

Presentation about LeDeR Programme in Gloucestershire

An Easy Read Summary

How the programme works.

LeDeR Learning Themes and Action from Learning

What is LeDeR?

LeDeR is learning about peoples lives and deaths so that we can make healthcare better.



What is LeDeR?



We talk about people with a Learning Disability from aged 4 and autistic people over 18.



What does LeDeR tell us?



LeDeR tells us the main reasons why people die too soon.



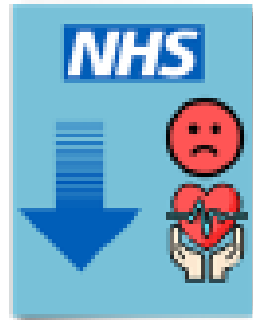
LeDeR tells us how to make things better.

LeDeR Programme Aims



1

Improve health and social care for people with a learning disability and autistic people.



2

Reduce health inequalities for people with a learning disability and autistic people.

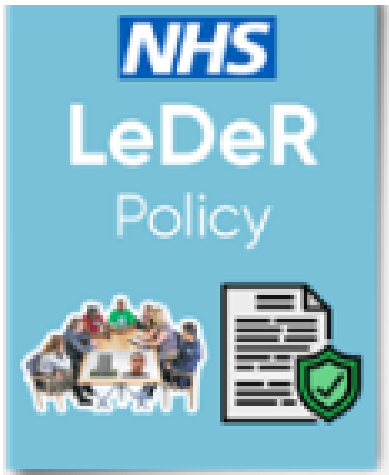
Health inequalities are unfair and preventable differences in health.



3

Stop more people from dying too soon by making care better.

LeDeR in Gloucestershire



1. A reviewer works to find out what happened during someone's life and death.
2. They will talk to someone who knows the person well, including family, carers and the doctor.
3. The review gets checked by the Quality Assurance panel, which includes: doctors, pharmacists, nurses and experts by experience. If needed, the case will have a focused review.
4. We learn from each review and share the learning



Importance of Experts by experience in LeDeR



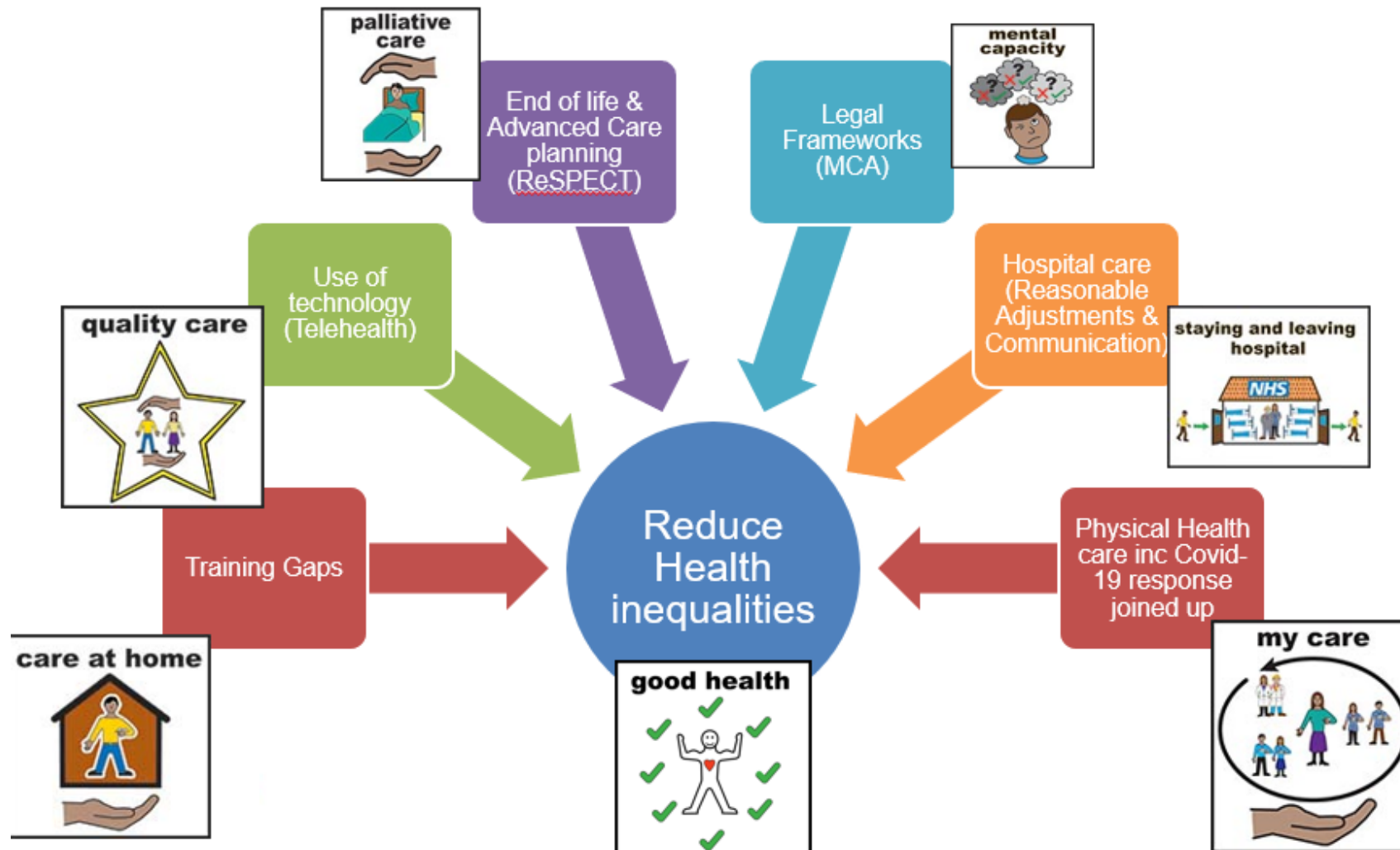
In Gloucestershire Sammy and Paul are part of the *Quality Checking Panel* to make sure that the voices of people with Learning Disabilities and Autism are heard.

Reporting a Death

Anyone can report a death to LeDeR through this website:

<https://leder.nhs.uk/>

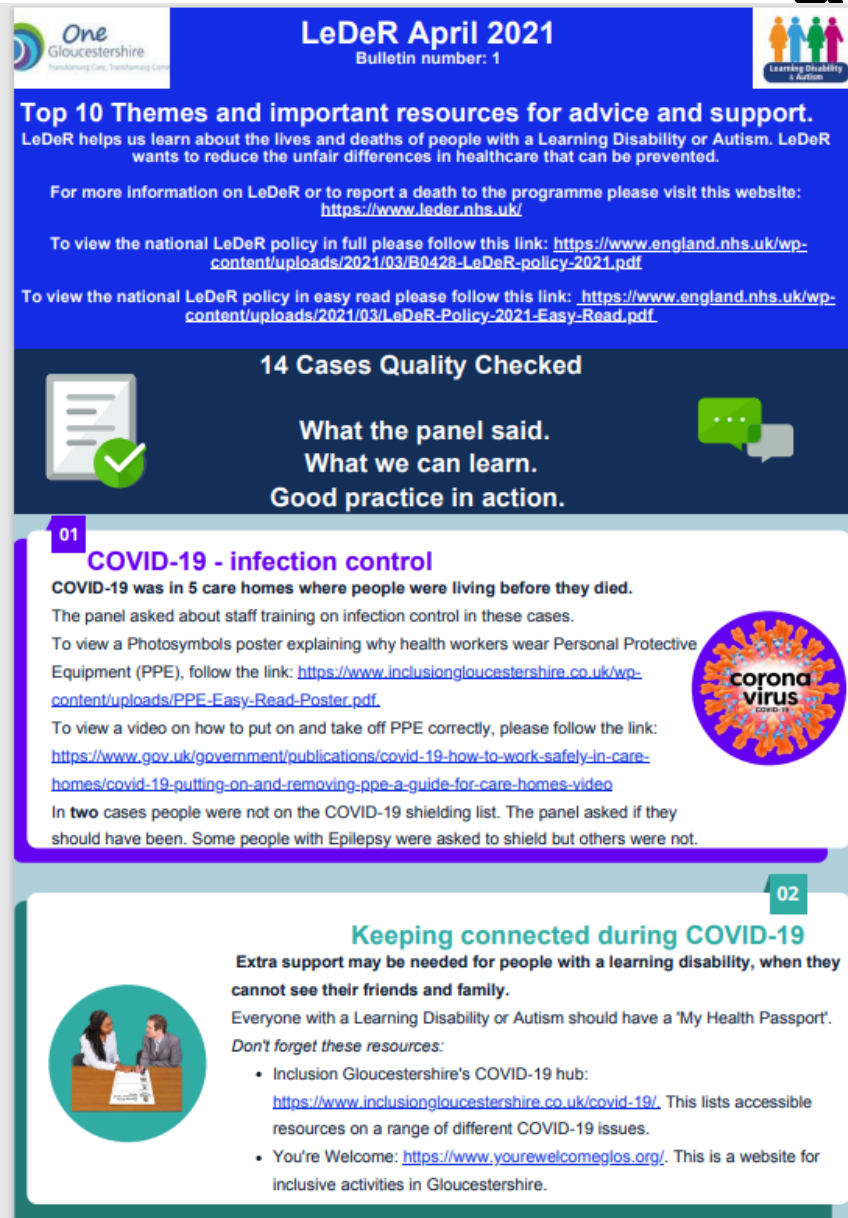
Action from Learning – Gloucestershire Themes we are working on over the next year



How we share what we are doing and learning from reviews?

- Annual reports
- Gloucestershire LeDeR Newsletter
- Easy read resources
- Access information on Gloucestershire LeDeR Webpage:

<https://www.inclusiongloucestershire.co.uk/engagement/leder/>



One Gloucestershire
Transforming Care, Transforming Communities

LeDeR April 2021
Bulletin number: 1

Top 10 Themes and important resources for advice and support.
LeDeR helps us learn about the lives and deaths of people with a Learning Disability or Autism. LeDeR wants to reduce the unfair differences in healthcare that can be prevented.

For more information on LeDeR or to report a death to the programme please visit this website: <https://www.leder.nhs.uk/>

To view the national LeDeR policy in full please follow this link: <https://www.england.nhs.uk/wp-content/uploads/2021/03/R0428-LeDeR-policy-2021.pdf>

To view the national LeDeR policy in easy read please follow this link: <https://www.england.nhs.uk/wp-content/uploads/2021/03/LeDeR-Policy-2021-Easy-Read.pdf>

14 Cases Quality Checked

What the panel said.
What we can learn.
Good practice in action.

01 COVID-19 - infection control
COVID-19 was in 5 care homes where people were living before they died.
The panel asked about staff training on infection control in these cases.
To view a Photosymbols poster explaining why health workers wear Personal Protective Equipment (PPE), follow the link: <https://www.inclusiongloucestershire.co.uk/wp-content/uploads/PPE-Easy-Read-Poster.pdf>.
To view a video on how to put on and take off PPE correctly, please follow the link: <https://www.gov.uk/government/publications/covid-19-how-to-work-safely-in-care-homes/covid-19-putting-on-and-removing-ppe-a-guide-for-care-homes-video>
In **two** cases people were not on the COVID-19 shielding list. The panel asked if they should have been. Some people with Epilepsy were asked to shield but others were not.

02 Keeping connected during COVID-19
Extra support may be needed for people with a learning disability, when they cannot see their friends and family.
Everyone with a Learning Disability or Autism should have a 'My Health Passport'.
Don't forget these resources:

- Inclusion Gloucestershire's COVID-19 hub: <https://www.inclusiongloucestershire.co.uk/covid-19/>. This lists accessible resources on a range of different COVID-19 issues.
- You're Welcome: <https://www.yourewelcomeglos.org/>. This is a website for inclusive activities in Gloucestershire.

Being on the Learning Disability Register (a list of people with Learning Disabilities).



Being on the list can mean you get extra support (we call this reasonable adjustments), this could be extra time, easy read leaflets, quiet space to wait or home visits.

It will also make sure you are invited for an Annual Health Check (if you are aged 14 or older).



Find out more information from Supercharged Me (encouraging people to get their Annual Health Check: <https://bit.ly/3zQOIVo>)

Encouraging people to get their Annual Health Check.

A Health Check is an appointment with your doctor or a nurse every year that you can have even if you feel well.



Anyone with a Learning Disability aged 14 or over can have a Health Check.

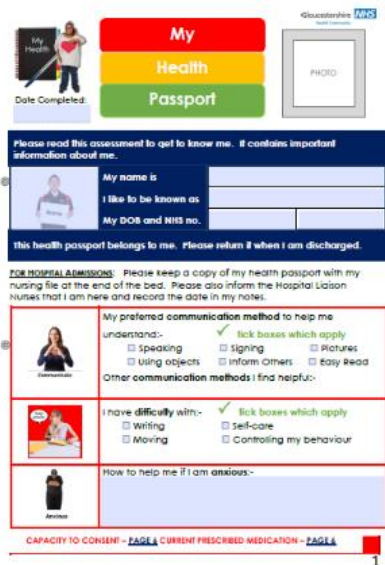


This video tells you more:
<https://bit.ly/3ENJyeg>

Promoting the use of My Health Passport (sometimes called Hospital Passport)

A health passport helps doctors and other healthcare workers find out important things about you. Such as:

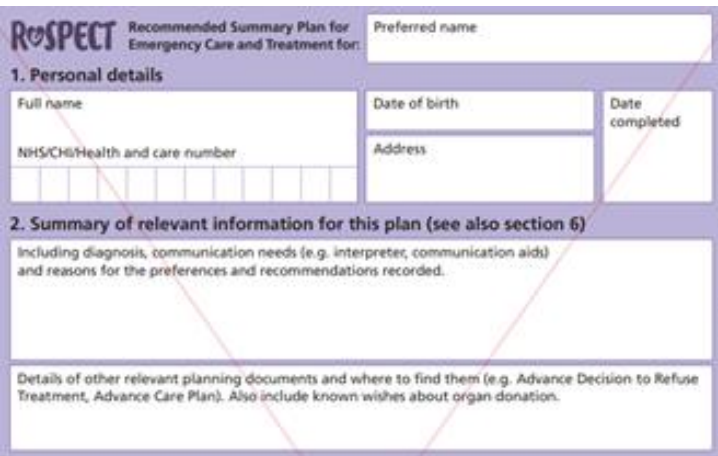
- What medication you take.
- What reasonable adjustments you require
- Other important information to help your hospital stay



The image shows a digital form titled 'My Health Passport'. At the top, there is a header with the Gloucestershire NHS logo and a 'PHOTO' placeholder. Below this is a section for personal information with fields for 'My name is', 'I like to be known as', and 'My DOB and NHS no.'. A note states 'This health passport belongs to me. Please return it when I am discharged.' The main body of the form is divided into three sections: 'My preferred communication method to help me understand', 'I have difficulty with', and 'How to help me if I am anxious'. The first section includes checkboxes for 'Speaking', 'Using objects', 'Sign', 'Inform Others', 'Pictures', and 'Easy Read', with a note to 'tick boxes which apply'. The second section includes checkboxes for 'Writing', 'Self-care', 'Moving', and 'Controlling my behaviour', also with a note to 'tick boxes which apply'. The third section is a text area for 'How to help me if I am anxious'. At the bottom, there is a footer with the text 'CAPACITY TO CONSENT - PAGE 1' and 'CURRENTLY PRESCRIBED MEDICATION - PAGE 1'.

Here is a 'My Health Passport' that can be filled in on the computer: <https://bit.ly/3jzZk46>

What do people want if they have to go into hospital - Advanced Care Planning using the ReSPECT form.



The image shows a ReSPECT form template. It is titled 'ReSPECT Recommended Summary Plan for Emergency Care and Treatment for:'. The form is divided into sections. Section 1, 'Personal details', includes fields for 'Preferred name', 'Full name', 'Date of birth', 'Date completed', 'NHS/CHI/Health and care number', and 'Address'. Section 2, 'Summary of relevant information for this plan (see also section 6)', includes a large text area for 'Including diagnosis, communication needs (e.g. interpreter, communication aids) and reasons for the preferences and recommendations recorded.' and another text area for 'Details of other relevant planning documents and where to find them (e.g. Advance Decision to Refuse Treatment, Advance Care Plan). Also include known wishes about organ donation.'

- ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment.
- This form can include any reasonable adjustments needed or a persons end of life wishes.
- They should be completed when a person is well.
- RESPECT Easy read leaflet - <https://g-care.glos.nhs.uk/uploads/files/Easy%20read%20ReSPECT-3%20leaflet%201-%20Introduction.pdf>

ReSPECT resources

5 Easy Read guides: <https://bit.ly/3w20751>

Training resources for healthcare staff:
<https://bit.ly/3sUu03O>

Myth buster: <https://bit.ly/3lTeXhz>

Top tips guide: <https://bit.ly/3tFtEye>



Knowing about the link between Dementia and Down's Syndrome

People with Down's Syndrome are more likely to develop a Dementia.

In Gloucestershire there is an early diagnosis assessment pathway available to people with Down's Syndrome.



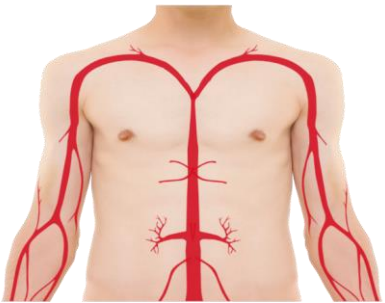
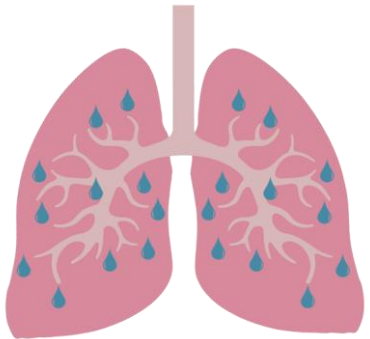
Information leaflet about the Memory Assessment Pathway (MAP) by NHS Gloucestershire Health and Care Foundation Trust: <https://bit.ly/3Fmly1k>

The MAP is available to people with Down's syndrome from the age of 30

Keeping your mouth Clean



- Keeping your mouth clean can help stop infections such as sepsis or aspiration pneumonia.
- Aspiration pneumonia is a type of infection that happens when someone breathes something into their lung instead of swallowing it.
- Sepsis is an infection in the blood



The importance of Advocacy how we use the Mental Capacity Act



Better outcomes have been seen when the Mental Capacity Act has been used to support decision making, using an advocate.

What is the Mental Capacity Act?



What is an Advocate?

The Best Interests Process

Principle 1 – assumption of capacity

Principle 2 – support in decision making

Principle 3 – capacity and unwise decisions

Principle 4 – decisions in best interests
(where an assessment has shown there to be a lack of capacity)



Fluctuating Capacity

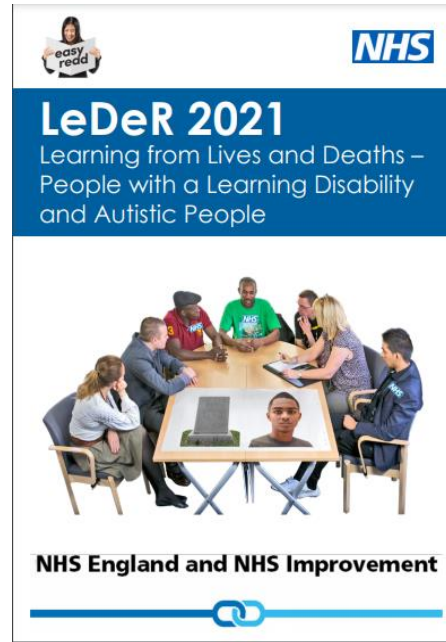


Decision

Someone may be able to make a decision for themselves on one occasion and not another.

A persons capacity could be temporarily reduced due to their health or other reason (including their environment)

Want to find out more about LeDeR?



To read the National LeDeR policy, visit:

<https://bit.ly/3ITxXgk>