCD (n = 100)	People who did not have pneumonia in part 1 of the MCCD (n = 80)
	%	%
Cancer	9%	21%
Cardiovascular conditions (other than hypertension)	11%	10%
Cerebral palsy	14%	13%
Dementia	10%	11%
Diabetes	17%	18%
Down syndrome	21%	10%
Epilepsy	46%	41%
Hypertension	21%	24%
Mental health conditions	17%	28%
Musculoskeletal conditions	29%	31%
Renal conditions	12%	18%
Respiratory conditions	26% (excluding pneumonia)	26%
Sensory impairment	24%	29%

Risk factors

Table 6 (overleaf) shows the presence of clinical risk factors for pneumonia in the group who died from pneumonia and the comparison group who died from other causes.

30% of the group who died from pneumonia were reported to have **impaired airway clearance**. 16% of people who died from other causes were reported to have impaired airway clearance. Similarly, 45% of people who died from pneumonia had postural problems and 32% of people who died from other causes had **postural problems**. 47% of people who died from pneumonia had **swallowing difficulties**. 28% of people who died from other causes had swallowing difficulties.

Minimal differences were evident between the group of people who died from pneumonia and the comparison group for impaired mobility, previous hospital admissions, and smoking status. Of note, is that 20% people who did not die of pneumonia were recorded as being obese. 12% of people who died from pneumonia were obese. However, the high levels of “not known” data in this variable warrants cautious interpretation of this finding.

Table 6: Clinical risk factors for community-acquired pneumonia

	People with pneumonia in part 1 of their death certificate (n = 100)			People who did not have pneumonia in part 1 of their death certificate (n = 80)				
	Yes %	No %	Not known %	Yes %	No %	Not known %		
Obesity	12%	25%	63%	20%	14%	66%		
Impaired mobility	63%	27%	10%	61%	31%	8%		
Previous hospital admissions in 12 months before death	58%	26%	16%	55%	34%	11%		
Impaired airway clearance	30%	42%	28%	16%	66%	18%		
Postural problems	45%	47%	8%	33%	54%	14%		
Swallowing difficulties	47%	43%	10%	26%	66%	8%		
	Yes %	No %	Previous smoker %	Not known %	Yes %	No %	Previous smoker %	Not known %
Smoking status (past or present)	5%	80%	5%	10%	8%	82%	2%	8%

The number of hours of support someone receives may be used to indicate frailty or a greater degree of impairment due to more severe learning disability. There were no notable differences in the amount of informal care support hours recorded between the two groups but people who died from pneumonia did receive more hours of professional care support (Table 7, overleaf).

Table 7: Informal and formal care support hours

	People with pneumonia in part 1 of the MCCD (n = 100)			People who did not have pneumonia in part 1 of the MCCD (n = 80)		
	0 hours of support %	Between 1 and 35 hours of support %	More than 35 hours of support %	0 hours of support %	Between 1 and 35 hours of support %	More than 35 hours of support %
Informal care support hours recorded	66%	9%	25%	69%	6%	25%
Professional care support hours recorded	13%	19%	68%	21%	21%	58%

Logistic regression analyses

In this dataset, limited statistical analysis was appropriate. This is due to difficulty with matching the groups, as well as limitations in both sample size and data type.

However, we conducted logistic regressions (controlling for age and sex) with the aim of identifying factors associated with dying from pneumonia. Swallowing difficulties were shown to be a statistically significant risk factor associated with death from pneumonia with an odds ratio of 2.38 (95%CI 1.24, 4.58, $p=0.009$) as was impaired airway clearance (odds ratio 2.34, 95%CI 1.03, 4.84, $p=0.041$). The association between postural problems and dying from pneumonia approached statistical significance (odds ratio 1.79, 95%CI 0.94, 3.41, $p=0.078$). No other risk factor was found to be significantly predictive of dying from pneumonia in this sample. The full logistic regression analysis completed in this report is provided in Appendix 4.

Table 8: The results of a logistic regression looking at the risk factors associated with dying from pneumonia, controlling for age and sex.

Variable	Odds ratio	Standard error	z	p	95% Confidence interval
Swallowing difficulties	2.38	.795	2.60	0.009	1.24, 4.58
Impaired airway clearance	2.34	.881	2.05	0.041	1.03, 4.84
Postural problems	1.79	.590	1.76	0.078	0.94, 3.41
Obesity	0.56	.289	-1.12	0.264	0.21, 1.54
Impaired mobility	1.03	.325	0.11	0.915	0.56, 1.91
Previous hospital admission in the last 12 months	1.16	.355	0.47	0.636	0.63, 2.11
Current smoker	0.6	.378	-0.82	0.414	0.17, 2.06

There was a trend towards increased odds of dying of pneumonia as the level of learning disability increased, such that people with profound learning disability were found to have an odds ratio more than twice that of those with mild learning disability (Table 9). However, this was not statistically significant, perhaps because of the relatively small number of people in the sample and amount of missing data.

Table 9: Logistic regression for people who died from pneumonia and their reported level of learning disability, controlled for age and sex

Level of learning disability	Odds Ratio	Standard error	z	p	95% Confidence interval
Mild (reference group)	1.00	-	-	-	-
Moderate	0.98	.435	-0.05	0.961	0.41, 2.34
Severe	1.28	.550	0.56	0.573	0.55, 2.97
Profound/-Multiple	2.38	1.604	1.29	0.196	0.64, 8.91
Not known	2.88	1.500	2.03	0.042	0.98, 1.02

Care factors

The group who died from pneumonia and the group of people who did not die from pneumonia were similar in terms of COVID-19 and pneumococcal vaccination status (Table 10). 79% of people who died from pneumonia had a medication review in the year prior to death. 87% of people who did not die from pneumonia had a medication review in the year before death. A similar trend exists for flu vaccination. 64% of people who died from pneumonia were reported to have reviewed a flu vaccination. 75% of people who did not die from pneumonia received a flu vaccination. 38% of people who died from pneumonia had family/carers that were aware of the dysphagia recommendations and were trained to support the person at mealtimes. 21% of the comparison group of people who died from other causes had family/carers that were aware of the dysphagia recommendations and were trained to support the person at mealtimes. This possibly reflects the greater proportion who had support needs in these areas.

Table 10: Health monitoring factors

	People with pneumonia in part 1 of their death certificate (n = 100)		People who did not have pneumonia in part 1 of their death certificate (n = 80)	
	Yes %	No %	Yes %	No %
Medication review in the year prior to death	79%	21%	87%	13%
COVID-19 fully vaccinated	81%	19%	83%	17%
Flu vaccine	64%	36%	75%	25%
Pneumococcal vaccine	29%	71%	31%	69%
Family/carer aware of the dysphagia recommendations, did they get training to support at mealtimes	38%	62%	21%	79%

People died from pneumonia appeared to have more Speech and Language Therapy (SaLT) involvement, positioning and nutritional support compared to people who did not die from pneumonia (Table 11). 19% of people who died from pneumonia had oral care support. 26% of the comparison group who died from other causes had oral care support. However, as with obesity earlier, the large percentage of “not known” data precludes definitive interpretation.

Table 11: Preventative care measures

	People with pneumonia in part 1 of their death certificate (n = 100)			People who did not have pneumonia in part 1 of their death certificate (n = 80)		
	Yes %	No %	Not known %	Yes %	No %	Not known %
Positioning support	37%	45%	18%	25%	60%	15%
Speech and Language Therapy involvement	42%	0%	58%	26%	66%	8%
Oral care support	19%	11%	70%	26%	10%	64%
Nutritional Support	57%	36%	7%	34%	41%	11%

Problems identified with specific aspects of care

People who died from pneumonia had a similar level of problems with specific aspects of care to the comparison group who died from other causes (Table 12). The most commonly reported issues for both groups were care delays and care system problems.

Table 12: Problems with specific aspects of care

	People with pneumonia in part 1 of the MCCD (n = 100)		People who did not have pneumonia in part 1 of the MCCD (n = 80)	
	Yes %	No %	Yes%	No%
Care delays	38%	62%	41%	59%
Gaps in care	17%	83%	24%	76%
Care system problems	38%	62%	36%	64%
Care packages met the needs of the person	77%	23%	75%	25%

Communication and decision-making

54% of those who died from pneumonia were considered to have had the Mental Capacity Act followed correctly. 76% of people who did not die from pneumonia were considered to have had the Mental Capacity Act followed correctly (Table 13). The two groups were similar in learning disability liaison nurse involvement and the number of people on an end-of-life care pathway[4]. 76% of people who died from pneumonia were considered to have appropriate advocacy. 65% of people who did not die from pneumonia were considered to have appropriate advocacy. 19% of people who died from pneumonia were considered to have had their wishes identified and followed. 26% of people who did not die from pneumonia were considered to have had their wishes identified and followed. There were no notable differences between groups for DNACPR adherence (see Table 14).

Table 13: Percentage of people who experienced various factors related to communication and decision making of their care in both the people who died from pneumonia and the comparison sample.

	People with pneumonia in part 1 of their death certificate (n = 100)			People who did not have pneumonia in part 1 of their death certificate (n = 80)		
	Yes %	No %	Not mentioned %	Yes %	No %	Not mentioned %
Appropriate advocacy	76%	11%	13%	65%	8%	27%
Mental Capacity Act followed	54%	12%	34%	76%	13%	11%
Learning disability nurse involvement	40%	40%	20%	43%	41%	16%
Patient's wishes identified and followed	19%	16%	65%	26%	10%	64%
On an End-of-Life Care plan	7%	26%	67%	8%	30%	63%

Table 14: Percentage of people who had a DNACPR that was completed and followed correctly for the sample of people who died from pneumonia and the comparison sample.

DNAPCR	People with pneumonia in part 1 of their death certificate (n = 100)	People who did not have pneumonia in part 1 of their death certificate (n = 80)
Correctly completed and followed	46%	50%
Incorrectly completed and followed	5%	6.25%
Neither completed nor followed correctly	1% (will make <5%)	1.25% (will make <5%)
Correctly completed but not followed	2% (will make <5%)	0% (will make <5%)
Don't know	27%	20%

Aspiration pneumonia

Focused LeDeR reviews and all associated documents were scrutinized for 36 people who were reported to have died from aspiration pneumonia. People who died from aspiration pneumonia were defined as those with an ICD-10 code J69 listed in part 1 of the MCCD. The research team looked through each review of a recorded aspiration pneumonia death and searched for evidence of a noted aspiration event, or recorded risk factors (see Appendix 3) in their LeDeR reviews. An aspiration event occurs when food, liquid or other material enters a person's airways and may have been reported in the focused review or in other documents supplied to LeDeR reviewers. This figure may underestimate the total number of people who experienced an aspiration event because some aspiration events may not have been witnessed or recorded by the reviewer or found within the supporting documentation of the review.

Of the 36 people who were recorded as having died from aspiration pneumonia, 13 (36%) had evidence of an 'aspiration event' in their review and/or associated documents.

In cases of sudden death, the person may not have received investigative tests to confirm aspiration pneumonia. Upon further analysis, the majority (20 of the remaining 23 people who were recorded as having died from aspiration pneumonia) were judged likely to have died from aspiration pneumonia due to the presence of several risk factors for aspiration pneumonia (e.g. they had well-documented evidence of swallowing difficulties, previous aspiration events etc.).

A single aspiration event does not have to have occurred for a death to be from aspiration pneumonia (Simpson et al., 2023). Aspiration pneumonia is often characterized by bacteria-rich secretions from the throat into the lungs and is often associated with swallowing difficulties. In people who present with CAP, a risk factor analysis of potential aspiration pneumonia should be carried out. In this data we have limited contextual information to determine whether this was done; future work is needed to determine the frequency of examination to determine whether a death from pneumonia was aspiration related or not.

Qualitative analyses

Positive practice comments were made in 98% of reviews and comments relating to issues with care were identified in 97% of LeDeR focused reviews of people who had died from pneumonia. Many reviews contained multiple comments in both domains. In total, there were 146 'positive practice' comments and 316 'issues' comments that were related to pneumonia/respiratory health or hospital care.

Positive practice:

Four themes were generated from the positive practice comments relevant to respiratory illness and hospital care:

Theme 1: Involvement of family and loved ones

This theme describes the inclusion of family, friends, and carers in discussions about the person's condition while they were in hospital, and having their views documented and respected. Other comments reflect adaptations being made to ensure loved ones were allowed to support the person during hospital stays. Involvement of family in decisions around end-of-life planning and palliative care, such as completion of DNACPR and ReSPECT forms was noted.

"The children's hospice had an open door policy and the family were able to access clinical staff for [Name] at home to avoid unplanned hospital admissions"

"Excellent palliative care on the ward. Everyone made sure the patient was comfortable and pain free, and treated with compassion and dignity. The patient was in a side room so the family could stay with her all the time to offer her comfort and reassurance"

Theme 2: Reasonable adjustments

Comments captured in this theme often reflected the provision of appropriate reasonable adjustments to ensure access to relevant health services and ongoing monitoring for people with comorbidities and clinical vulnerability. Examples include the provision of home visits, translators, communication passports, and the allocation of a named GP. Some comments reflected the importance of desensitisation work (e.g. around needle phobia) and adjustments to allow the person to comfortably have their health monitored or treated (e.g. at-home care), which could support prevention of conditions such as pneumonia. Reasonable adjustments to ensure principles of the Mental Capacity Act were followed were noted as important for ensuring the person could be as involved as possible in decision making, particularly during end-of-life planning or decisions such as DNACPR (e.g. using communication aids).

"[Name] did not like healthcare environments however he was made to feel comfortable at their GP practice and reasonable adjustments were made to support the family with language barriers enabling [Name] to attend annual health checks"

"[Name] had challenging behaviours and found having their physical observations done at the GP challenging. Therefore, the residential care home put into place daily observations to be taken at home including blood pressure and pulse. This was effective and resulted in observations being taken and sent to the GP for review."

"There is evidence of the practice nurse using pictures during asthma review to explain causes and treatment."

Theme 3: Staff training

Positive practice around this theme captures instances of staff being appropriately trained and skilled to support the person with a learning disability with their physical health. Comments gave examples of named professionals providing care going “above and beyond” their role. Provision of training to recognise the signs and symptoms of deterioration in the person’s physical health was an area of positive practice particularly relevant to the care and treatment of pneumonia.

“The community learning disability nurse provided the team with a copy of signs to look out for.”

“Early acute physio advice was given to minimise the risk of escalation, plans were clear and comprehensive for staff to follow in emergency situations.”

Theme 4: Timely care

Comments included in this theme reflected professionals recognising signs of deterioration in the person with a learning disability and escalating these through the appropriate channels. Comments demonstrated professionals completing referrals and treatment within recommended timeframes. Timely assessments for swallowing issues were noted which are important in reducing the risk of aspiration. Evidence of effective and timely end-of-life care planning was noted.

“District nursing team escalated care concerns via safeguarding when the pressure ulcer reached stage 3 and there was cause for concern for tissue viability. MDT was instigated promptly and the issues were swiftly rectified and pressure ulcer healed shortly after.”

“Speech and Language Therapy provided timely assessment and continued ongoing review and treatment for dysphagia. This supported [Name] with their end-of-life care plans and he avoided any hospital admission related to their swallow and eating and drinking.”

Issues with care:

Four themes were generated from the comments about issues with care relevant to respiratory illness and hospital care.

Theme 1: Lack of staff training, skills or expertise for supporting people with a learning disability with complex health needs

Comments captured within this theme included examples of professionals not appearing to have the appropriate skills or training needed to support a person with a learning disability. Several examples referred to social care staff (paid carers) lacking awareness in signs of physical deterioration, failing to escalate changes in health, or not receiving appropriate training to manage health conditions. Other examples included a lack of awareness of the unique challenges of caring for a person with a learning disability in hospital settings. Of particular relevance to the risk of pneumonia, there were examples of staff not following eating and drinking plans.

“Staff in care home and agency nursing team unfamiliar with signs of sepsis and signs of deterioration in vulnerable client”

“Carers reported that initially emergency department medical staff assumed [Name]’s quality of life was poor due to their learning disability until they were challenged by one of the junior doctors.”

"[Name] was on a recommended diet plan initially, however it appeared staff were giving them bacon, pastry and gammon, which could create risk of aspiration. This had been previously raised in a safeguarding consultation due to staff members giving [Name] food outside of their [Speech and Language Therapy] plan."

Theme 2: Delays in care

This theme includes delays in different aspects of care. This includes delays in recognising and escalating signs of deterioration, delays in diagnosing conditions, delays in completing referrals, delays in obtaining medical equipment (which can be important for positioning support), and delays in admission or discharge from the hospital.

"[Name] did not have access to a wheelchair for approximately 4 months; their wheelchair was crucial to their psychological and physical health in being able to be in the correct position for the PEG feed."

"Delay in ambulance response to initial emergency call when [Name] was found face down on the floor"

Theme 3: Issues with health monitoring, risk assessment and documentation relating to known clinical risk factors for pneumonia

This theme relates to issues relating to the proactive monitoring of risk factors for respiratory conditions and pneumonia. Reviewer's comments highlighted a lack of health action plans resulting from annual health checks, and examples of health checks failing to include basic assessments such as weight or blood pressure. Other comments reflected issues with recognising and implementing needs around eating and drinking which are crucial for managing the risk of aspiration pneumonia.

"Annual health assessment not being carried out using a consistent robust assessment template with no clear written action plan."

"It was known [Name] was at risk of developing aspiration pneumonia which was their cause of death. Throughout their GP notes and the latest review, this risk does not come through and there were no flags or patient status alerts on [the GP record system] regarding this. Eating and drinking risk management sheet is referred to in documentation as 'guidelines' but they are more than this – they are three pages of important information."

Theme 4: Issues with emergency and end-of-life care planning

Reviewers commented on issues with emergency care planning which often referred to the absence of advanced planning, such as completion of ReSPECT forms (ReSPECT process includes a personalised plan including recommendations for a person's care and treatment in the event of a future emergency where they are unable to express their choices). A lack of advanced care planning was noted to impact on the person's wishes being followed around their death and lead to the person dying in hospital against their wishes. A lack of provision of reasonable adjustments to support engagement in advanced care plans or decision making in hospital was noted.

“Opportunities were missed to listen to [Name] and gather their wishes as to how they wanted to be treated at end of life. [Name] did not have a ReSPECT form completed until they was [sic] admitted to hospital at their last episode of care. His family stated this is something he would have liked to be involved in creating.”

“[Name] died in hospital due to their care provider saying that they were unable to come home when well enough to do so as they were unable to meet their increasing needs. As an elderly person with Down syndrome, care provided took no account of the predictability of her increasing frailty.”

Discussion of the findings from the LeDeR data

Causes of death

The sample of 100 people who died from pneumonia comprised 56 people who had pneumonia recorded as their underlying cause of death, 36 people with aspiration pneumonia recorded, and 8 who had acute respiratory infections as a cause of death.

Socio-demographic variables

The group who died from pneumonia share similar socio-demographic characteristics with those who died from other causes, including very similar ages at death.

Risk factors and death

The data demonstrate that a greater proportion of people who died from pneumonia had Down syndrome, received Speech and Language Therapy (SaLT) and/or nutritional support, and had postural support needs than the comparison group who died from other causes of death.

A logistic regression found two factors that were significantly associated with dying from pneumonia; swallowing difficulties and impaired airway clearance. It is unsurprising that these factors were identified and it confirms the need to ensure optimal management of these risk by carers of people who experience them.

Care factors

People who had pneumonia as a cause of death were less likely to have had a medication review in the 12 months before death than the people who did die from other causes. Thirty-eight percent of the reviews for people in the pneumonia group stated that the family or carers of the person received training on mealtime support and received dysphagia awareness training. Just under half (47%) of the pneumonia group were reported as having dysphagia and 36% died from aspiration pneumonia. People who had pneumonia listed in part one of their death certificate were less likely to have had a medication review in the 12 months prior to death than people who did not have pneumonia listed in part one of their death certificate. Vaccination rates were similar across the two samples.

Quality of care

No differences were found between the types of problems that were experienced by those who died from pneumonia in comparison to those who died from other causes.

Use of the Mental Capacity Act

The accurate use of the Mental Capacity Act was in place for a higher percentage of people who did not die from pneumonia in comparison to those who did, though this difference was relatively small. LeDeR reviewers were less likely to report that the person had their wishes identified and followed for the sample of people who died from pneumonia in comparison to the sample of people who did not die from pneumonia. The use and understanding of statutory duties relating to the Mental Capacity Act were further highlighted in the qualitative analysis of the reviewer's comments on positive practice in the reviews of people who died from pneumonia. A potential reason for this may be due to the acute nature of deaths due to pneumonia, resulting in less time to record or follow the Mental Capacity Act. However, with the limited data in this sample, further evidence is required to ascertain whether these findings are significant or not.

Qualitative findings – positive practice and issues with care

The qualitative findings highlight the importance of staff training, health monitoring for people with a learning disability with comorbidities and awareness of signs and symptoms of deterioration. Timely investigations, referrals and treatment were found to be important, and the consequences of delays in care are particularly crucial to reflect on in deaths from pneumonia.

Aspiration pneumonia

Only a minority of people who died from aspiration pneumonia had clear evidence of an 'aspiration event' documented in their LeDeR review or associated documentation. However, owing to some of the limitations of the available data, it is not possible to say with certainty that an aspiration event did not occur. Furthermore, it is not always the case that a single aspiration event occurs prior to the development of aspiration pneumonia. When we considered the prevalence of risk factors associated with aspiration, the majority of those who were recorded to have died from aspiration pneumonia did have either an aspiration event or risk factors for aspiration. However, based on our data, it is not possible to say whether aspiration pneumonia is systematically under- or over-recorded as a cause of death in people with a learning disability and alternative methods will be necessary to determine the accuracy of death certificate information.

Importantly, the identified risk factors for people who died from pneumonia (postural support needs, swallowing difficulties, and impaired airway clearance) are also risk factors for aspiration pneumonia. Aspiration pneumonia is not always associated with an identifiable aspiration event, it can occur due to complications arising from a person's natural secretions which can be difficult to manage in people with a learning disability, especially those with postural problems or conditions which make it difficult to clear secretions (Legg et al., 2023).

The management of risk of aspirations pneumonia in people with a learning disability involves risk management with patients, carers and relevant professionals. Strategies to manage risk include good oral hygiene, SaLT involvement, positioning support, eating and drinking support, and medications (Legg et al., 2023).

The logistic regression identified several risk factors for death from pneumonia, all of which are identified risk factors for aspiration pneumonia (swallowing difficulties and impaired airway clearance). This could be interpreted as evidence suggesting that aspiration pneumonia is under-reported in the deaths of people with a learning disability. Further research is therefore required regarding this.

Strengths and limitations of the analyses using LeDeR reviews

This deep dive used data from LeDeR focused reviews and associated documents gathered as part of the review process to investigate deaths due to pneumonia in people with a learning disability. This allowed for an in-depth analysis of individual risk factors and an exploration of the quality of care people received prior to their death in hospital. Such insights may go some way to improving care for people are reducing poor outcomes (including death) of people with a learning disability who have pneumonia. Some of the findings may be applicable to the management of other acute or infectious illnesses.

This work has some limitations. First, the LeDeR analysis may be under-powered to detect differences between the groups who died from pneumonia and those who did not. Second, the data used in this deep dive are unlikely to be representative of the wider group of people with a learning disability who are at risk of, or who develop pneumonia. The cohort were those who died from pneumonia and therefore does not include any information on those who had pneumonia but did not die, including those who may have suffered other adverse outcomes. The data used here are all obtained from focused reviews; focused reviews are reviews that are selected for a more detailed investigation by reviewers based on specific criteria (i.e. cases identified as presenting significant learning opportunities, people of an ethnic minority background, or people who were under mental health or criminal justice restrictions at the time of death or within 5 years previously). In some regions of England, all pneumonia deaths are forwarded for a focused review.

Third, although LeDeR is an invaluable source of data for in-depth analysis of many aspects of the mortality of people with a learning disability, there are limitations to the data related to specific conditions that are available, even in the focused reviews. This meant that it was not possible to gather information on several risk factors and elements of care for pneumonia in learning disability.

This deep dive was limited by the information included in LeDeR review forms. See appendix 5 for a full description of these limitations.

Overall conclusions

The objectives of this work were:

1. To conduct a systematic literature review to establish risk factors for poor outcomes of community-acquired pneumonia in adults with a learning disability to establish high-risk groups.
2. To undertake an in-depth review of a subset of LeDeR reviews where the person died from pneumonia to determine the presence of risk factors and areas where care can be improved.
3. To explore the evidence for aspiration pneumonia as a cause of death of people with a learning disability.

Through both the systematic review of existing literature and an analysis of the LeDeR data, the following are identified as risk factors for poor outcomes of community-acquired pneumonia in adults with a learning disability:

- People with Down syndrome and certain other genetic conditions,
- Individuals with reduced mobility,
- Those with advancing age,
- People with reduced functional independence
- People who have more specific physiological issues including impaired airway clearance, swallowing difficulties, and postural problems.

Increased awareness of these risk factors amongst health providers and caregivers could help reduce the chances of a person developing pneumonia, and ensure treatment is provided promptly. Preventative action, such as adequate carer training and timely access to referrals, and treatments, could reduce premature mortality from pneumonia.

Regarding aspiration pneumonia, it may be that these deaths are under-reported in that the deaths of people with defined risk factors for aspiration pneumonia is greater than the recordings of aspiration pneumonia deaths. This is an important suggestion and one that requires further examination through further work.

Implications for practice

The following implications can be drawn:

- Appropriate training and knowledge for carers in the signs and symptoms of pneumonia is essential to ensure deterioration is identified quickly.
- Risk factors for pneumonia include advancing age, poor mobility, postural problems, impaired airway clearance, comorbidities such as dysphagia and cardiovascular conditions, and genetic conditions such as Down syndrome. Those with such conditions should be monitored closely for signs and symptoms of respiratory illness, and for signs of deterioration when they do develop a respiratory infection
- Vaccination programs for respiratory conditions (such as age thresholds for pneumococcal vaccines) need to be reviewed for those at high risk such as people with Down syndrome and certain other genetic conditions to ensure optimal coverage
- Continued focus on the importance of person-centred care with clear communication for all those involved.
- Continued focus on the importance of timely referrals, investigations, treatment, and efforts to reduce delays in care.

Overall implications for research

- Additional work is needed to increase the quality of focused LeDeR reviews and we suggest that the implementation of compulsory questions is reconsidered to enable more data to be collected about the health conditions a person experienced before they died.
- Additional work is required to determine whether or not aspiration pneumonia is under or over-reported in the deaths of people with a learning disability. This could include research linking multiple sources of data including the person's medical and social care documentation. Research into the local validity of these findings could also provide benefit on to planning on a regional level.

References

- Baksh, R. A., Strydom, A., Pape, S. E., Chan, L. F., & Gulliford, M. C. (2022). Susceptibility to COVID-19 Diagnosis in People with Down Syndrome Compared to the General Population: Matched-Cohort Study Using Primary Care Electronic Records in the UK. *Journal of general internal medicine*, 37(8), 2009–2015. <https://doi.org/10.1007/s11606-022-07420-9>
- Blake, J. M., Estrada Gomez, D., Skotko, B. G., Torres, A., & Santoro, S. L. (2021). Pneumonia and respiratory infection in Down syndrome: A 10-year cohort analysis of inpatient and outpatient encounters across the lifespan. *American journal of medical genetics. Part A*, 185(10), 2878–2887. <https://doi.org/10.1002/ajmg.a.62355>
- Chang, C. K., Chen, C. Y., Broadbent, M., Stewart, R., & O'Hara, J. (2017). Hospital admissions for respiratory system diseases in adults with intellectual disabilities in Southeast London: a register-based cohort study. *BMJ open*, 7(3), e014846. <https://doi.org/10.1136/bmjopen-2016-014846>
- Franquet E. (2017). Pneumonia. *Seminars in roentgenology*, 52(1), 27–34. <https://doi.org/10.1053/j.ro.2016.12.001>
- Hayes, S. A., Kutty, S., Thomas, J., Johnson, J. T., & Yetman, A. T. (2017). Cardiovascular and general health status of adults with trisomy 21. *International Journal of Cardiology*, 241, 173–176. <https://doi.org/10.1016/j.ijcard.2017.03.040>
- Heslop, P., Blair, P. S., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2014). The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *Lancet (London, England)*, 383(9920), 889–895. [https://doi.org/10.1016/S0140-6736\(13\)62026-7](https://doi.org/10.1016/S0140-6736(13)62026-7)
- Hilton, J. M., Fitzgerald, D. A., & Cooper, D. M. (1999). Respiratory morbidity of hospitalized children with trisomy 21. *Journal of Paediatrics and Child Health*, 35(4), 383–386. <https://doi.org/10.1046/j.1440-1754.1999.00386.x>
- Hirose, N., Morita, K, Jo, T., Hagiwara, Y., Matsui, H., Fushimi K., Yasunaga, H. (2022) Differences in disease severity and in-hospital mortality in patients hospitalised for pneumonia with and without intellectual disabilities: A matched-pair retrospective cohort study using nationwide in-patient database. *Journal of Intellectual & Developmental Disability*, 47(1), 65–73. <https://doi.org/10.3109/13668250.2021.1877644>
- Hosking F. J., Carey I. M., Shah S. M., Harris T., Dewilde S., Beighton C. et al. (2016) Mortality among adults with intellectual disability in England: comparisons with the general population. *American Journal of Public Health* 106, 1483–1490.
- Jensen, K. M., Sevick, C. J., Seewald, L. A. S., Halbower, A. C., Davis, M. M., McCabe, E. R. B., ... Abman, S. H. (2015). Greater risk of hospitalization in children with Down syndrome and OSA at higher elevation. *Chest*, 147(5), 1344–1351. <https://doi.org/10.1378/chest.141883>
- Landes, S. D., Stevens, J. D., & Turk, M. A. (2021). Cause of death in adults with intellectual disability in the United States. *Journal of intellectual disability research : JIDR*, 65(1), 47–59. <https://doi.org/10.1111/jir.12790>

Legg, J., Allen, J. L., Andrew, M., Annesley, C., Chatwin, M., Crawford, H., Elverson, J., Forton, J., Oulton, K., Renton, K., Tavare, A., Tedd, H., & Simpson, A. J. (2023). BTS Clinical Statement on the prevention and management of community-acquired pneumonia in people with learning disability. *Thorax*, 78(Suppl 1), s22–s52. <https://doi.org/10.1136/thorax-2022-219698>

MacKay, J., Leonard, H., Wong, K., Wilson, A., & Downs, J. (2018). Respiratory morbidity in Rett syndrome: an observational study. *Developmental medicine and child neurology*, 60(9), 951–957. <https://doi.org/10.1111/dmcn.13726>

Mackenzie G. (2016). The definition and classification of pneumonia. *Pneumonia (Nathan Qld.)*, 8, 14. <https://doi.org/10.1186/s41479-016-0012-z>

Medrano, C., Garcia-Guereta, L., Grueso, J., Insa, B., Ballesteros, F., Casaldaliga, J., ... CIVIC Study Group from the Spanish Society of Pediatric Cardiology and Congenital Heart Disease. (2007). Respiratory infection in congenital cardiac disease. Hospitalizations in young children in Spain during 2004 and 2005: The CIVIC epidemiologic study. *Cardiology in the Young*, 17(4), 360–371. <https://doi.org/10.1017/S104795110700042X>

Motegi, N., Yamaoka, Y., Moriichi, A., & Morisaki, N. (2022). Causes of death in patients with Down syndrome in 2014-2016: A population study in Japan. *American journal of medical genetics. Part A*, 188(1), 224–236. <https://doi.org/10.1002/ajmg.a.62526>

O’Leary, L., Cooper, S.-A., & Hughes-McCormack, L. (2018). Early death and causes of death of people with intellectual disabilities: Asystematic review. *Journal of Applied Research in Intellectual Disabilities*, 31(3), 325–342. <https://doi.org/10.1111/jar.12417>

Office for National Statistics. (2024) Deaths registered weekly in England and Wales, provisional . Retrieved from <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/weeklyprovisionalfiguresondeathsregisteredinenglandandwales>

Oppewal, A., Schoufour, J. D., van der Maarl, H. J. K., Evenhuis, H. M., Hilgenkamp, T. I. M., & Festen, D. A. (2018). Causes of Mortality in Older People With Intellectual Disability: Results From the HA-ID Study. *American journal on intellectual and developmental disabilities*, 123(1), 61–71. <https://doi.org/10.1352/1944-7558-123.1.61>

Ottosen, J., & Evans, H. (2014). Pneumonia: challenges in the definition, diagnosis, and management of disease. *The Surgical clinics of North America*, 94(6), 1305–1317. <https://doi.org/10.1016/j.suc.2014.09.001>

Patja, K., Mölsä, P., & Iivanainen, M. (2001). Cause-specific mortality of people with intellectual disability in a population-based, 35-year follow-up study. *Journal of intellectual disability research : JIDR*, 45(Pt 1), 30–40. <https://doi.org/10.1046/j.1365-2788.2001.00290.x>

- Santoro, S. L., Chicoine, B., Jasien, J. M., Kim, J. L., Stephens, M., Bulova, P., & Capone, G. (2021). Pneumonia and respiratory infections in Down syndrome: A scoping review of the literature. *American journal of medical genetics. Part A*, 185(1), 286-299. <https://doi.org/10.1002/ajmg.a.61924>
- Simpson, A. J., Allen, J. L., Chatwin, M., Crawford, H., Elverson, J., Ewan, V., Forton, J., McMullan, R., Plevris, J., Renton, K., Tedd, H., Thomas, R., & Legg, J. (2023). BTS clinical statement on aspiration pneumonia. *Thorax*, 78(Suppl 1), s3-s21. <https://doi.org/10.1136/thorax-2022-219699>
- Tansarli, G. S., & Mylonakis, E. (2018). Systematic Review and Meta-analysis of the Efficacy of Short-Course Antibiotic Treatments for Community-Acquired Pneumonia in Adults. *Antimicrobial agents and chemotherapy*, 62(9), e00635-18. <https://doi.org/10.1128/AAC.00635-18>
- Trollor, J., Srasuebkul, P., Xu, H., & Howlett, S. (2017). Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. *BMJ open*, 7(2), e013489. <https://doi.org/10.1136/bmjopen-2016-013489>
- Truesdale, M., Melville, C., Barlow, F., Dunn, K., Henderson, A., Hughes-McCormack, L. A., McGarty, A., Rydzewska, E., Smith, G. S., Symonds, J., Jani, B., & Kinnear, D. (2021). Respiratory-associated deaths in people with intellectual disabilities: a systematic review and meta-analysis. *BMJ open*, 11(7), e043658. <https://doi.org/10.1136/bmjopen-2020-043658>
- Tyrer, F., & McGrother, C. (2009). Cause-specific mortality and death certificate reporting in adults with moderate to profound intellectual disability. *Journal of intellectual disability research : JIDR*, 53(11), 898-904. <https://doi.org/10.1111/j.1365-2788.2009.01201.x>
- Tyrer, F., Morriss, R., Kiani, R., Gangadharan, S. K., & Rutherford, M. J. (2022). Mortality disparities and deprivation among people with intellectual disabilities in England: 2000-2019. *Journal of epidemiology and community health*, 76(2), 168-174. <https://doi.org/10.1136/jech-2021-216798>
- Tyrer, F., Smith, L. K., & McGrother, C. W. (2007). Mortality in adults with moderate to profound intellectual disability: a population-based study. *Journal of intellectual disability research : JIDR*, 51(Pt 7), 520-527. <https://doi.org/10.1111/j.1365-2788.2006.00918.x>
- White, A; Sheehan, R; Ding, J; Roberts, C; Magill, N; Keagan-Bull, R; Carter, B; Ruane, M; Xiang, X; Chauhan, U; Tuffrey-Wijne, I; Strydom, A; (2022). Learning from Lives and Deaths - People with a learning disability and autistic people (LeDeR) report for 2021 (LeDeR 2021). Autism and learning disability partnership, King's College London
- White, A; Sheehan, R; Ding, J; Roberts, C; Magill, N; Keagan-Bull, R; Chauhan, U; Tuffrey-Wijne, I; Strydom, A; (2023). Learning from Lives and Deaths - People with a learning disability and autistic people (LeDeR) report for 2022 (LeDeR 2022). Autism and learning disability partnership, King's College London



APPENDIX

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University of
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Appendix 1: Full search strategy

("Intellectual Disability"[Mesh] OR Intellectual disabil*[tw] OR learning disabil* [tw] OR mental retardation [tw] OR learning disorder* [tw] OR "Down Syndrome"[Mesh] OR Down* Syndrome* [tw] OR Trisomy 21 [tw] OR Fragile X Syndrome [tw] OR Williams syndrome [tw] OR Prader-Willi Syndrome [tw]) AND ("Pneumonia"[Mesh] OR Pneumoni* [tw] OR lower respiratory tract infection [tw] OR lung infection [tw] OR Lobar pneumoni* [tw] OR "Bronchopneumonia"[Mesh] OR Bronchopneumoni* [tw] OR "Lung Diseases, Interstitial"[Mesh] OR interstitial lung disease* [tw]) AND ("Hospitalization"[Mesh] OR Hospitalization* [tw] or Hospitalisation* [tw] OR "Respiratory Care Units"[Mesh] OR respiratory care unit* [tw] OR "Intensive Care Units"[Mesh] Or intensive care unit* [tw] OR intensive-care-unit* [tw] OR intensive therapy unit* OR intensive treatment unit* [tw] OR critical care unit* [tw] OR high dependency unit* [tw] OR "Mortality"[Mesh] OR mortalit* [tw] OR "Mortality, Premature"[Mesh] OR premature mortalit* [tw] OR "Death"[Mesh] OR death [tw])

Appendix 2: Data collected by reading the LeDeR reviews in full

1. previous hospital admissions in the last year
2. impaired airway clearance
3. postural problems
4. nutrition support
5. oral care support
6. positioning support
7. family communication
8. patient's wishes identified and followed
9. Appropriate advocacy
10. mental capacity act needed
11. Learning disability nurse specialist input

The following list of factors were excluded due to unavailable information:

- impaired lung function test result (data available in 1/10 reviews)
- prophylactic antibiotics (0/10 reviews - difficult to determine whether use of antibiotics was preventative)
- chest physio (data available in 1/10 reviews)
- intensive care review/discussion (data available in 0/10 reviews)
- prescription of antipsychotics reviewed (data available in 2/10 reviews - only a small proportion of the sample on antipsychotics)
- family and carers aware of risk factors for pneumonia (data available in 3/10 reviews)

Appendix 3: Risk factors for aspiration pneumonia

The following list of risk factors was taken from Sanivarapu and Gibson’s article (2022)

- Stroke
- Drug overdose
- Alcohol use disorder
- Seizures
- General anaesthesia
- Head trauma
- Intracranial masses
- Dementia
- Parkinson disease
- Oesophageal strictures
- Gastroesophageal reflux disease
- Pseudobulbar palsy
- Tracheostomy
- NG tube
- Bronchoscopy
- Protracted vomiting

Appendix 4: Logistic regression analyses looking at the risk factors associated with dying from pneumonia controlling for age and sex

Variable	Odds ratio	Standard error	z	p	95% Confidence interval
Swallowing difficulties	2.38	.795	2.60	0.009	1.24, 4.58
Impaired airway clearance	2.34	.881	2.05	0.041	1.03, 4.84
Postural problems	1.79	.590	1.76	0.078	0.94, 3.41
Obesity	0.56	.289	-1.12	0.264	0.21, 1.54
Impaired mobility	1.03	.325	0.11	0.915	0.56, 1.91
Previous hospital admission in the last 12 months	1.16	.355	0.47	0.636	0.63, 2.11
Current smoker	0.6	.378	-0.82	0.414	0.17, 2.06

Appendix 5: Limitations with the availability of data

The two major issues we encountered in completing this work were the skip logic system, and the supplementary documents.

The skip logic in use in the LeDeR review form means that people need to be identified as having a respiratory condition by the reviewer in order for a new set of questions (the 'respiratory form') to be revealed. Of the 100 people who died from pneumonia that formed our sample, only 46 were recorded as having a respiratory condition before they died, therefore most did not include data from the respiratory form (a more targeted set of 39 questions). Within this, 23 of the questions on the form are only triggered following certain responses to previous questions. For example, reviewers are only presented with certain questions (including how many respiratory infections in the 12 months prior to death did the person have that required antibiotics? how many times were steroids prescribed in the last year for their respiratory condition? Did the person have a regular cough?) if they recorded that the person had asthma or COPD. These questions may be relevant to people who experienced respiratory conditions other than asthma and COPD.

Supplementary documents, which can include a person's medical records or care plans, may be uploaded alongside LeDeR reviews and were used by the research team for the first time in this work. We found a great deal of variability in the number and type of documents that were uploaded by reviewers and there was inconsistent information available about certain risk factors. In particular, we were often unable to distinguish whether a risk factor was not recorded because it was not present or because it had merely not been recorded. We suggest, therefore, that other methods are better suited to future in-depth audits of care for specific conditions (e.g. local or prospective data collection).