

Learning Disability Mortality
Review (LeDeR) programme:

Helpful resources for Action from Learning report 2019/20



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Introduction

This document accompanies the [Action from Learning Report](#) 2019/20 which provides NHS England and NHS Improvement's response to the 2019 Learning Disability Mortality Review Programme (LeDeR) report and updates on progress since last year's [Action from Learning Report](#).

The [LeDeR programme](#) is a service improvement programme which aims to reduce the number of avoidable deaths amongst people with a learning disability and improve the quality of care and support they receive, so reducing health inequalities. An essential part of this work is to share the learning from the reviews which have happened throughout the year and the positive practice, resources and materials needed to achieve this.

This document contains a range of resources which will support local systems to understand the wider context of their action from learning, to make improvement and to share good practice. It includes guidance from our national partners, including those which describe the required standards for providing and monitoring care, and examples and links to resources created by services and their partners through action from learning.

This is not an exhaustive list of guidance and we have not included the many examples of positive practice we have received from across England in this document. These examples are instead being gradually added to our online network where they can be viewed. We encourage local systems and teams to share their work with us through the online network so we can add to this repository and make it available so that others can learn from you. If you would like to access these resources or have examples of work that can be shared, please contact england.lederprogramme@nhs.net.

1. Useful documents and resources

1.1 Policy documents, quality standards and national guidance

NHS England and NHS Improvement

www.longtermplan.nhs.uk/

The [NHS Long Term Plan](#) explains the ambitious improvements in care we want to see for patients over the next ten years and sets out how we can overcome the challenges the NHS faces. The [easy read version](#) is here:

www.longtermplan.nhs.uk/wp-content/uploads/2019/01/easy-read-long-term-plan-v2.pdf

NHS England and NHS Improvement

www.england.nhs.uk/operational-planning-and-contracting/

[The NHS Operational Planning and Contracting Guidance 2020/21](#) – this guidance covers system planning, full operational plan and workforce transformation requirements, the financial settlement and the process and timescales for submitting plans, including LeDeR, that are needed to meet NHS priorities for 2020/21

NHS England and NHS Improvement

www.improvement.nhs.uk/resources/patient-safety-strategy/

[NHS Patient Safety Strategy](#) and supporting materials (with [easy read version](#))

NHS England and NHS Improvement

www.england.nhs.uk/learning-disabilities/about/ask-listen-do/

[Ask Listen Do](#) supports organisations to learn from and improve the experiences of people with a learning disability, autism or both, and their families and carers when giving feedback, raising a concern or making a complaint. It also makes it easier for people, families and paid carers to give feedback, raise concerns and complain.

Public Health England

www.gov.uk/government/collections/reasonable-adjustments-for-people-with-a-learning-disability

PHE information and guidance on [making reasonable adjustments](#). Organised by health subject area, from annual health checks to substance misuse, this is aimed at health and social care professionals and family members / carers who support and plan care for people with a learning disability. Each topic also has an easy read version.

<p>NICE www.nice.org.uk/guidance/qs101</p>	<p>Quality standard: Behaviour that challenges (with easy read version)</p>
<p>NICE www.nice.org.uk/guidance/qs187</p>	<p>Quality standard: Care and support for people growing older (and easy read version)</p>
<p>NICE www.nice.org.uk/guidance/ng56</p>	<p>Guideline: Multiple long-term conditions</p>
<p>NICE www.nice.org.uk/guidance/ng96</p>	<p>Guideline: Care for people growing older (and easy read version)</p>
<p>NICE www.nice.org.uk/guidance/ng142</p>	<p>Guideline: End of life care for people with life-limiting conditions</p>
<p>NICE www.nice.org.uk/about/nice-communities/social-care/quick-guides/person-centred-future-planning</p>	<p>Quick guide: Future planning</p>
<p>NICE www.nice.org.uk/guidance/ng150</p>	<p>Guideline: Supporting adult carers</p>
<p>NICE www.nice.org.uk/guidance/ng27</p>	<p>Guidance: Transition from hospital to community or care home setting for adults with social care needs</p>
<p>Public Health England www.e-lfh.org.uk/programmes/all-our-health/</p>	<p>PHE's All our health e-learning programme is available through Health Education England's e-learning for healthcare platform to give health and social care professionals more confidence and skills to make prevention, staying well and promoting wellbeing a part of their everyday practice. Its bite-sized films include an introductory animation:</p> <p>www.youtube.com/watch?time_continue=122&v=5JtV8B_z7uo&feature=emb_logo</p>
<p>Public Health England www.publichealthmatters.blog.gov.uk/2019/04/09/supporting-all-health-and-care-professionals-to-boost-their-prevention-impact/</p>	<p>This blog provides more information on the new resources that PHE have been developing with e-learning for healthcare.</p>

NHS Digital and NHS England

www.digital.nhs.uk/services/reasonable-adjustment-flag

The [reasonable adjustment flag](#) will mean that if someone needs reasonable adjustments this can be flagged on their record so wherever they are treated it will be immediately visible to other services, who can then access information on what is needed.

1.2 Reports

University of Bristol

www.bristol.ac.uk/sps/leder/resources/annual-reports/

The [Learning Disabilities Mortality Review Programme](#) (LeDeR) is managed for NHS England by the University of Bristol. Each year it publishes an annual report about its findings over the past calendar year.

The fourth annual report was published in June 2020 and covers reviews during the calendar year of 2019. This report and all previous reports can be found on its [website](#).

[Easy read versions](#) are available here:

www.bristol.ac.uk/sps/leder/easy-read-information/annual-reports/

NHS England and NHS Improvement

www.england.nhs.uk/publication/leder-action-from-learning/

[Action from Learning Report 2019](#) – this was our first report on work to translate learning into action in relation to the Learning Disability Mortality Review (LeDeR) programme between spring 2018 and spring 2019. It gives our response to the [third annual LeDeR report](#) and provides an update on actions from the second annual LeDeR report in 2018.

An [easy read version](#) is here:

www.england.nhs.uk/wp-content/uploads/2019/05/action-from-learning-easy-read.pdf

Department of Health and Social Care (DHSC)

www.gov.uk/government/publications/leder-third-annual-programme-report-government-response

The [Government response to the third annual LeDeR report](#) sets out the Government's response to each recommendation from the [third annual LeDeR report](#) in May 2019, and updates on the actions identified in its response to the second annual LeDeR report published in 2018.

An [easy read version](#) is here:

www.assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/865211/leder-response-easy-read.pdf

DHSC

www.gov.uk/government/publications/government-response-to-the-learning-disabilities-mortality-review-leder-programme-2nd-annual-report

The [joint response from the Department of Health and Social Care and NHS England](#) to the Learning Disabilities Mortality Review (LeDeR) second annual report.

An [easy read version](#) is here:
www.assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/738894/easy-read-response-to-leder.pdf

1.3 Data

NHS Digital

www.digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/standardised-mortality-ratio-indicator

[Standardised mortality ratio indicator](#) – this three-year rolling indicator provides the ratio of deaths among people with a learning disability to the number of expected deaths, compared with that of the general population. It contributes to an understanding of the impact of changes in care to address premature mortality.

PHE

www.fingertips.phe.org.uk/profile/learning-disabilities

The [fingertips profile](#) for learning disabilities includes tools and data for professionals to help with planning and reduce health inequalities.

Child Outcomes Research Consortium (CORC)

www.corc.uk.net/resource-hub/working-with-learning-disabilities/

CORC's resource hub for professionals [working with children and young people with learning disabilities](#) includes guidance and tools to support the development and use of outcome measures and feedback

1.4 Respiratory guidance and resources

Public Health England

www.campaignresources.phe.gov.uk/resources/campaigns/34-stay-well-this-winter---flu/resources

Stay Well This Winter and flu vaccination resources

NICE

www.nice.org.uk/guidance/ng103

Guideline: [Increasing uptake of flu vaccination](#)

Public Health England

www.gov.uk/government/publications/flu-leaflet-for-people-with-learning-disability
www.gov.uk/government/publications/flu-vaccination-easy-read-invitation-letter-template

An [easy read flu leaflet](#) and [poster](#), supported the national Immunisation and Stay Well This Winter campaign and raises awareness about why flu vaccination is important. A template [easy read letter](#) to invite people with a learning disability for a flu vaccine is also available.

1.5 Cancer guidance and resources

Northern Cancer Alliance

www.northerncanceralliance.nhs.uk/wp-content/uploads/2019/08/LDN_cancer_pack_2.pdf

[Cervical screening information pack](#)

which includes information on capacity and consent, best interest guidance, easy read invite letters for GPs, sample letters for parents and carers and links to national easy read materials

Public Health England (PHE)

www.gov.uk/government/publications/cancer-screening-and-people-with-learning-disabilities

PHE's **[cancer screening reasonable adjustments guidance](#)** for health and social care professionals and family members/carers, with **[easy read version](#)**.

PHE

www.gov.uk/government/publications/cervical-screening-supporting-women-with-learning-disabilities

Information, resources and guidance for healthcare professionals on supporting women with a learning disability to access **[Cervical screening](#)** (2017) with **[easy read invitation letter template](#)**

PHE

www.gov.uk/government/publications/breast-screening-programme-supporting-women-with-learning-disabilities

Information, resources and guidance for healthcare professionals on supporting women with a learning disability to access **[Breast screening](#)** (2018) with **[easy read invitation letter template](#)**

PHE

www.gov.uk/government/publications/bowel-cancer-screening-colonoscopy-easy-guide

Bowel cancer screening: an easy read guide to **[having a colonoscopy](#)**

PHE

www.gov.uk/government/publications/bowel-cancer-screening-an-easy-guide-to-having-a-ctc-scan

Bowel cancer screening: an easy read guide to **[having a CTC scan](#)**

PHE

www.gov.uk/government/publications/bowel-cancer-screening-helping-people-with-learning-disabilities

Information, resources and guidance for healthcare professionals on supporting people with a learning disability to access **[bowel cancer screening](#)** (2020), including easy read materials and **[short films](#)**

PHE

www.phescrining.blog.gov.uk/?s=learning+disabilities

[Public Health England blog](#) on work relevant to screening for people with a learning disability

People First Merseyside

The '**[red flag](#)**' symptom awareness campaign by People First Merseyside was created to raise

www.youtube.com/watch?v=2ve16vQ4UGE

awareness of red flag symptoms of cancer for people with a learning disability.

1.6 Sepsis and deterioration guidance and resources

NHS England and NHS Improvement

www.england.nhs.uk/publication/easy-read-information-sepsis/

Easy read information about how to avoid sepsis, spotting the signs of sepsis, and problems after sepsis:

- [How to avoid sepsis](#)
- [Signs of sepsis and what to do](#)
- [Problems after sepsis](#)

Health Education England

HEE has a series of training films about **sepsis and managing deterioration using NEWS2** which highlights how anyone can spot these signs early. While aimed at care home workers, this resource can be used by all.

www.youtube.com/playlist?list=PLrVQaAxyJE3cJ1fB9K2poc9pXn7b9WcQg

Health Education England

www.e-lfh.org.uk/programmes/sepsis/

HEE's **Think sepsis** e-learning programme provides training materials and advice for health and social care professionals. Resources include how to identify sepsis in people with a learning disability, people with a learning disability who have communication difficulties, and identifying sepsis in children and young people.

Sepsis Trust

www.sepsistrust.org/professional-resources/education-resources/

Short films and guidance for professionals about sepsis and how to identify it – includes the **sepsis six**.

East and North Hertfordshire NHS Trust

Hertfordshire County Council

www.hertfordshire.gov.uk/services/adult-social-services/disability/learning-disabilities/my-health/how-to-stay-healthy.aspx

Easy read signs of sepsis information leaflet from Hertfordshire

www.hertfordshire.gov.uk/media-library/documents/adult-social-services/learning-difficulties-and-dementia/sepsis/

Purple All Stars

www.youtube.com/watch?v=FZq5sYulOB8

Purple All Stars (a **creative arts group of people with a learning disability**) has produced a **song** about sepsis which they are promoting via live performances and social media. This is aimed at people with a learning disability who may not access other sources of health information.

1.7 Constipation guidance and resources

[Books beyond Words](#)

www.booksbeyondwords.co.uk/bookshop/trouble-with-poo

NHS England and NHS Improvement

www.england.nhs.uk/publication/constipation-learning-disability-resources/

The Trouble with Poo is a story book to make conversations about constipation easier. It describes how a healthy diet, drinking fluid and taking exercise are important and when to seek help. Available as paperback and e-book.

Information for people with a learning disability, their families and carers and healthcare professionals about constipation and what to do about it:

- [Easy read leaflet about constipation](#)
- [Constipation leaflet for healthcare professionals](#)
- [Print ready constipation leaflet for healthcare professionals](#)
- [Constipation leaflet for families and carers](#)
- [Print ready constipation leaflet for families and carers](#)

NICE

www.nice.org.uk/guidance/cg49

Clinical guideline: **Management of faecal incontinence in adults**

NICE

www.nice.org.uk/guidance/qs54

Quality standard: **Faecal incontinence in adults**

1.8 Epilepsy guidance and resources

NHS England and NHS Improvement

www.england.nhs.uk/rightcare/products/pathways/epilepsy-toolkit/

NHS RightCare toolkit for epilepsy was developed in partnership with Epilepsy Action, SUDEP Action and Young Epilepsy to help systems, commissioners and services understand the priorities for epilepsy care and what action is needed to address them.

NICE

www.nice.org.uk/guidance/qs26

Quality standard: **Epilepsy in adults**

NICE
www.nice.org.uk/guidance/qs27

Quality standard: [Epilepsy in children and young adults](#)

NICE
www.nice.org.uk/guidance/cg137

Clinical guideline: [Diagnosis and management of epilepsies](#)

1.9 Diabetes guidance and resources

Diabetes UK
www.diabetes.org.uk/professionals/resources/share-d-practice/for-people-with-learning-disability

[Improving care for people with diabetes and a learning disability](#) is a collection of resources and tools for professionals to improve care for people with a learning disability. Includes easy read information.

NHS RightCare
www.england.nhs.uk/rightcare/products/pathways/diabetes-pathway/

[Guidance on reasonable adjustments for people with a learning disability who have diabetes](#) is part of the NHS RightCare pathway and supports commissioners and providers to improve diagnosis and management of care for people with a learning disability

1.10 Oral care guidance and resources

NICE
www.nice.org.uk/guidance/ng48

Guideline: [Oral health for adults in care homes](#)

PHE
www.gov.uk/government/publications/oral-care-and-people-with-learning-disabilities

Public Health England guidance about [oral care and dental treatment for people with learning disabilities](#) is aimed at dental and learning disability staff as well as family and others carers helping someone with their daily oral care and with accessing dental services. Includes [easy read summary](#).

Oral Health Foundation
www.dentalhealth.org/dental-care-for-people-with-special-needs
helpline@dentalhealth.org

Information from the [Oral Health Foundation](#) includes helping someone with a disability to access dental care, oral care for [people with a learning disability](#) and information about common procedures. It also has a [free and confidential helpline](#) for advice:

- 01788 539780

1.11 DNACPR guidance and resources

Learning Disability England

www.learningdisabilityengland.org.uk/news/dnar-a-guide-for-understanding-your-rights-and-challenging-decisions/

www.learningdisabilityengland.org.uk/wp-content/uploads/2020/06/DNACPR-Support-Pack.pdf

Learning Disability England worked with charity Turning Point to produce guidance to help families to talk to health professionals about DNACPR.

1.12 Mental Capacity Act guidance and resources

NICE

www.nice.org.uk/guidance/ng108

Guideline: [Decision-making and mental capacity](#)

NHS

www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/

NHS information about the [Mental Capacity Act](#)

Mencap

www.mencap.org.uk/sites/default/files/2016-06/mental_capacity_act_resource_pack_1.pdf

Mencap's [Mental Capacity Act resource pack](#) for family carers of people with a learning disability explains in detail the purpose of the act, how and when it applies to someone's care, what it means for decision making, where to get more information and what to do if you have complaints and concerns.

1.13 Commissioning guidance and resources

NHS England and NHS Improvement

This [national service model](#) (also available [in easy read](#)) is supported by [supplementary guidance for commissioners](#) and describes what good services should look like.

There are also three [model service specifications](#), also available in [easy read](#) which explain to commissioners the specialist support they could provide

1.14 Annual Health Checks guidance and resources

ACE Anglia

www.aceanglia.com/resource/peer-health-educator-network/

The [Learning Disability Annual Health Check Peer Educator Network](#) at advocacy charity Ace Anglia has published its education workshop materials online including a video, top-tips and worksheets to help people with a learning disability understand the need for annual health checks and what happens during an annual health check.

Contact

www.contact.org.uk/

www.contact.org.uk/media/1525830/annual_health_checks_parents.pdf

Contact has a [factsheet](#) to help parents make sure their young person is on the learning disability register and has an annual health check.

It also has two co-produced resources for health professionals:

- [Making GP practices more welcoming for disabled children and their families](#)
- [Health services for disabled children](#)

Mencap

www.mencap.org.uk/advice-and-support/health/dont-miss-out

Mencap's [Don't Miss Out](#) resources explain the benefits of the learning disability register and an annual health check. Materials include easy read guides, an introductory [video](#) and a short film in which [people with a learning disability talk about the benefits of health checks](#), as well as information for healthcare professionals.

NHS England and NHS Improvement

www.england.nhs.uk/publication/improving-identification-of-people-with-a-learning-disability-guidance-for-general-practice/

NHS England and NHS Improvement's [guidance for general practice](#) explains how GPs should update their registers to make sure eligible patients are flagged for a health check, under the [Quality Outcomes Framework \(QOF\) programme](#).

1.15 Guidance and resources for admission to hospital and discharge

NHS

www.nhs.uk/conditions/learning-disabilities/going-into-hospital/

Information and links to resources about [going into hospital](#) are on the NHS website to help people with a learning disability as well as families and carers. The information includes reasonable adjustments, consent and the Mental Capacity Act and an [easy read guide](#) and video about what to take with you.

Enfield Integrated Learning Disabilities Service
A2A London

www.royalfree.nhs.uk/patients-visitors/disabled-facilities/patients-with-a-learning-disability/

Enfield's [integrated learning disabilities service](#) (a partnership between local authority and health services) created an easy read discharge booklet [My hospital visit – information to take home with me](#) so that people with a learning disability have the information they need about their treatment and can share that with others involved in their care. It is used at the Royal Free London Hospitals

[http://s3-eu-west-1.amazonaws.com/files.royalfree.nhs.uk/Safeguarding/\(Final\)_My_hospital_visit_-_information_to_take_home.pdf](http://s3-eu-west-1.amazonaws.com/files.royalfree.nhs.uk/Safeguarding/(Final)_My_hospital_visit_-_information_to_take_home.pdf)

EasyHealth

www.easyhealth.org.uk/index.php/health-leaflets-and-videos/hospital/

Included in its online library, EasyHealth has a range of leaflets and helpful information to support people with a learning disability and others who need [hospital treatment](#), either as an inpatient or for outpatient care.