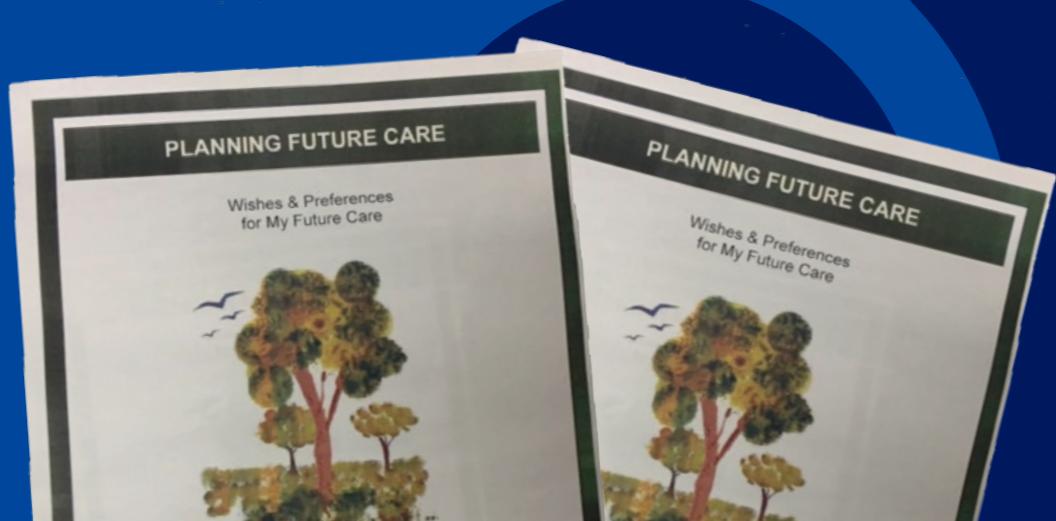


# Developing a Community Based Respiratory Pathway for Adults with Learning Disabilities in Sussex

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## Background

- Respiratory disease is one of the leading causes of death and the most common final event in adults with Learning Disabilities (CIPOLD, 2013)
- In England, twice as many people with Learning Disabilities die from respiratory illness than the general population (Glover & Ayub 2010)
- Learning Disability Physiotherapists in Sussex have developed standards to help address respiratory health inequalities
- Grounded in evidenced based practice, it considers 4 main issues that make up a holistic respiratory service



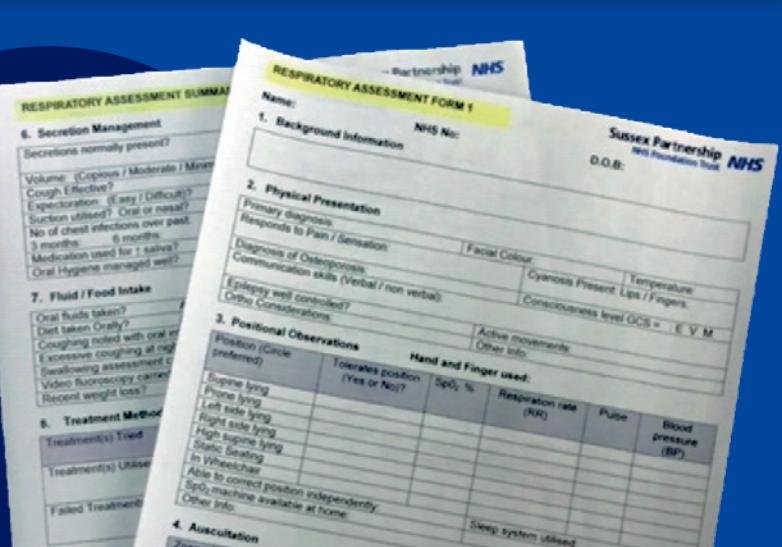
## Management of life shortening conditions

- There are incidences when respiratory failure is inevitable for some patients
- This can be distressing for everyone involved in their care
- Co-ordinating and planning care can help to manage care at times of excessive emotional pressure <sup>1</sup>

"Using the advanced care plan to facilitate care, allowed us to support Jo, her family and her staff team to keep her at home." Unit manager.

## Assessment

"The assessment was very comprehensive and identified things wrong with my son's respiratory care. He has not had any further hospital admission since the changes"  
Parent of a son who had 12 hospital admissions last year



## Comprehensive Respiratory Assessment

- To identify risk factors and symptoms, some often linked to people with Learning Disabilities
- To capture baseline presentations that often fall outside the "norm" in the general population
- To note adults with complex physical disabilities at risk of respiratory failure

## Advanced care planning

## Working with specialist services to manage complex respiratory care

- Identifying people with complex respiratory presentations
- Nice (2018), recommended accessing local or specialist respiratory services <sup>1</sup>

"Why was my chest problem not found out before now. Was this why I was always going into hospital?"  
Patient with undiagnosed COPD

## To identify added respiratory risk



## Development of respiratory management plans

"We have 36 staff who could be supporting our client. Having concise, accessible, treatment protocols reduces risk and builds sustainability"  
Group home manager

## Individualised respiratory management plan

- Nice 2019, recommends access to Physiotherapy chest care programmes <sup>1</sup>
- Assists with antibiotic and hospital avoidance strategies <sup>1,2,3</sup>
- Support staff teams to apply consistent treatment
- Allows for evidence based treatment



## Why we have changed our service delivery

- Men with learning disabilities died, on average, 13 years sooner, women 20 years sooner
- 42% of deaths investigated were assessed as being premature
- Cost implications for poorly managed respiratory care in the community:  
Unspecified acute respiratory infection up to £5,582  
Bronchopneumonia up to £5,818  
Lobar, atypical pneumonia up to £7,866  
Respiratory failure up to £7,745

## Next Steps

- Delivery of the respiratory menu of care across Sussex
- Use data collected to reduce variations in care and inform workforce planning
- Work with specialist respiratory and advanced care services to develop high quality, holistic care within the Sussex area
- Collaborate with patients and stakeholders to further develop existing and future respiratory care service delivery

## References:

- Cerebral palsy in adults NICE guideline [NG119] Published date: January 2019
- Winfield et al, 2014 Non Pharmaceutical Management of Respiratory Mobility in Children with Severe Global Developmental Delay' – Cochrane Review.
- Hart N, Murray J, Standley D (2016)
- Developing an Integrated Respiratory Pathway for People with Complex Physical Disability

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