North East and Cumbria

Making LeDeR real

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Learning from reviews

Thematic analysis & learning shared at every Steering Group

What reviews have found out about people's lives

- Communication, attitudes and getting good care no matter who treats you

- Using Mental Capacity Act properly and getting consent

What reviews have found about people's lives

- End of life care
- Being able to access services and making reasonable adjustments
- Training

Reducing Premature Mortality in People with a Learning Disability Cumbria North East Steering Group
Work Plan on a Page
(LeDeR)

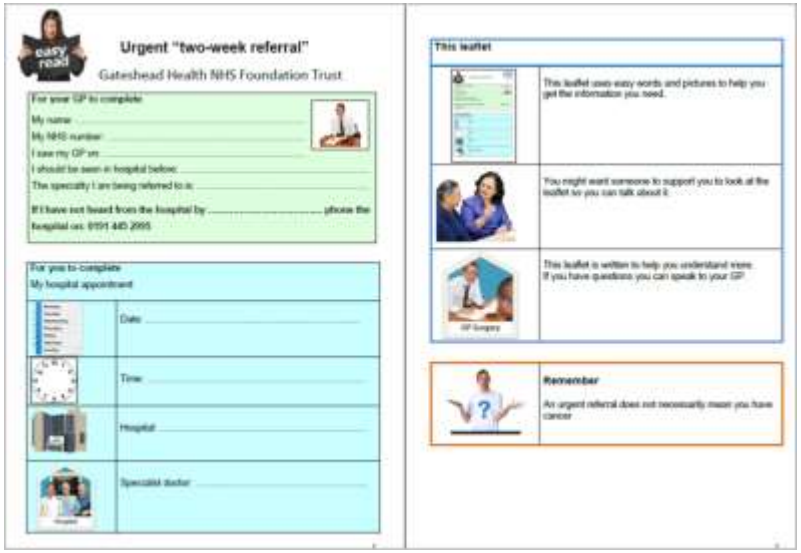
Role	How	Outcome / Impact	Gaps	Risks
Work in partnership with the regional LeDeR co-ordinator	• Membership on steering groups • Regular catch ups with chair and programme manager	• National and North Region updates • Link to national, regional and other sub regions		• Clinical Champion for the LeDeR programme is based out of area and is contracted to small amount of time making engagement difficult
To work in partnership with stakeholders to ensure a Local Area Contact is appointed in each locality who will have oversight of the programme	• Every CCG Director of Nursing is appointed as the local area contact • All local area contacts have appointed a deputy where appropriate • Steering group is established with all members (and other stakeholders) for regional oversight of the programme and local arrangements are in place	• Senior responsibility and ownership • Ability to align the programme in to established systems I,e. safeguarding, STEIS	• Good representation at regional level of the different stakeholders. Locally work is ongoing to ensure the system is joined up	• Capacity to engage other senior stakeholders of the system
Guide the implementation of the programme of local death reviews of people with a learning disability	• Local LeDeR steering groups established to support local delivery • Local groups feed in to regional strategic group • Aligned with Learning from deaths and CQC	• LeDeR progamme is being implemented across CNE • Deaths of people with a learning disability are being reviewed	• More reviewers needed in some areas (in particular social care)	• Capacity to train reviewers train the trainer programme?
Support the proportionate review of all deaths of people with a learning disability and those who require a more detailed review	•		• Comms needed in some areas low number of deaths being notified	
Receive regular updates about the progress and findings of reviews	• Regional template is being developed by NHS England CNE Nursing & Quality Team to capture themes • Anonymised case studies are presented at every steering group meeting • Annual learning and sharing event • Once regional template is developed active role of it's use will form part of the steering group	• Service improvement • Sharing best practice • Developing local and regional work to improve the care and life expectancy of people with learning disabilities	• Local area contacts submit reviews with learning & best practice examples. NHSE CNE nursing team need access to LeDeR system to access reviews and pull out themed learning. It is also aligned with LFD • LeDeR quarterly analysis reports provide identifiable information with information copied and pasted from submitted reviews and don't provide any themes from deaths that we develop a strategic regional work plan for. Given	• Local area contacts and reviewers duplicating work if NHSE access not granted loss of engagement and motivation. Local system established •

What we're doing

- Refreshing acute hospital care pathways across CNE
- Major campaign for increasing flu immunisation
- Increasing uptake & quality of annual health checks

What we're doing - cancer

MACMILLAN CANCER SUPPORT



- Bowel cancer screening flagging
- Holistic needs assessment
- Cancer screening for people who are in-patients
- Safety netting tool

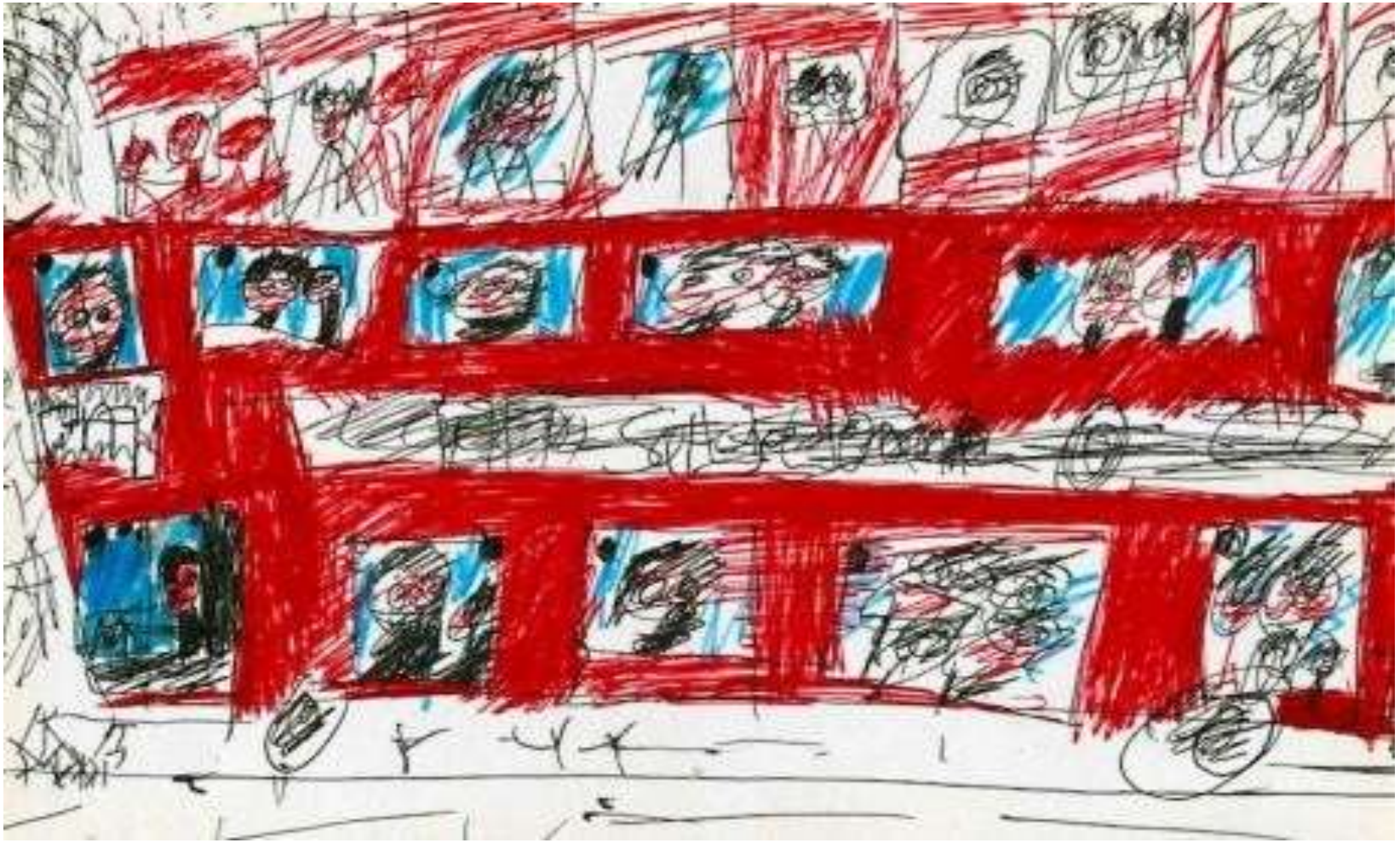
How will we keep going?

- Already doing our own analysis – being held to account
- Priorities;
- Constipation
- Recognising people deteriorating
- Aspiration pneumonia
- Health promotion

How will we keep going?

- Local Quality Assurance processes
- Strong LeDeR Steering Groups – North East & Cumbria
- Strong Confirm & Challenge Group
- Skilled reviewers
- Peer support for reviewers

How inclusive is inclusion?



Stop People Dying Too Young Confirm & Challenge Group

The Stop People with a Learning Disability Dying Too Young group is a committed team of people with a learning disability, family carers and people who work with us.

We use our own experiences to look closely at the Learning Disability Mortality Review Programme.

Cumbria North East LeDeR Steering Group

- We are involved in looking at reviews of people with a learning disability who have died.
- We meet monthly to look at what needs to change.
- We need to stop people with a learning disability dying too young.
- Men can die 23 years younger and women can die 29 years younger than people who do not have a learning disability.

Statement

In May this year, the Government published its annual report into the deaths of people with a learning disability.

Our team had a lot of discussion and wrote a statement in response.

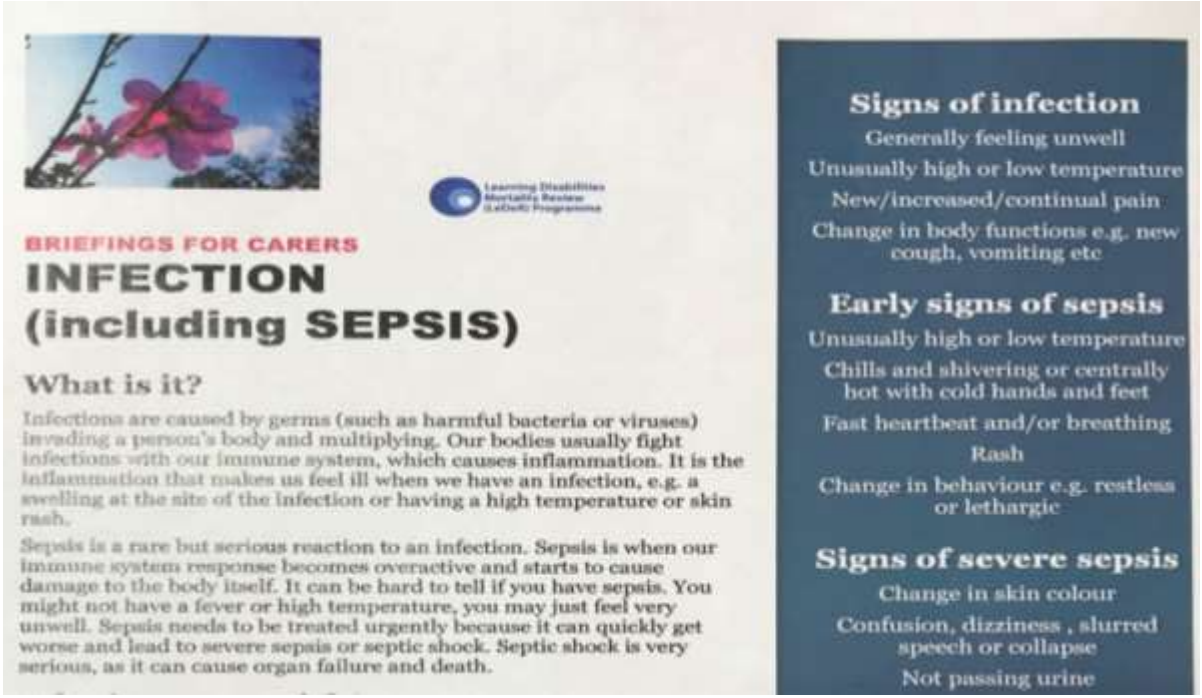
We have copies which we will leave today.

Some things we think need to be done are…

Support and training for people with a learning disability to be part of the reviews

Raise awareness of what we mean by Do Not Attempt Resuscitation and make sure people know how to use it properly to protect people's rights.

Provide and share easy read information about the main causes of early death of people with a learning disability



BRIEFINGS FOR CARERS

INFECTION (including SEPSIS)

What is it?

Infections are caused by germs (such as harmful bacteria or viruses) invading a person's body and multiplying. Our bodies usually fight infections with our immune system, which causes inflammation. It is the inflammation that makes us feel ill when we have an infection, e.g. a swelling at the site of the infection or having a high temperature or skin rash.

Sepsis is a rare but serious reaction to an infection. Sepsis is when our immune system response becomes overactive and starts to cause damage to the body itself. It can be hard to tell if you have sepsis. You might not have a fever or high temperature, you may just feel very unwell. Sepsis needs to be treated urgently because it can quickly get worse and lead to severe sepsis or septic shock. Septic shock is very serious, as it can cause organ failure and death.

Signs of infection

Generally feeling unwell

Unusually high or low temperature

New/increased/continual pain

Change in body functions e.g. new cough, vomiting etc

Early signs of sepsis

Unusually high or low temperature

Chills and shivering or centrally hot with cold hands and feet

Fast heartbeat and/or breathing

Rash

Change in behaviour e.g. restless or lethargic

Signs of severe sepsis

Change in skin colour

Confusion, dizziness , slurred speech or collapse

Not passing urine

The national team have produced information for carers around the common causes of early death.

There are now posters about things like pneumonia and sepsis.

We have contacted the Bristol team and asked that accessible information be provided for people with a learning disability.

They are parents and carers of people with a learning disability too. They need the information as well.

We believe that people with a learning disability should be directly involved in reviewing the deaths of people with a learning disability.

We bring a lot of experience and should be supported and trained to be part of the reviews.

By listening to the cases of people with a learning disability who have died too young, it is not always clear why a Do Not Attempt Resuscitation order has been used.

We know that it is a right for the person, their family and carers to be involved and informed about this decision.

We have asked how much value is placed on our lives

How are we learning the lessons from reviews?

As a team we would like to know how organisations and health services are learning from the lessons of the reviews.

We know that there are some key themes but it isn't clear how we put things in place to stop the same things happening.

Do you have any questions?

Keep in touch

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