MacIntyre
Providing support...your way

NHS
Guy's and St Thomas'
NHS Foundation Trust

BILD: Responding to LeDeR

Aspiration Pneumonia & Pneumonia

Sarah Ormston – Health, Dementia and Wellbeing Manager - MacIntyre

David Standley - Clinical Specialist Physiotherapist- Guy's and St Thomas' NHS Foundation Trust

Radhika Lingham - Highly Specialist Speech and Language Therapist - Guy's and St Thomas' NHS Foundation Trust

About MacIntyre

MacIntyre provides learning, support and care for more than **1,200 children, young people and adults** who have a **learning disability and/or autism** across England and Wales.

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What is LeDeR?

LeDeR was commissioned in 2015 with the aim of contributing to the improvement of quality of care and health outcomes for people with a learning disability.

We saw the release of the fourth report from the Learning Disability Mortality Review (LeDeR) programme.

Learning Disabilities Mortality Review (LeDeR) Programme

Overview

People with a learning disability die too young.

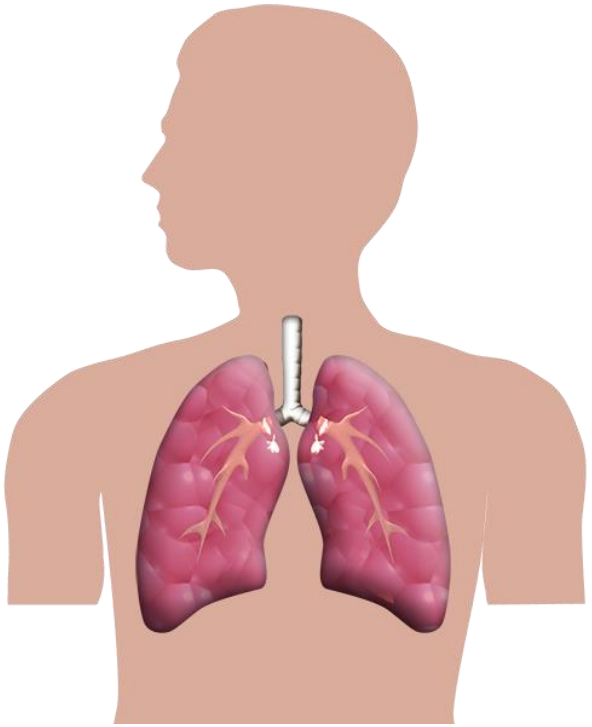
The report includes actions taken at a national level and a number of examples of improvements in local areas from across the country.

Most Common Cause of Premature Death

1. Respiratory Problems

(most significant causes of premature mortality)

Bacterial **pneumonia** was stated as a cause of death for **24%** of adults and 20% of children whose deaths were notified in 2019/20, with **aspiration pneumonia** cited in a further **17%** of adults and 3% of children's deaths.



40-77% of adults with a learning and complex physical disability such as severe cerebral palsy die from respiratory complications.

In total, these respiratory conditions accounted for **2,162** deaths of people with a learning disability.

LeDeR Report

The latest LeDeR Report is about people who have died.

They are people who matter.

In writing their report, they want to avoid people becoming impersonal numbers. They therefore started their report, by sharing stories of real people whose deaths have been reviewed by the LeDeR programme during 2019.

Meet Andrew

I will start with **Andrew.**

→ Andrew died aged 19 from pneumonia

→ Andrew was a friendly and outgoing person who loved to laugh and spend time with people

→ He was described as having a ‘sunny nature’ and a positive impact on those who supported him

→ Andrew took part in many activities that brought him joy including swimming, drumming, singing and going on regular ski trips with his family

Headline Statistics

From 1st July 2016 - 31st December 2019, **7,145 deaths** were notified to the programme (**6,629 were adults** and **516 were children** aged 4-17 years).

Month of death

There was a greater proportion of deaths of people with learning disabilities from October – December than in the general population.

Place of death

The proportion of people with learning disabilities dying in hospital was **60%** in 2019.

In the general population it was **46%** in 2018.

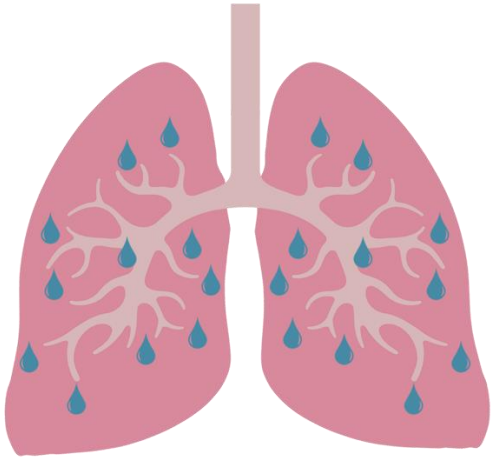
Why Should we focus on Pneumonia Today?

Pneumonia was the most frequently recorded cause of death in people with learning disabilities whose deaths were reviewed in 2019, as was the case in previous years.

	All deaths notified		Deaths notified in 2018		Deaths notified in 2019	
	Adults %	Children %	Adults %	Children %	Adults %	Children %
Bacterial Pneumonia	25%	18%	25%	16%	24%	20%
Aspiration Pnuemonia	17%	3%	16%	2%	17%	3%
Number	5,607	389	2,374	167	2,007	155

Table 17:
Proportion of deaths with bacterial pneumonia or aspiration pneumonia coded anywhere in Part 1 of the MCCD

What is Pneumonia?



→ Pneumonia is an infection in one or both lungs.

→ Bacteria, viruses, and fungi cause it.

→ The infection causes inflammation in the air sacs in your lungs, which are called alveoli.

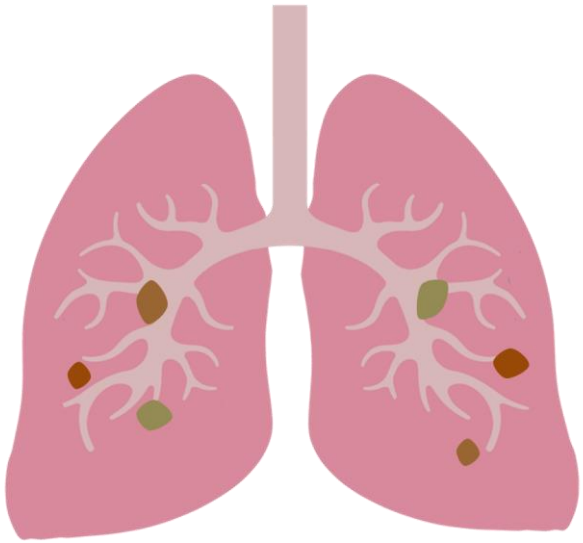
→ The alveoli fill with fluid or pus, making it difficult to breathe.

What is Aspiration Pneumonia?

→ Aspiration pneumonia is a pneumonia that's caused by bacteria entering the lungs and causing a severe infection.

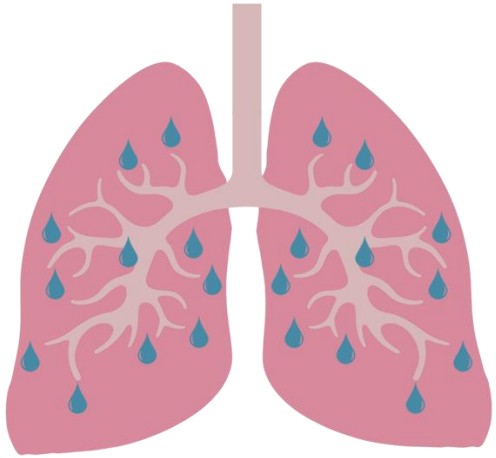
→ Often, the bacteria gets into the lungs through food, **fluid or saliva.**

It's a cause of death for many people with learning disabilities, which sometimes could be avoided.



Risk Factors for Developing Pneumonia/Aspiration Pneumonia

- → Swallowing difficulties (dysphagia)
- → Poor oral hygiene
- → Management of own fluids/secretions
- → Low weight
- → Weak cough
- → Chest Wall Deformity
- → Immobility
- → Constipation
- → Epilepsy

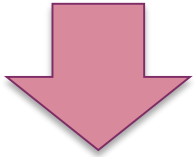


Common in people with Profound and Multiple Learning Disabilities (PMLD) or Severe Cerebral Palsy

Respiratory (Chest) Management

Aim of respiratory (chest) management is to:

- Improve the management of any risk factors that increase likelihood of developing pneumonia or aspiration pneumonia



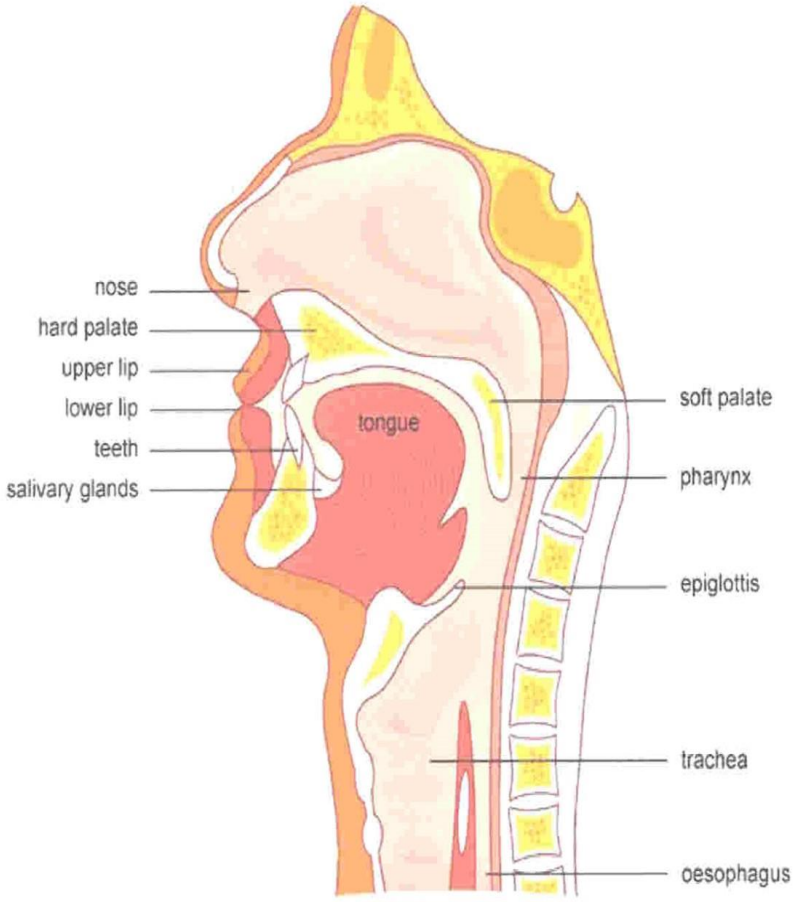
- Reduce risk, frequency and severity of chest infections

Swallowing Difficulties (Dysphagia)

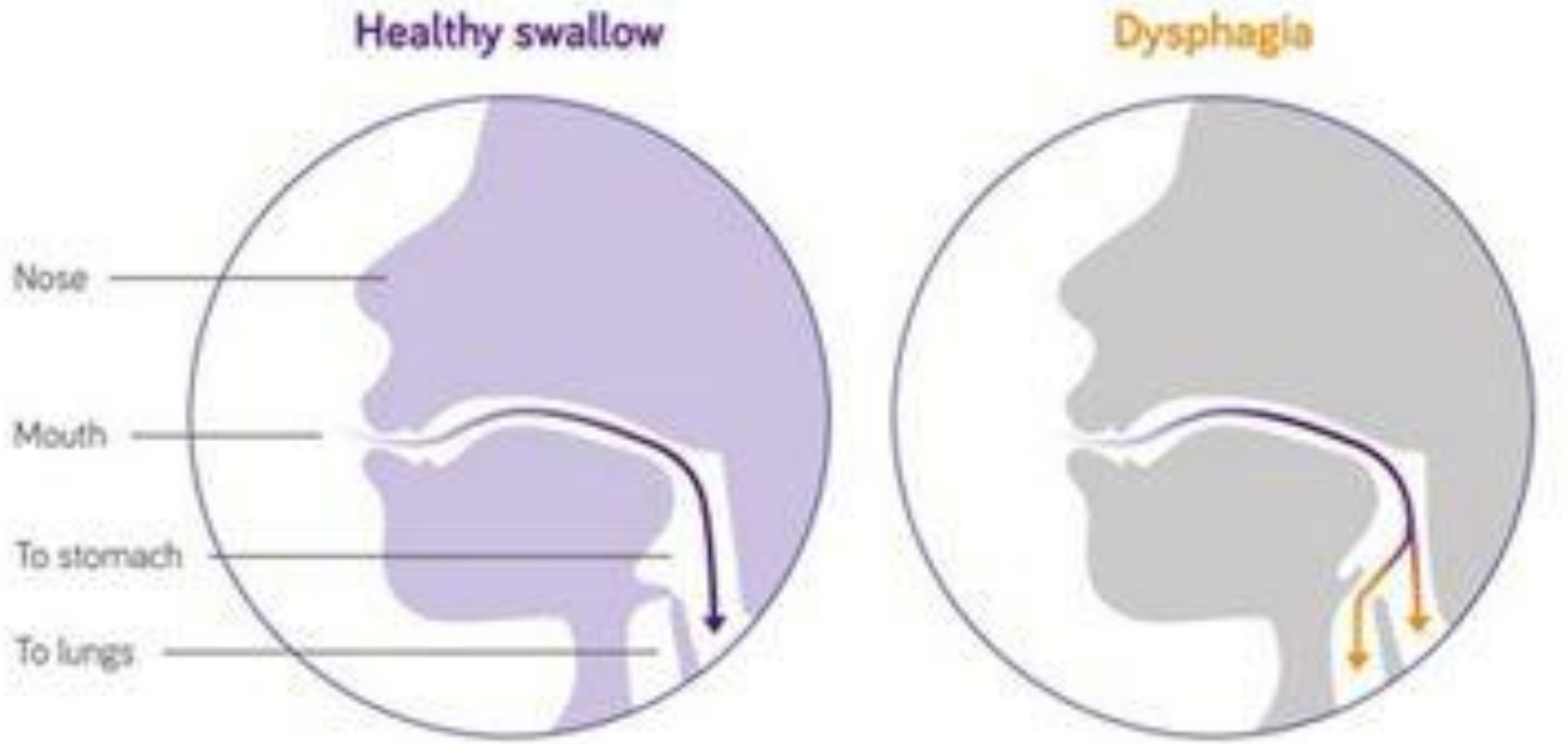
→ We use many muscles and nerves in order to swallow – a quick and complicated sequence of movements

→ If our swallow works well, food, drink and our own fluids such as saliva, go safely to the stomach

→ If a person's swallow does not work properly, food, drink or other fluids could go down "the wrong way" to the lungs instead of stomach.



Swallowing Difficulties (Dysphagia)



Swallowing Difficulties (Dysphagia)

→ Swallowing difficulties are common for people with learning disabilities – often gets missed.

→ So many factors affect swallowing: alertness, positioning/muscle tone with complex physical disability, behaviours such as eating very quickly, putting too much food in mouth at once.

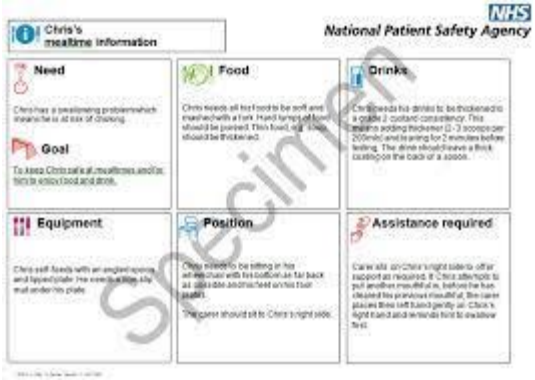
Being dependent on others for eating and drinking (needing a carer to raise food/drink to lips) is one of the biggest risk factors that can lead to aspiration pneumonia

Swallowing Difficulties (Dysphagia)

Speech and Language Therapy assessment and support plan/guidelines

→ Safe textures of food, thickness of drinks, positioning at meal times, physical support, prompting, communication and environment at meal times.

→ These must be followed to reduce the risk of chest infections that can cause aspiration pneumonia.



Swallowing Difficulties (Dysphagia)

→ It is vital to know and recognise signs of aspiration at meal and drink times

→ Once you notice signs, SLT assessment and guidelines for you to follow will help to reduce the risk of aspiration at meal times and help people have safe and comfortable meal and drink times.

→ You are SO important!

Aspiration: Signs to Look out for

Common signs of aspiration when eating or drinking:

→ Coughing during or just after meals/drinks
→ Difficulty breathing: the person may breathe rapidly, gasp or wheeze (look at movement of chest)
→ A wet or gurgly voice around mealtimes
→ Eyes watering at mealtimes
→ Raised temperature
→ Change in skin colour
→ Any signs of pain/discomfort when eating/drinking

Aspiration: Signs to Look out for

Longer term:

→ Weight loss

→ Recurrent chest infections or pneumonias

→ Refusing food or reduced enjoyment of eating

→ Dehydration or malnutrition

→ Consider Silent Aspiration

Swallowing Difficulties (Dysphagia): Strategies for Safe Support

General strategies for safe eating and drinking at meal times if you are supporting a person to eat/drink:

Do's

✓ **Follow SLT guidelines!**

→ Slow pace of eating and drinking – lots of time needed to swallow and then breathe afterwards

→ Give spoonfuls at the level of the person's mouth – not leaning over from above

→ Sit down when fully supporting the person

→ Person should be positioned as upright as possible with feet supported

Don'ts

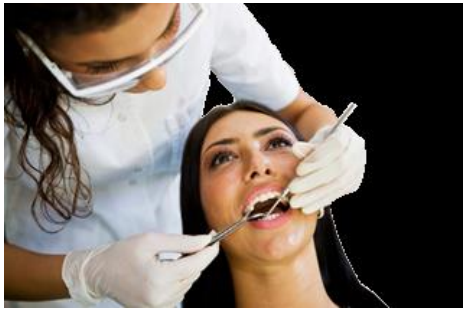
→ Don't give food if the person is too drowsy

→ If the person coughs, do not "wash food down" with a drink

→ Avoid too much talking/laughter and jokes whilst eating/drinking

Oral Hygiene

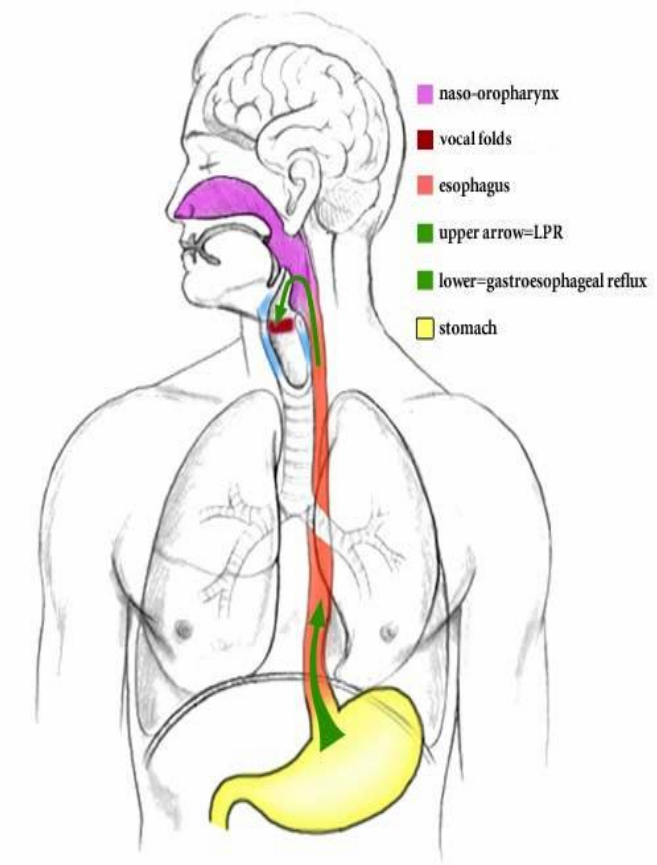
- All structures and saliva in our mouths should be clean and infection ... for both safety and quality of life.
- Bacteria naturally collects in our mouths on all surfaces and gets into our saliva.
- Keeping mouth clean = clean saliva = lower risk of aspirating bacteria from saliva down to the lungs
- Regular Oral Hygiene
  - brush teeth/gums twice per day with a soft toothbrush and toothpaste
  - Even if person has a feeding tube and takes nothing by mouth
  - Even if person has no teeth
- Regular dental check ups – just as we should!
- Dentures: clean with paste/soap and water daily



One of the biggest risk factors for aspiration pneumonia is being dependent on carers for oral hygiene.

Managing Own Fluids/Secretions/Reflux

- → Stomach acid/contents comes back up into the back of your mouth.
- → Can be due to positioning/posture, weak muscles (incl. PEG tube feed)
- → RISK: content of stomach can then be aspirated into lungs instead of swallowed back into stomach.
- → Watch for signs – pain/rubbing chest during/straight after meals, vomiting after meals, coughing outside meals, especially in the mornings.
- → Lifestyle changes: avoid very acidic foods, high fat foods, spicy foods, fizzy drinks, large heavy meals
- → GP: medication/further investigation



Managing Own Fluids/Secretions/Reflux

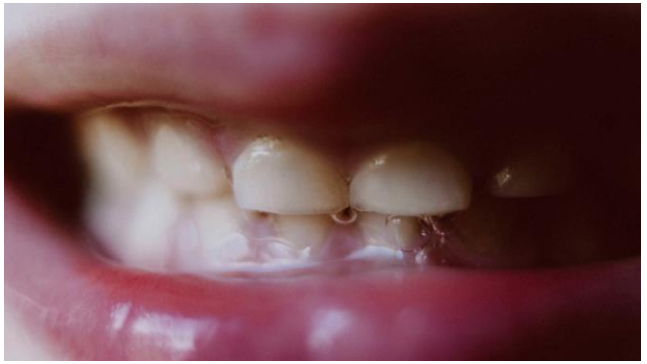
People with swallowing problems can find it difficult to swallow their saliva, e.g. if lip, tongue and cheek muscles do not work well.

→ may see saliva loss from lips

→ some medications can increase saliva production, making it harder to swallow

→ some medications can cause dry mouth

→ Reflux may increase production of saliva



Managing Own Fluids/Secretions/Reflux

→ Dry mouth: could be caused by medication, dehydration, mouth breathing at night

→ Saliva can become thick and sticky

→ Difficult to swallow = higher risk of aspiration

→ Good oral hygiene is so important!

→ Give oral care to clear thick saliva – use toothbrush (avoid pink swabs – choking risk)

→ Then offer drinks for hydration

If you notice any changes in saliva appearance or management e.g. increased coughing on saliva or loss from lips **– important to discuss with GP** in case of treatable infection/condition

Low Weight

- → Low weight/unplanned weight loss can be a long term symptom of aspiration.
- → Person may be having many chest infections and so eating less, and losing more weight
- → May be reluctant to eat due to aspiration
- → Low weight can lead to malnutrition, dehydration and reduced ability to fight off infections – chest infection, UTI, skin breakdown

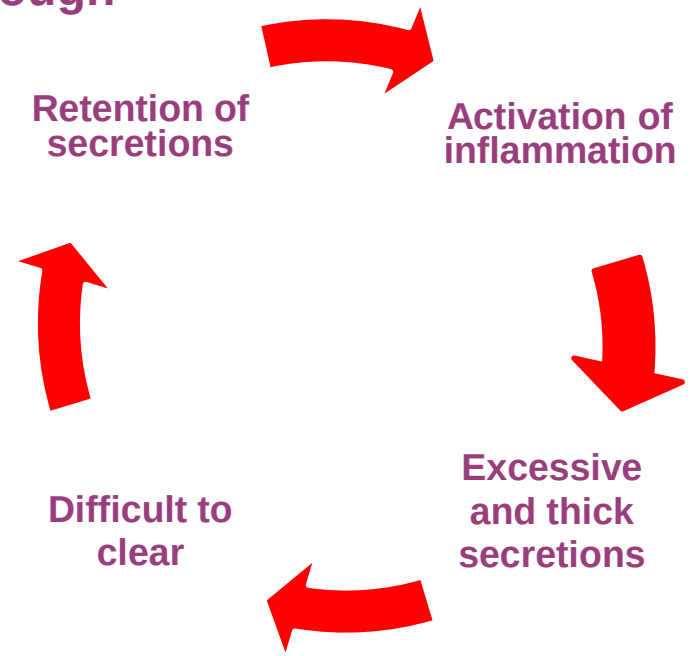
Important to discuss with GP for any further investigations into underlying causes, this might lead to a referral to dietitian who can help with increasing calorie content of foods/drinks, supplements.

Weak Cough

→ A strong, effective cough is important for maintaining a clear airway and respiratory health.

→ A strong cough loosens, moves, and clears mucus, food and/or fluid from the airway.

Weak cough =



→ Many people with learning disabilities are unable cough to command. However, have an effective spontaneous cough

Management

Vocalising, Shouting, Laughing, Movement and Activity




Physiotherapy and Equipment



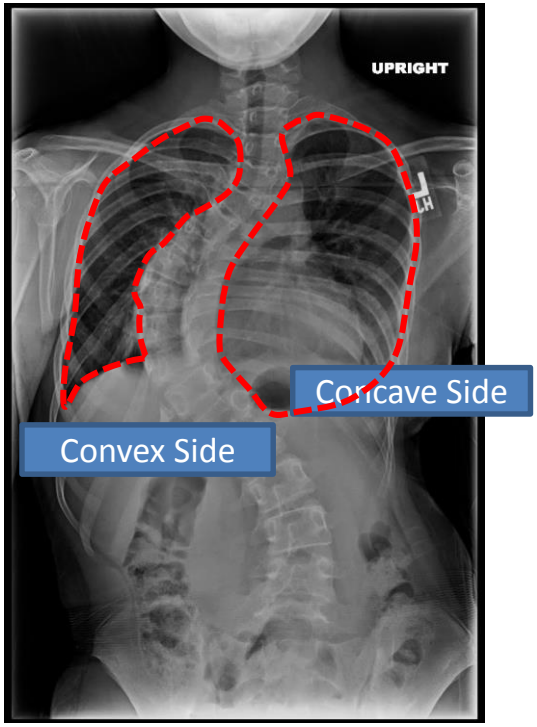


Chest Wall Deformity

Results from changes to the shape of the spine

Called:

- *Scoliosis,*
- *Kyphosis,*
- *Lordosis,*
- *Kyphoscoliosis*
- *Lordoscoliosis*



Chest wall deformity can:

→ Alter shape and function of the lungs and internal organs

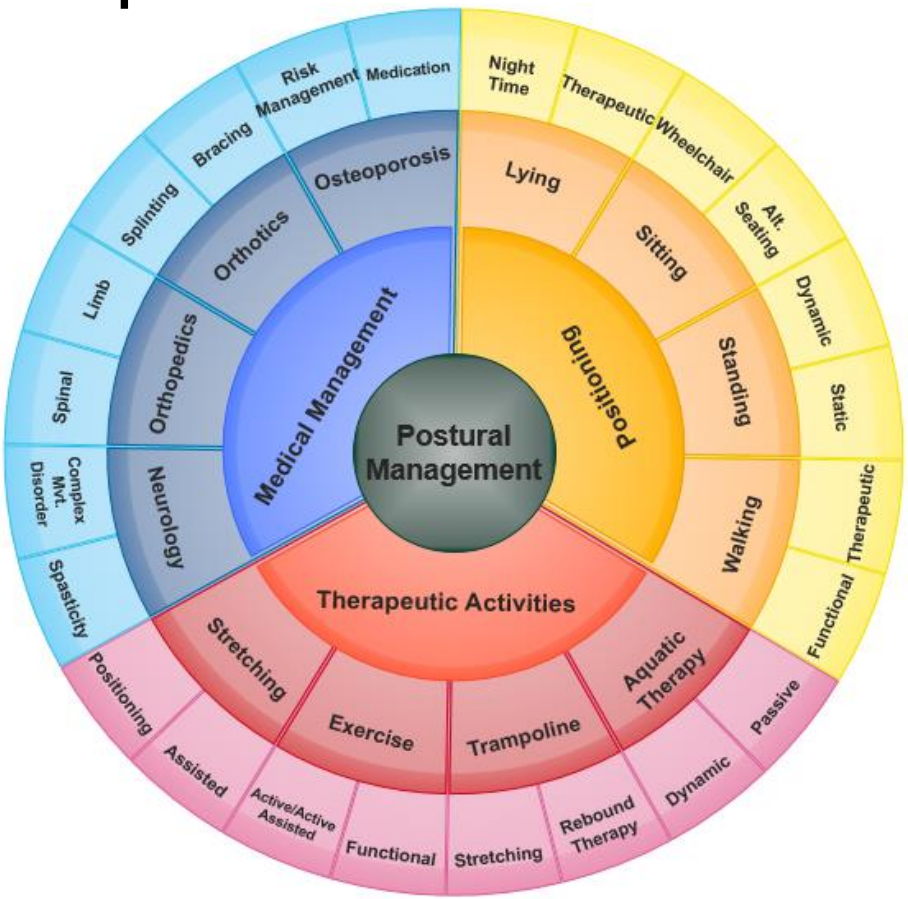
→ Reduce chest wall compliance/flexibility

→ lead to weak respiratory muscles

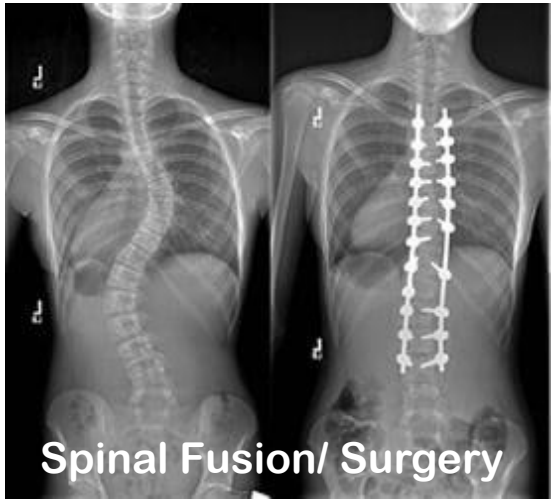
→ Weaken the person's cough

Postural Management

"….ensure that the body is appropriately supported over a 24 hour period to **promote and maintain function**; **prevent and reduce body shape distortion** and reduce the impact of **associated secondary complications.**"



"…..is a planned approach encompassing all activities and interventions which impact on an individual's posture and function."



Importance of Movement/Mobility

→ **Physical exercise is important** part of keeping healthy and for normal airway clearance.

→ Between **50-95%** of people with learning disability do not do enough exercise.

→ **99%** of people with learning and complex physical disability do not do enough exercise.

Moving More

It can be difficult to think of ways to engage people with a learning disability in activity and movement especially when the person's mobility is limited.

- Be creative
- Move
- Change position regularly
- Avoid spending long periods of time in one position
- Postural Management
- Therapeutic activities such as rebound therapy and hydrotherapy

Constipation

Constipation can impact respiratory health
because of:

- Bloating - Reduced lung expansion
- Excessive saliva
- Increased seizure activity
- Loss of appetite
- Reflux

- Up to **half of all people with a learning disability** have constipation.

- Unrecognised, untreated constipation has been known to cause **death**.

Free Webinar on Constipation hosted by BILD:
18 August 2021 – 12-1pm

bild

Epilepsy

The prevalence of epilepsy varies in direct proportion to the severity of the persons learning disability:

- 6% amongst people with a mild learning disability
- 24% in severe learning disability
- 50% in those with profound learning disability

Epilepsy impacts on Respiratory Function because of fluctuating levels of arousal associated with seizures can impact on:

- Dysphagia
- Posture and movement
- Saliva control

Anticipatory Care Calendar TM

1. Baseline Health Assessment

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Baseline Health Assessment

This document is NOT to be archived. To be kept for future comparison.

My Name: _____ **Date of Birth:** _____

Photo of Person

Date of Completion: _____
This document is designed to be completed as a team.

Completed by: _____ **Signature:** _____

Completed by: _____ **Signature:** _____

Completed by: _____ **Signature:** _____

Read by:	Date:	Signature:

Manager: _____ **Signature:** _____

Date for Review: _____
Review to be completed on the Monitoring Health Assessment

TO BE REVIEWED MINIMUM ANNUALLY OR WHEN SOMETHING CHANGES. ALL CHANGES TO BE NOTED ON MONITORING HEALTH ASSESSMENT.

Add to Risk Assessment Schedule for Annual Review

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What is normal for me?

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How I show I am feeling well. What is important to and for me to be healthy and well e.g. Smile, sleep well.

(i.e. mood, facial expressions)

How I communicate. What is my preferred method of communication e.g. Makaton, sequence cards, facial expressions, gestures, touch.

Communicate

Anticipatory Care Calendar TM

MacIntyre Wellbeing for Life
Keep Going ……Don't Stop!

Good Example

What is normal for me?

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Providing support...your way

How I show pain and distress. e.g. Withdrawn, touching the painful area, uncomfortable, rapid pulse, increased respirations.

Tina will let you know if she is in pain and where her pain might be located. She could become fairly quiet if she is in pain and will need prompting to take pain relief.

Tina might also show signs of anxiety or distress when in pain. For example she might hold the part of her body where she is feeling pain or discomfort.

She might rock backwards and forwards if the pain is severe.

Tina will communicate that she is in pain, and exactly where she is in pain.

(i.e. pinching, withdrawal, screaming)

My normal urine pattern. If self caring please say so, if it's normal for me to have e.g. blood in urine, incontinence, please say.

Does not have any problems passing urine. Goes to the toilet independently.

Please note if passing large volumes of fluid this can be a sign of diabetes.

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Good Example

What is normal for me?

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My normal bowel pattern. If self caring please say so, If it's normal for me to have constipation, hard, loose, or diarrhoea in a month, please say

It is usual for Tina to have diarrhoea—2 or 3 episodes a month would be considered normal. If Tina is constipated she could have blood in her stool. She is not on any medication. She goes to the toilet independently but is willing to let you check if you have any concerns.

When she has diarrhoea 2 –3 times a month, Tina will normally be Type 6 or 7 on the Bristol Stool Chart.

Type 6	Type 7
	

(You can use the Bristol Stool Chart to help you)

My normal menstruation cycle. What is normal for me when it comes to my periods? e.g. Bleeding may be light or heavy lasting 3-7 days. Colour maybe brown to red. Do I show discomfort? If so how do I show this?

Tina has a normal 28 day menstrual cycle. She often suffers with pre-menstrual behaviour change by becoming very emotional. To support her with this, reassure her. If she tells you her cramps are really painful, give her the option and prompt to take pain relief.

Bleeding will be quite light and last roughly 4 days. Colour is normally a red and Tina will make it clear that she is in discomfort. She will normally hold her stomach and be more withdrawn.

She may not want to go to the Day Services, however as she is so social, with reminding that she will see all her friends, she often will change her mind and then want to attend the Learning Centre.

Anticipatory Care Calendar TM

2. Monitoring Health Assessment

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Monitoring Health Assessment

My Name: _____ **Date of Birth:** _____

Photo of Person

Date of Completion: _____
This document is designed to be completed as a team.

Completed by: _____ **Signature:** _____

Completed by: _____ **Signature:** _____

Completed by: _____ **Signature:** _____

Read by:	Date:	Signature:

Manager: _____ **Signature:** _____

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Add to Risk Assessment Schedule for Annual Review

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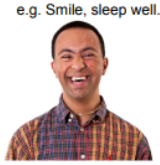


(i.e. mood, facial expressions)

How I communicate. What is my preferred method of communication e.g. Makaton, sequence cards, facial expressions, gestures, touch.

Communicate

Anticipatory Care Calendar TM

3. Anticipatory Care Calendar

Anticipatory Health Care Calendar (Adult version)

Page 1 (please see over)

Month/Year	
Name	
Date of Birth	

Key for actions	
	Needs immediate action
	Requires action
	No action required
H	If away on holiday
F	If with family

Health Screening Information	
Cervical screening (Females) (25 to 49 years of age every three years (50 to 64 years of age every 5 years)	
Date of last screening	Next screening due:
Results:	
Breast screening (Females) (47 to 73 years of age every three years)	
Date of last screening	Next screening due:
Results:	
Bowel screening (males and females) (60 - 74 years of age every two years)	
Date of last screening	Next screening due:
Results:	
Dental screening (as directed by a dentist)	
Date of last screening	Next screening due:
Outcome:	
Eye testing (every two years or as directed by an optician)	
Date of last screening	Next screening due:
Outcome:	

If not attending cancer screening programmes(s) but eligible, please state why. If not applicable, please indicate with N/A

Anticipatory Care Calendar TM

3. Anticipatory Care Calendar

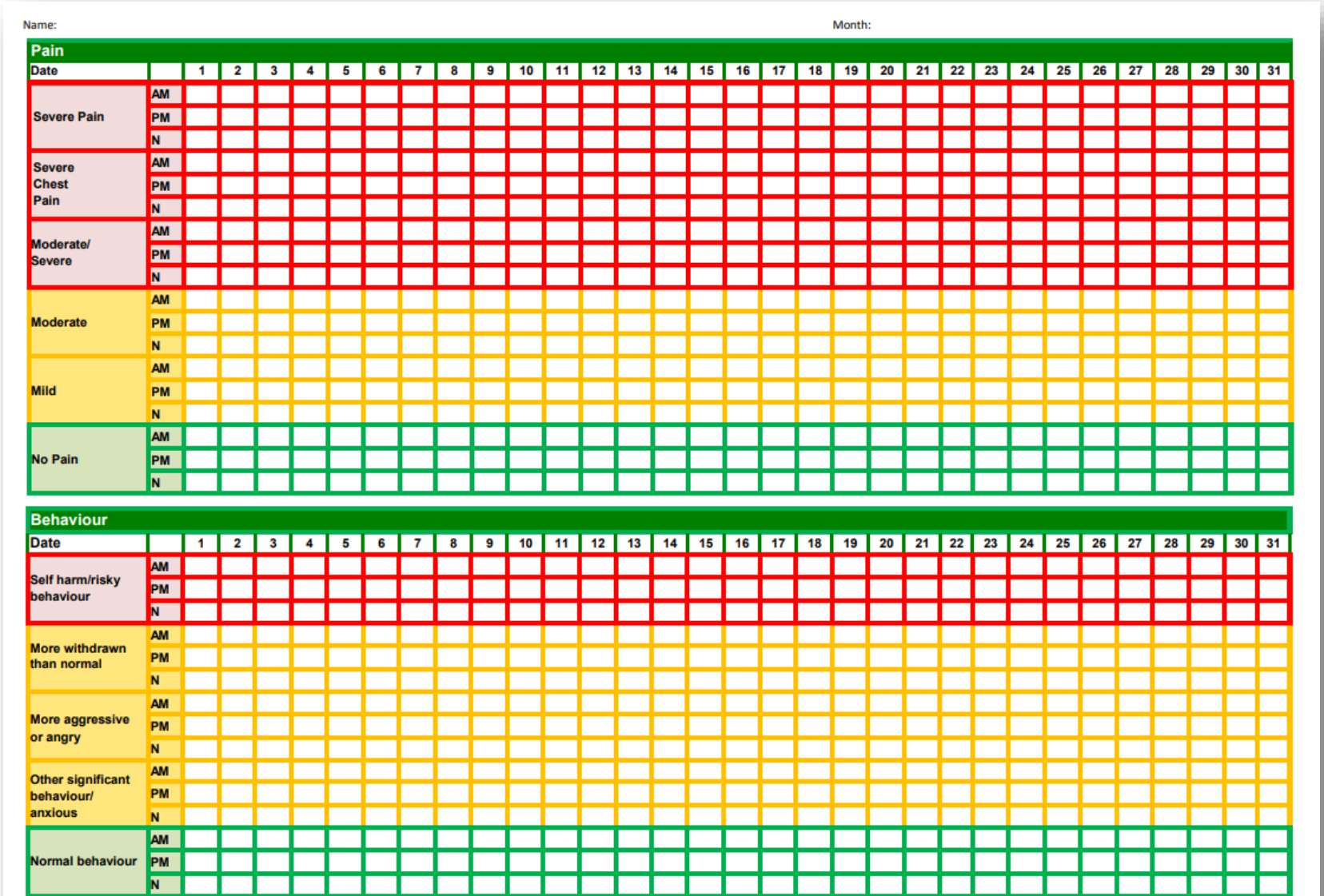
Page 2

Annual Health Check (14+)	
Date of last check	Next check due
Outcome	
NHS Healthcheck (40 - 74)	
Date of last check	Next check due
Outcome	
NHS Abdominal Aortic Aneurysm (65 + Male)	
Date of last check	Next check due
Outcome	
Prostate Cancer Risk Management (50 + Male)	
Date of last check	Next check due
Outcome	
Auditory Check (as directed)	
Date of last check	Next check due
Outcome	
Podiatry Check (as directed)	
Date of last check	Next check due
Outcome	
Managers signature to acknowledge screening information completed:	**Date**

INNOVATION AGENCY
Academic Health Science Network for the North West Coast

Anticipatory Care Calendar TM

3. Anticipatory Care Calendar



Name: Month:

Pain

Date		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Severe Pain	AM																															
	PM																															
	N																															
Severe Chest Pain	AM																															
	PM																															
	N																															
Moderate/ Severe	AM																															
	PM																															
	N																															
Moderate	AM																															
	PM																															
	N																															
Mild	AM																															
	PM																															
	N																															
No Pain	AM																															
	PM																															
	N																															

Behaviour

Date		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Self harm/risky behaviour	AM																															
	PM																															
	N																															
More withdrawn than normal	AM																															
	PM																															
	N																															
More aggressive or angry	AM																															
	PM																															
	N																															
Other significant behaviour/ anxious	AM																															
	PM																															
	N																															
Normal behaviour	AM																															
	PM																															
	N																															

Anticipatory Care Calendar TM

3. Anticipatory Care Calendar

Name: Month:

Bowels																														
Date		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Blood/ Mucous	AM																															
	PM																															
	N																															
Diarrhoea	AM																															
	PM																															
	N																															
Loose	AM																															
	PM																															
	N																															
Hard/Soft	AM																															
	PM																															
	N																															
Constipation	AM																															
	PM																															
	N																															
No Bowel Movement	AM																															
	PM																															
	N																															
Normal	AM																															
	PM																															
	N																															
Self Caring/ Unobserved	AM																															
	PM																															
	N																															

Anticipatory Care Calendar TM

3. Anticipatory Care Calendar

Name: Month:

Sleeping

Date		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Drowsy & Unable to wake	AM																															
	PM																															
	N																															
Unusually tired	AM																															
	PM																															
Normal naps throughout the day	AM																															
	PM																															
Frequent waking disturbed sleep	N																															
Normal sleep (Night Staff)	N																															

Urine

Date		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Not passing Urine	AM																															
	PM																															
	N																															
Blood in Urine	AM																															
	PM																															
	N																															
Urgency	AM																															
	PM																															
	N																															
Frequency/ Incontinence	AM																															
	PM																															
	N																															
Normal	AM																															
	PM																															
	N																															
Self Caring/ Unobserved	AM																															
	PM																															
	N																															

Anticipatory Care Calendar TM

3. Anticipatory Care Calendar

Name: Month:

Seizures																														
Date		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Seizure activity requiring emergency/ hospital assistance	AM																															
	PM																															
	N																															
Change to normal seizure activity	AM																															
	PM																															
	N																															
Normal seizure activity	AM																															
	PM																															
	N																															
No seizure activity	AM																															
	PM																															
	N																															

Mobility/Falls																														
Date		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Refusal or unable to mobilise	AM																															
	PM																															
	N																															
Changes in mobility	AM																															
	PM																															
	N																															
Reoccurring falls	AM																															
	PM																															
	N																															
Falls	AM																															
	PM																															
	N																															
Normal activity	AM																															
	PM																															

Anticipatory Care Calendar TM

3. Anticipatory Care Calendar

Name: Month:

Eating & Drinking																															
Date		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Persistent/ frequent vomiting	AM																															
	PM																															
	N																															
Vomiting	AM																															
	PM																															
	N																															
Less interested in food than normal	AM																															
	PM																															
	N																															
More thirsty than normal	AM																															
	PM																															
	N																															
Less interested in drinking than normal	AM																															
	PM																															
	N																															
Normal eating & drinking	AM																															
	PM																															
	N																															

Anticipatory Care Calendar TM

3. Anticipatory Care Calendar

Name: Month:

Health Observations																															
Date		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Lumps in the testicles	AM																															
	PM																															
	N																															
Breast abnormalities	AM																															
	PM																															
	N																															
Abnormal periods/Vaginal discharge	AM																															
	PM																															
	N																															
Changes to genitals/private parts	AM																															
	PM																															
	N																															
Mouth/Teeth problems	AM																															
	PM																															
	N																															
Seeing/Hearing Problems	AM																															
	PM																															
	N																															
Normal observations																																
Weight	Current Month:																Last Month:															

Anticipatory Care Calendar TM

3. Anticipatory Care Calendar

Name: Month:

Other symptoms																														
Date		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Photophobia	AM																															
	PM																															
	N																															
Fast or irregular breathing more than 1 every 2 seconds	AM																															
	PM																															
	N																															
Non blanching rash or mottled skin	AM																															
	PM																															
	N																															
Blue lips	AM																															
	PM																															
	N																															
Responds only to voice, shaking or unresponsive	AM																															
	PM																															
	N																															
Fast or irregular breathing	AM																															
	PM																															
	N																															
Fast heart beat/ palpitations	AM																															
	PM																															
	N																															
Fever/Sweating with shaking high temperature	AM																															
	PM																															
	N																															
New confusion or difficult to wake up	AM																															
	PM																															
	N																															
Episodes of coughing	AM																															
	PM																															
	N																															

Anticipatory Care Calendar TM

3. Anticipatory Care Calendar

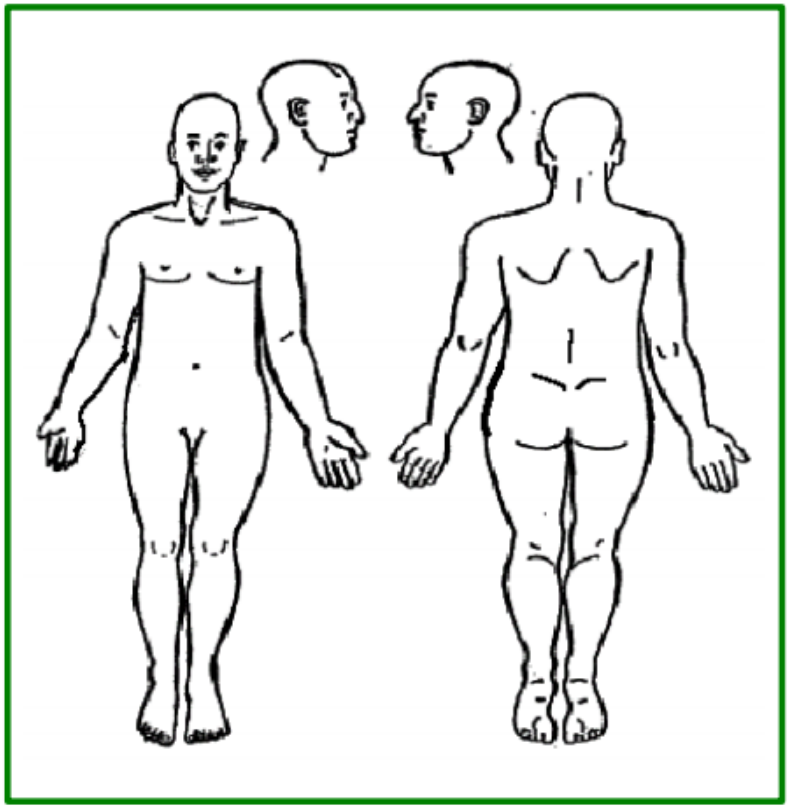
Name: Month:

Problems swallowing (dysphagia)																														
Date		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Recurrent chest infections	AM																															
	PM																															
	N																															
Unexplained weight loss/ Underweight	AM																															
	PM																															
	N																															
Coughing/ choking when eating/drinking	AM																															
	PM																															
	N																															
Reluctance to eat or drink	AM																															
	PM																															
	N																															
Normal swallowing	AM																															
	PM																															
	N																															

3. Anticipatory Care Calendar

Month/Year																														
Significant changes to the skin																														
Date		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31

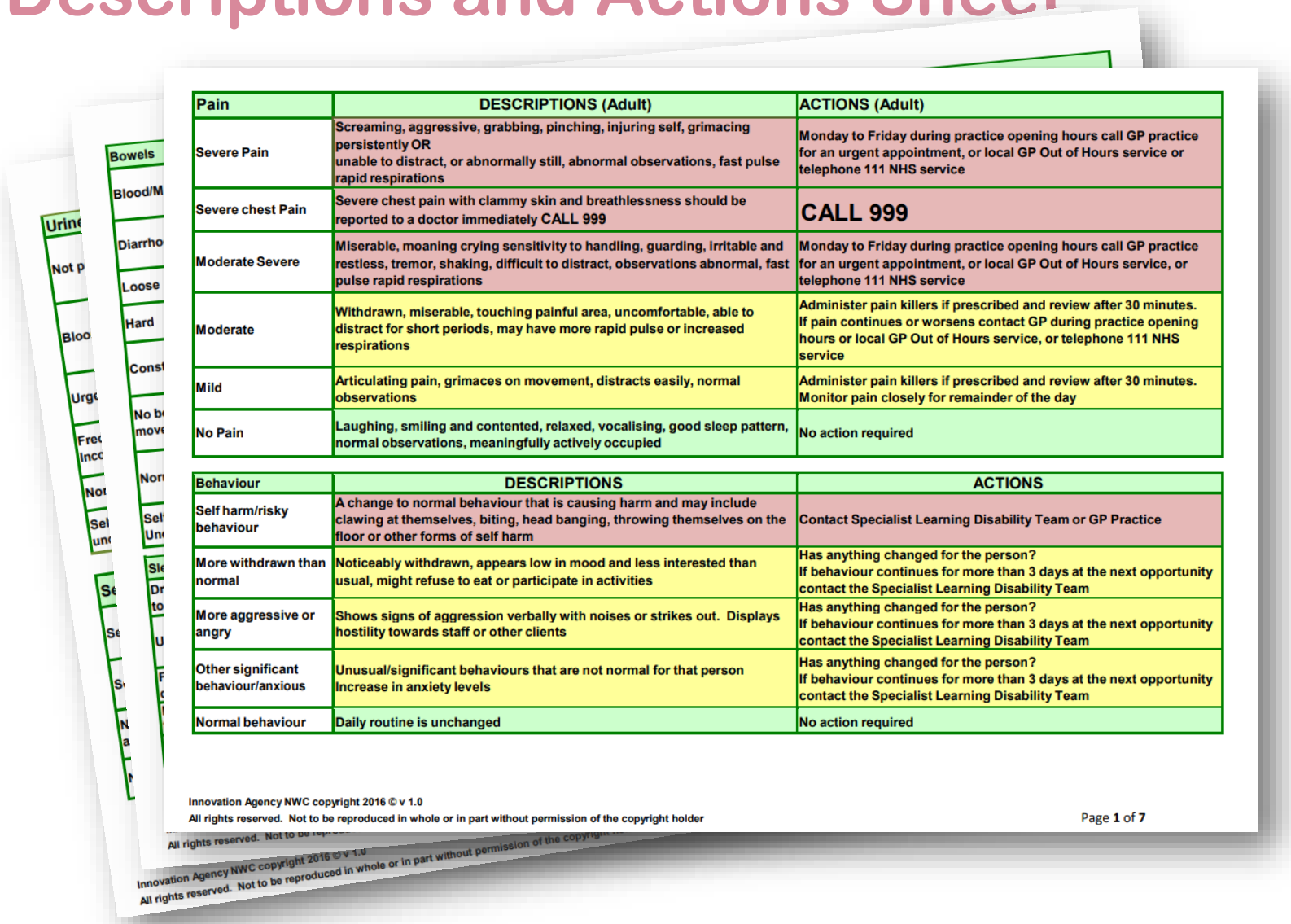
Please indicate any significant changes to the skin i.e. alterations to any mole size or shape which also may bleed, sore areas caused by friction or pressure, new rashes without explanation and any lumps occurring on the body or any unusual swelling or bruising
Circle the date to identify and clearly give description in the box provided



Location of pain or symptom	Description of pain or symptom
A	
B	
C	
D	
E	

Anticipatory Care Calendar TM

4. Descriptions and Actions Sheet



Pain	DESCRIPTIONS (Adult)	ACTIONS (Adult)
Severe Pain	Screaming, aggressive, grabbing, pinching, injuring self, grimacing persistently OR unable to distract, or abnormally still, abnormal observations, fast pulse rapid respirations	Monday to Friday during practice opening hours call GP practice for an urgent appointment, or local GP Out of Hours service or telephone 111 NHS service
Severe chest Pain	Severe chest pain with clammy skin and breathlessness should be reported to a doctor immediately CALL 999	CALL 999
Moderate Severe	Miserable, moaning crying sensitivity to handling, guarding, irritable and restless, tremor, shaking, difficult to distract, observations abnormal, fast pulse rapid respirations	Monday to Friday during practice opening hours call GP practice for an urgent appointment, or local GP Out of Hours service, or telephone 111 NHS service
Moderate	Withdrawn, miserable, touching painful area, uncomfortable, able to distract for short periods, may have more rapid pulse or increased respirations	Administer pain killers if prescribed and review after 30 minutes. If pain continues or worsens contact GP during practice opening hours or local GP Out of Hours service, or telephone 111 NHS service
Mild	Articulating pain, grimaces on movement, distracts easily, normal observations	Administer pain killers if prescribed and review after 30 minutes. Monitor pain closely for remainder of the day
No Pain	Laughing, smiling and contented, relaxed, vocalising, good sleep pattern, normal observations, meaningfully actively occupied	No action required

Behaviour	DESCRIPTIONS	ACTIONS
Self harm/risky behaviour	A change to normal behaviour that is causing harm and may include clawing at themselves, biting, head banging, throwing themselves on the floor or other forms of self harm	Contact Specialist Learning Disability Team or GP Practice
More withdrawn than normal	Noticeably withdrawn, appears low in mood and less interested than usual, might refuse to eat or participate in activities	Has anything changed for the person? If behaviour continues for more than 3 days at the next opportunity contact the Specialist Learning Disability Team
More aggressive or angry	Shows signs of aggression verbally with noises or strikes out. Displays hostility towards staff or other clients	Has anything changed for the person? If behaviour continues for more than 3 days at the next opportunity contact the Specialist Learning Disability Team
Other significant behaviour/anxious	Unusual/significant behaviours that are not normal for that person Increase in anxiety levels	Has anything changed for the person? If behaviour continues for more than 3 days at the next opportunity contact the Specialist Learning Disability Team
Normal behaviour	Daily routine is unchanged	No action required

Anticipatory Care Calendar TM

4. Descriptions and Actions Sheet

Pain	DESCRIPTIONS (Adult)	ACTIONS (Adult)
Severe Pain	Screaming, aggressive, grabbing, pinching, injuring self, grimacing persistently OR unable to distract, or abnormally still, abnormal observations, fast pulse rapid respirations	Monday to Friday during practice opening hours call GP practice for an urgent appointment, or local GP Out of Hours service or telephone 111 NHS service
Severe chest Pain	Severe chest pain with clammy skin and breathlessness should be reported to a doctor immediately CALL 999	**CALL 999**
Moderate Severe	Miserable, moaning crying sensitivity to handling, guarding, irritable and restless, tremor, shaking, difficult to distract, observations abnormal, fast pulse rapid respirations	Monday to Friday during practice opening hours call GP practice for an urgent appointment, or local GP Out of Hours service, or telephone 111 NHS service
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Behaviour	DESCRIPTIONS	ACTIONS
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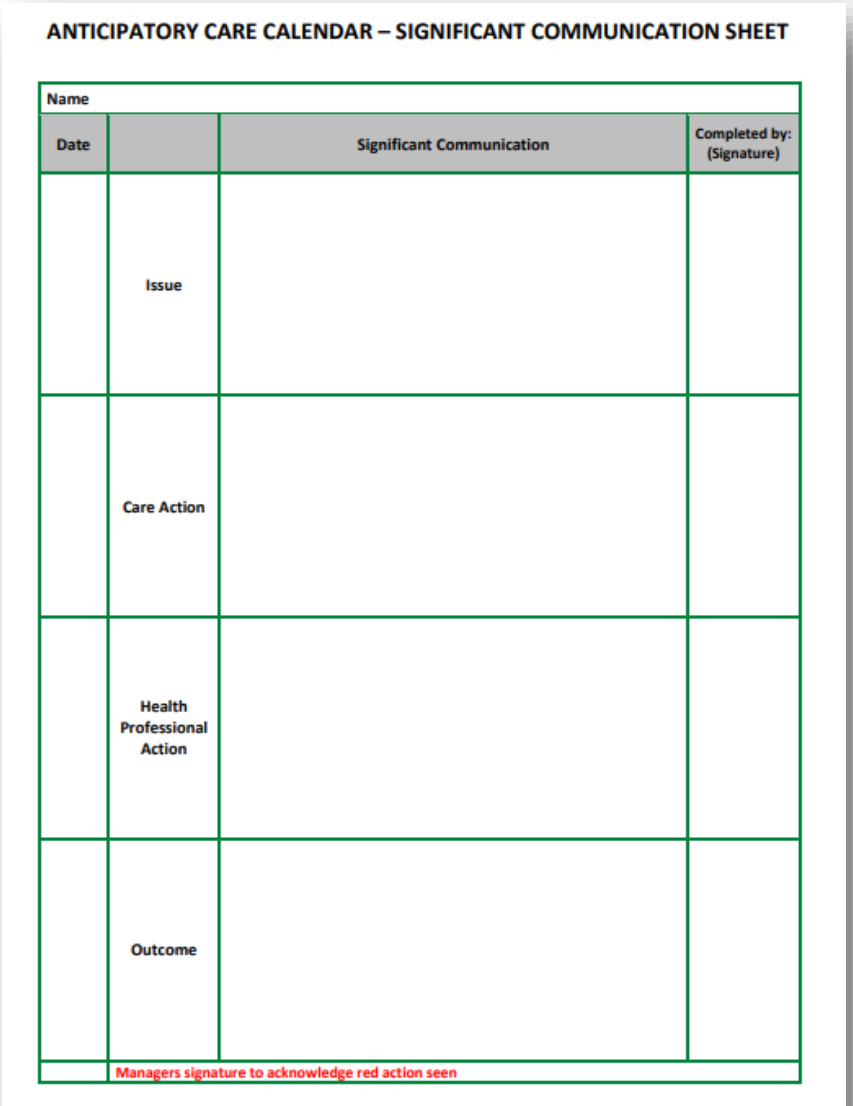
Other significant behaviour/anxious	Unusual/significant behaviours that are not normal for that person Increase in anxiety levels	Has anything changed for the person? If behaviour continues for more than 3 days at the next opportunity contact the Specialist Learning Disability Team
Normal behaviour	Daily routine is unchanged	No action required

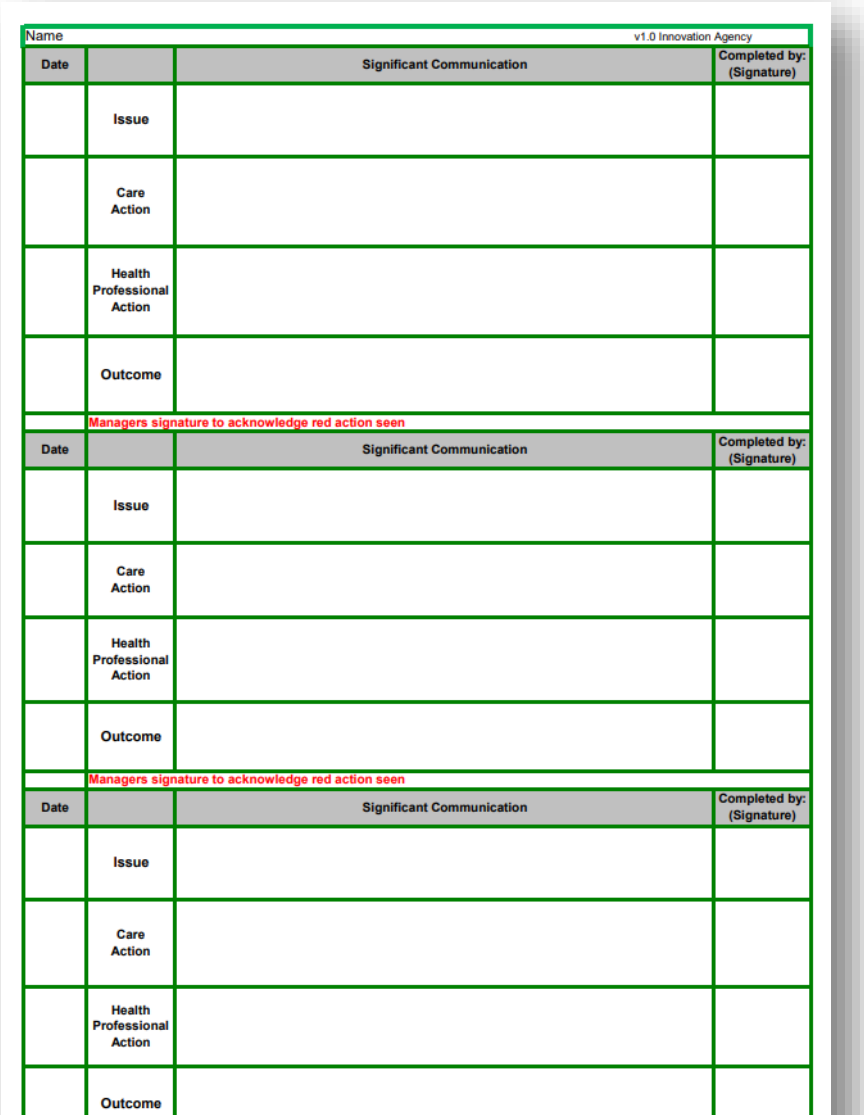
Anticipatory Care Calendar TM

5. Significant Communication Sheet



ANTICIPATORY CARE CALENDAR – SIGNIFICANT COMMUNICATION SHEET

Name			
Date		**Significant Communication**	**Completed by: (Signature)**
	Issue		
	Care Action		
	Health Professional Action		
	Outcome		
	Managers signature to acknowledge red action seen		



Name v1.0 Innovation Agency

Date		**Significant Communication**	**Completed by: (Signature)**
	Issue		
	Care Action		
	Health Professional Action		
	Outcome		
	Managers signature to acknowledge red action seen		
Date		**Significant Communication**	**Completed by: (Signature)**
	Issue		
	Care Action		
	Health Professional Action		
	Outcome		
	Managers signature to acknowledge red action seen		
Date		**Significant Communication**	**Completed by: (Signature)**
	Issue		
	Care Action		
	Health Professional Action		
	Outcome		

Who Else Can Help?

General Practitioner (GP)

Dietician

Physiotherapist

Speech and Language Therapist (SALT)

Occupational Therapy

Network of Care

Nurse

Respiratory Consultant

LeDeR Recommendations

LeDeR's Recommendations specific to pneumonia that were made by reviewers included:

→ Improving the training of families, paid Support Staff and professionals about risk factors for aspiration pneumonia and how to alleviate these

→ The need for a national clinical care pathway for people with learning disabilities who have been identified as having a problem with swallowing

→ Attention to postural support, particularly when feeding a person in bed or if they are at risk of vomiting

→ A review of the effects of antipsychotic medications on people who are prone to chest infections or at risk of aspiration pneumonia

→ The importance of people receiving the pneumococcal vaccine and the annual influenza vaccine

→ The provision of good oral hygiene and dental care

Any other Business

Any Questions ?

Additional Resources

PMLD link Health Matters (page 23): http://www.pmldlink.org.uk/wp-content/uploads/2017/01/PMLD-Link-Issue-85.pdf

LeDeR Report *https://www.england.nhs.uk/publication/leder-action-from-learning/*
Anticipatory Care Calendar *https://www.innovationagencynwc.nhs.uk/our-work/health-and-social-care/patient-safety/acc*
Guidelines for identification and management of swallowing difficulties in adults with learning disabilities www.guidelines.co.uk/wpg/dysphagia-with-learning-disability
Pamis leaflet on respiratory health for people with learning disabilities pamis.org.uk/cms/files/leaflets/respiratory_leaflet.pdf
Glover, G., & Ayub, M. (2010). How people with learning disabilities die. Durham: Improving Health & Lives: Learning Disabilities Observatory. www.improvinghealthandlives.org.uk/uploads/doc/vid_9033_IHAL2010-06%20Mortality.pdf
Guideline for the identification and management of swallowing difficulties in adults with learning disability Working Party—Wright, Beavon, Branford, Griffith, Harding, Howseman, Rasmussen, Sandhu, Shmueli, Smith & Whit: www.guidelines.co.uk/wpg/dysphagia-with-learning-disability
Flu plan 2014/15
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/500928/FluPlan2014_accessiblesu perseded.pdf

Any other Business

Thank You!

MacIntyre

Providing support...your way

NHS

Guy's and St Thomas'

NHS Foundation Trust

Sarah Ormston – Health, Dementia and Wellbeing Manager - MacIntyre

David Standley - Clinical Specialist Physiotherapist- Guy's and St Thomas' NHS Foundation Trust

Radhika Lingham - Highly Specialist Speech and Language Therapist - Guy's and St Thomas' NHS Foundation Trust

E: health.team@macintyrecharity.org

www.macintyrecharity.org