

# Sepsis amongst People with Learning Disabilities

Anne Hunt RGN BSc (Hons) Nursing Science, MSc  
Health Sciences

@huntanne @SepsisSrLister anne.hunt1 @nhs.net



# Sepsis

- What is Sepsis?
- Sepsis morbidity and mortality in people with learning disabilities
- Prevention strategies
- Spotting early signs of deterioration that may herald sepsis
- Potentially reversible signs - and how to reverse them
- When to seek medical attention
- Useful information to convey to hospital staff & questions to ask

## What is Sepsis?

- Sepsis is a life threatening condition where the body over reacts to an infection & injures its own tissues and organs
- Sepsis can lead to shock, multiple organ failure and death especially if not recognized early and treated promptly.
- Caught early, the outlook is good for the vast majority of patients.
- **It is crucial that escalation to doctors is not delayed**

# Sepsis

## UK Sepsis Trust, 2018

- 260,000 cases sepsis / year in the UK
- At least 52,000 deaths/ year attributed to sepsis in the UK
  - Likely nearer 80,000
  - Suspicion of Sepsis <https://www.sos-insights.co.uk/>
- 75% of infections leading to sepsis originate in the community
  - About 1/3 of deaths could be prevented with quicker treatment

To be amongst the best...

# Sepsis amongst People with Learning Disabilities: LEDER 2018

- Sepsis identified as primary cause of 11% of deaths
- Half of the top 8 causes of death fit the SoS criteria
  - 54% of deaths from SoS
  - Potentially many more people with learning disabilities dying of Sepsis

**Table 3.5: Most common conditions identified as causes of death anywhere on Part 1 of MCCD**

Most frequent causes of death	No.	%
Pneumonia – unspecified	140	24
Aspiration pneumonia	96	17
Sepsis	66	11
Dementia	34	6
Epilepsy	28	5
Down syndrome	25	4
Cardiac arrest	24	4
Respiratory infection	22	4
Total (where cause of death is reported at notification)	576	n/a

# Sepsis amongst People with Learning Disabilities

- USA study (Ailey et al, 2014) found Sepsis was the third most common reason for Adults with Intellectual Disability to be admitted to hospital (5.4% of admissions)
  - 8.3% of admissions were for Respiratory, kidney or urine infections (=>13.7%)
  - Apply Suspicion of Sepsis criteria: probably the leading cause for admission
- Hosking et al (2017) found people with Intellectual Disability were five times more likely to be admitted to hospital with a respiratory or urine infection than someone the same age & sex, without Intellectual Disability

# Sepsis amongst People with Learning Disabilities

- Morbidity as well as Mortality
- Around 40% of survivors suffer from Post Sepsis Syndrome
  - Physical
  - Cognitive
  - Psychological
- Do we investigate whether People with Learning Disabilities are suffering with Post Sepsis Syndrome?

# Recovery from Sepsis

- Can take weeks, months, occasionally years
- Physical
  - Fatigue and/or trouble sleeping; difficulty concentrating
  - Hair loss, brittle nails; itchy & dry skin
  - New allergies or food intolerances
  - Joint pains, headaches, migraine
  - Recurrent infections
- Psychological
  - Flashbacks, PTSD



# How do we Prevent Sepsis?

- Prevent Infection
  - Hand Hygiene
  - Vaccinations
  - Sensible Infection prevention precautions in communal living
  - Extra care with invasive lines (PEG, Urinary catheter) *Keep it clean!*

## How do you spot deterioration?

- Early signs are ‘soft’ signs – slight changes from normal
  - Reduced mobility
  - Reduced functional ability
  - Inattentive, Muddled, ‘Not herself’
  - Change in appetite or thirst
  - Change in sleep pattern
  - Diarrhoea, Vomiting
  - Flu like symptoms
  - Pain behaviour

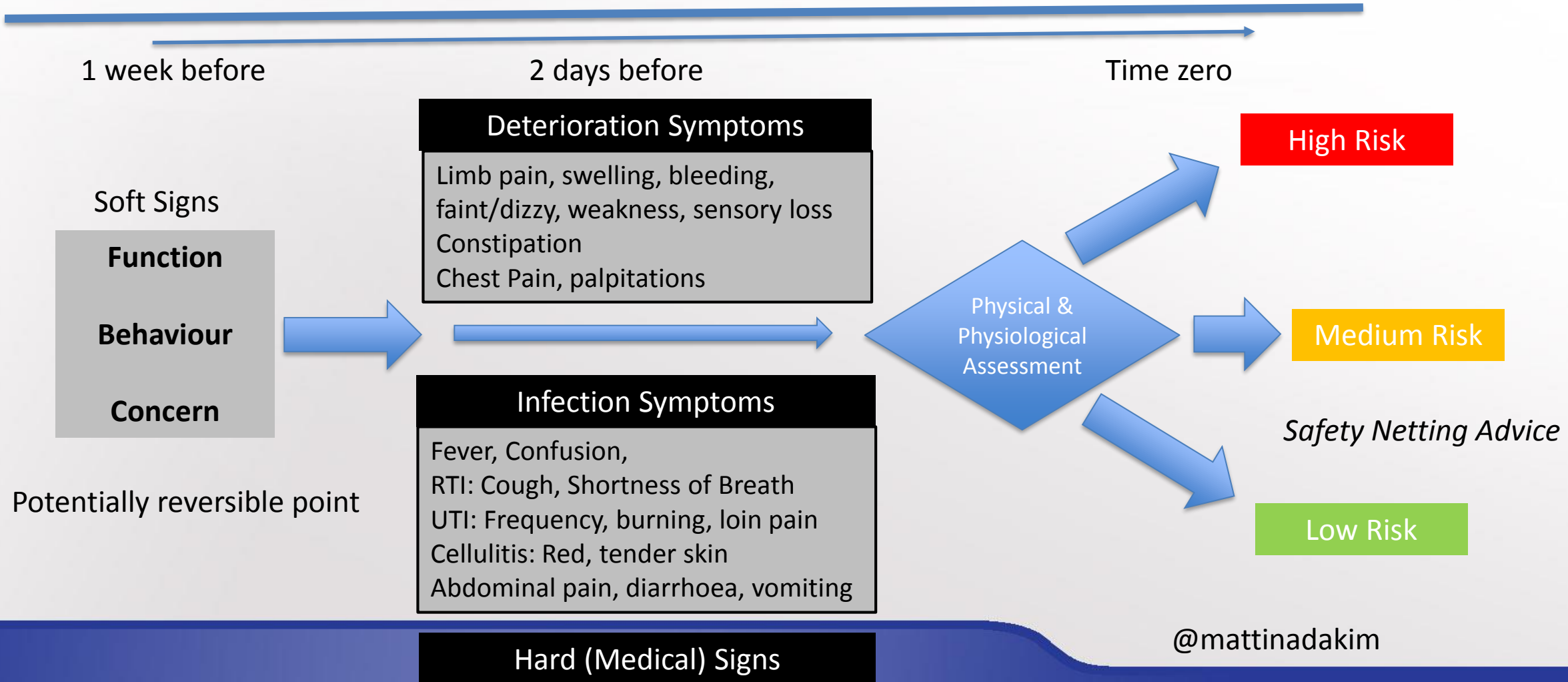
You need to know what is normal to spot deterioration

## Early deterioration: What you can do...

- Consider changes significant, note them down
- Keep warm & hydrated
- Watch for fever, chills and pain
- Watch for reduction in urine output
- Watch for changes to skin colour & rashes
- Watch for fast breathing

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# Timeline of Actionable Acute Deterioration Dr Matt Inada-Kim (2018)



# Infection Symptoms

- Fever
- Confusion
- Chest Infection: Cough, Shortness of Breath, Chest Pain
- Urine Infection: Going frequently, burning, loin pain
- Skin Infection: Red, tender skin, Pus
- Abdominal pain, constipation, diarrhoea, vomiting

## Early identification and treatment of infections

- GP review at earliest opportunity (within 24 hours)
  - Some practices have fast track system
  - Insist on specific safety net instructions for what 'worse' looks like & what to do next
- If recurrent infections
  - Consider the 'early warning' signs in the preceding days
  - Ask your GP about a rescue prescription
    - Insist on clear criteria for starting treatment

## What does 'worse' look like?

- Fast breathing – more than 25 breaths a minute
- Mottled skin, blue around lip or finger tips
- Passing very little urine – less often, small amounts
- Drowsy, inattentive or more confused

# Complications

- Malabsorption of critical medicines
  - Epilepsy
  - Risk of seizures
  - Know your rescue plan & ensure responsible others know it too
- Aspiration
  - Positioning
  - Weak swallow
  - Drainage (PEG)



## Danger Signs: Immediate assessment by Doctor

- S Slurred speech or confusion
- E Extreme shivering or muscle pain
- P Passing no urine (in a day)
- S Severe breathlessness
- I It feels like I am going to die
- S Skin mottled or discoloured



## In Hospital

- Teamwork – if you know the person best, stay with them, assist with examination & tests if poss – you have the trust
  - If you can't stay, handover as much information as possible
  - Keep hospital passports up to date – allergies, pain behaviour
- Don't assume Health Professionals will be looking for Sepsis
  - Tell them what you have noticed
  - Listen to their observations & challenge them if necessary if making assumptions
  - Ask questions:
    - *Could this be Sepsis?*
    - Can you explain how you have ruled sepsis out?
    - Do you know the source of the infection?

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## Hospital Passports: keep up to date & include...

Hunt & Marsden (2018) <http://www.wecomunities.org/tweet-chats/chat-details/4167>

- Drug History, Vaccination record
- Allergies
  - Including nature/severity eg Penicillin – rash? Anaphylaxis?
- Recent infections and treatment
  - Previous history of severe infection, pneumonia or aspiration
  - Any previous antimicrobial resistance
- Baseline observations
  - Could be from previous admission or annual health check
- Baseline function & Medical history
  - outline of the implications of any rare conditions

## What Reasonable Adjustments should you expect in hospital?

- Access to Senior Clinicians
- Increased vigilance and monitoring
- Proactive investigation
- Access to LD Liaison Nurse
  - ENH Care Alerts: Sepsis Nurse, Matrons & Adult safeguarding team
  - Surveillance via eObs
- Use of adjuncts to achieve IV access and blood tests
- *Extra Time*

## Useful links and Information

- <https://sepsistrust.org/>
- <https://www.nhs.uk/conditions/sepsis/>
- Spotting Sepsis in Children
- <https://www.nhs.uk/Video/Pages/spotting-sepsis-in-under-5s.aspx>
- **Warning: video describes the heart breaking death of a 3 year old girl**  
<https://www.youtube.com/watch?v=vxmUVCu6CDI>