



*Why and how to address the health inequalities experienced by people with learning disabilities*

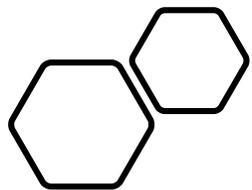
**Professor Sheila Baroness Hollins**

**Emeritus Professor of Psychiatry, St George's University of London**

**Founder and Chair, Beyond Words**

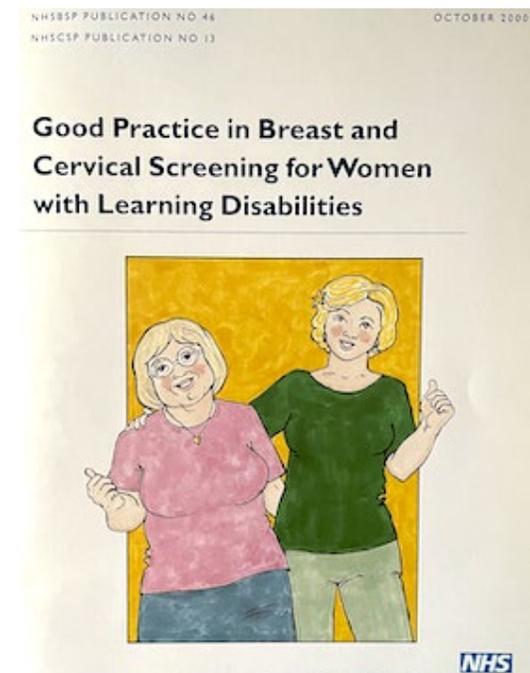
**Crossbench member, House of Lords**

**President Royal College of Occupational Therapists**



## Screening uptake by people with learning disabilities remains poor

- What progress has been made since Good Practice Guidance published in 2000?
- Have GP learning disability registers helped?



# Consider the inequalities experienced by people with learning disabilities and how to empower them

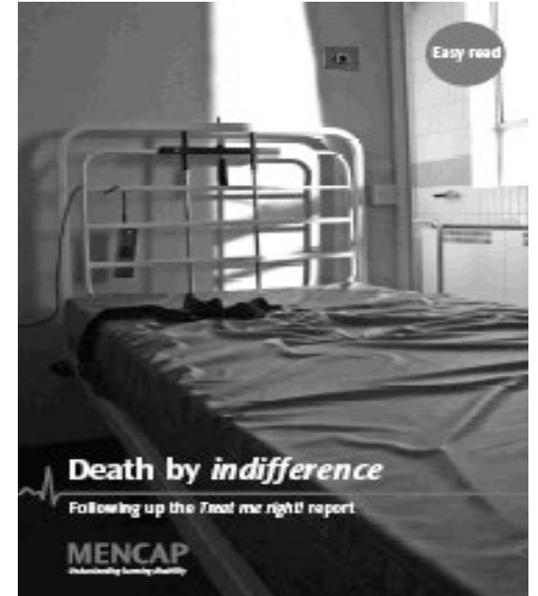
- Improve access to healthcare: Oliver McGowan's story
- Why it matters more during the pandemic
- Remember the social determinants of health
- Understand Legislation: Mental Capacity Act; Equality Act
- Know how to make reasonable adjustments
- Improve access to screening
- Consider using Books Beyond Words and the BWStoryApp as a resource



# 2008: Independent Inquiry into Access to Healthcare for People with Learning Disabilities: Healthcare for All

## Why?

To see if the problems raised in Mencap's report 'Death by Indifference' were widespread in the NHS



- People with learning disabilities have worse health and get worse care
- Staff knowledge and **attitudes** are poor
- Staff have too little training
- **'Reasonable adjustments'** are not made to services despite the law
- Good practice exists but is patchy

# Barriers sometimes created by clinicians

- Health professionals struggle to understand what is worrying the patient, and to explain health tests and procedures.
- The value of the intervention to THIS patient is seen as less important: e.g. blanket DNAR orders
- Symptoms of physical ill health are mistakenly attributed as:
  - inherent to the person's learning disability (this is sometimes called '**diagnostic overshadowing**')
  - a mental health or behavioural problem



## The Oliver McGowan Mandatory training for health and social care professionals is being piloted now

Oliver died prematurely. His parents ask:

- Make sure that you understand the Mental Capacity Act, Autism Act and the Human Rights Act, Equality Act. These are laws for which you can be held accountable if they are not followed.
- Put people at the heart of all decision making.
- Respect their point of view.
- Do not make decisions without them.
- Enable them to understand complex decisions in a way that is relevant to all and provide information and explanation.

**Much higher rate of avoidable and premature mortality (pre-pandemic)**

In 2019 (LeDeR) :

People died on average 25 years earlier than the general population.

Fewer than 2 in 5 people lived beyond 65 years of age

**During COVID-19 – the first wave**

- Overall death rate for people with ID was estimated to be up to 6.3 times higher than the general population

# Premature and avoidable mortality

8% of deaths in the general population are from 'avoidable medical causes'

**one *third*** of deaths of people with LD are avoidable.

## **Some of the most consistent reasons:**

- Poor uptake of screening
- Delays or problems with diagnosis or treatment
- Problems with identifying needs
- Difficulty providing appropriate care in response to changing needs.



**Gary Butler**  
Author and adviser

## Involving experts by experience

- People with learning disabilities must be involved throughout the development, training and delivery of services

Involving experts by experience



# Legal requirements in England and Wales

Mental Capacity Act 2005 –an empowering Act

- Capacity assumed
- Best interest decisions

Equality Act 2010 requires services to:

- anticipate the needs of people with ‘protected characteristics’
- **make reasonable adjustments** to support people to make full use of a service



Using the TEACH approach – make reasonable adjustments adapted from *Jim Blair, Being Alert: Changing culture, shaping care* 2016

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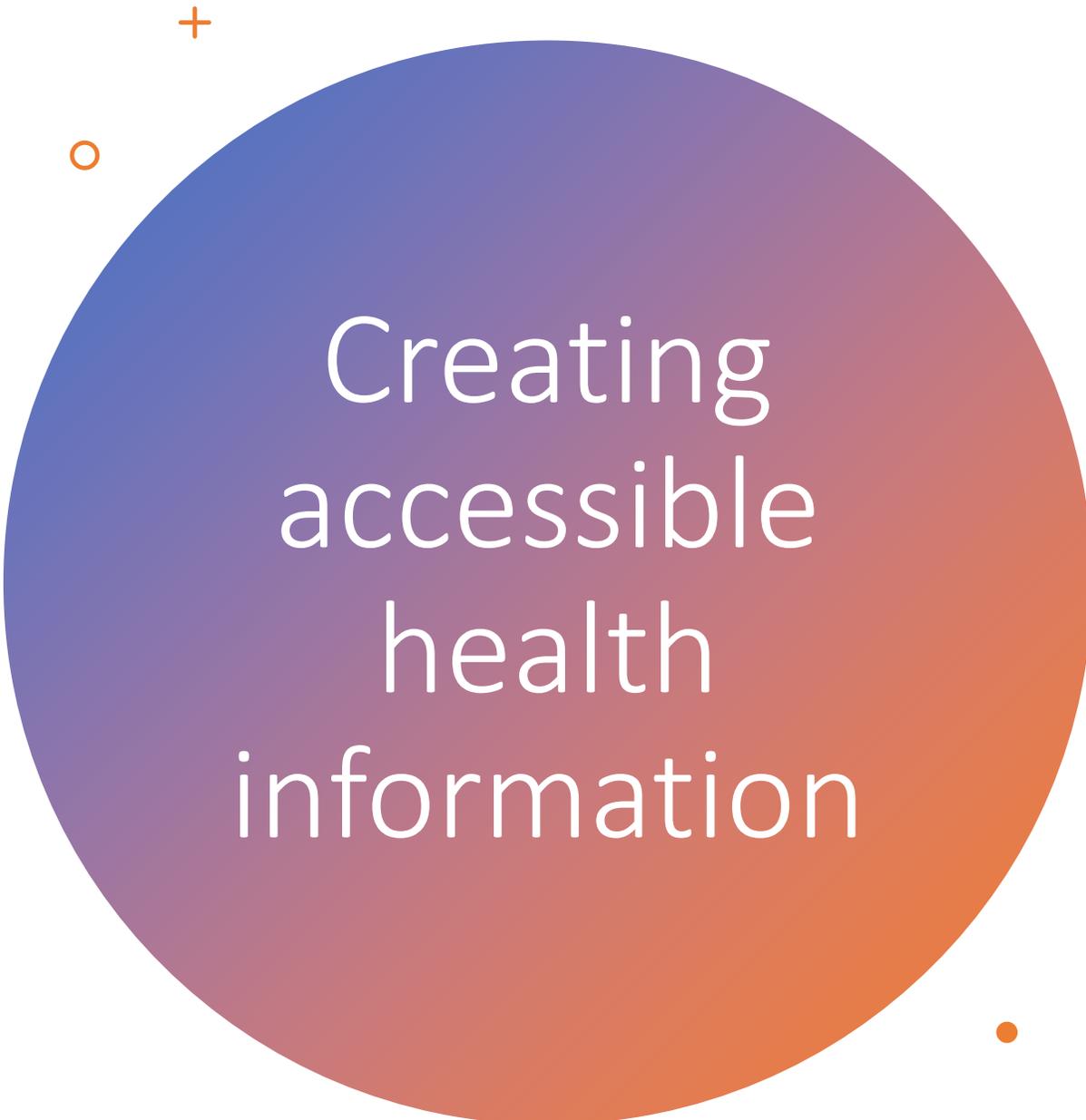
- **T Time** – take time to work with the patient
- **E Environment** – alter the environment
- **A Attitude** – be positive
  - avoid *diagnostic overshadowing*
- **C Communication** – check the person's needs
  - Listen very carefully to the patient
  - Use pictures or other communication aids to support you.
- **H Help** – what help does the patient need
  - Make sure the right supporter/carer attends with the patient

# Supporting Health Literacy

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- People themselves and their supporters/carers often struggle to explain their symptoms, and may not understand why or when to check things out with a health professional





# Creating accessible health information

- Co-production standards for Easy read information are available
- [https://improvement.nhs.uk/documents/2927/improvement-standards-easy-read-iores\\_v4pages.pdf](https://improvement.nhs.uk/documents/2927/improvement-standards-easy-read-iores_v4pages.pdf)

An example of an  
Easy Read leaflet



**NHS**

see  
[www.easyhealth.org](http://www.easyhealth.org)

**Have you seen blood in  
your pee, even once?**

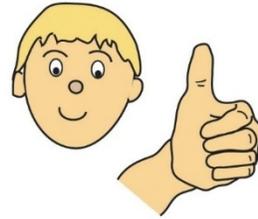
**Then it is time to tell your doctor.**

EasyRead version

**BE CLEAR  
ON CANCER**



I like



I don't understand

???

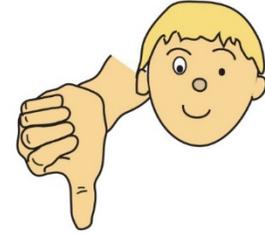


I don't know

???



I don't like



Pretend Play - Band




PECS:  
picture exchange  
communication system



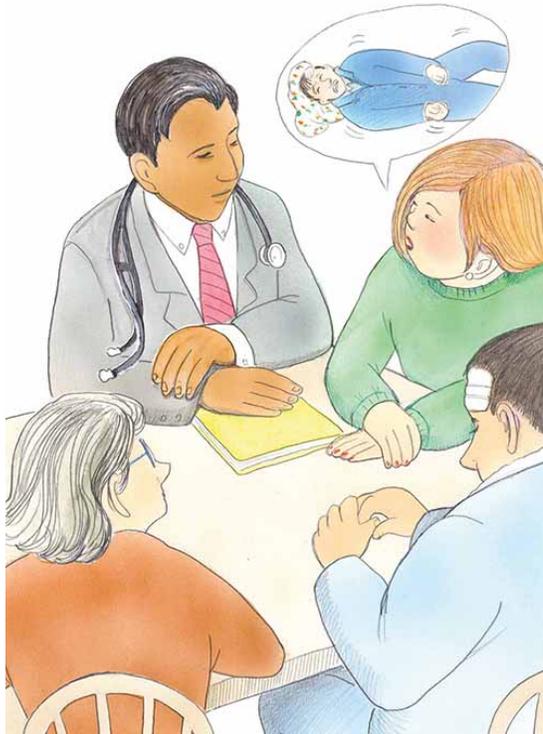
# Can pictures help?

- Hibbing and Rankin-Erickson's review of literature (2003)
- ... **Supporting understanding through pictures was found to resolve difficulties decoding words**
- **The pictures helped to activate background knowledge, reflect and make predictions about what might happen.**

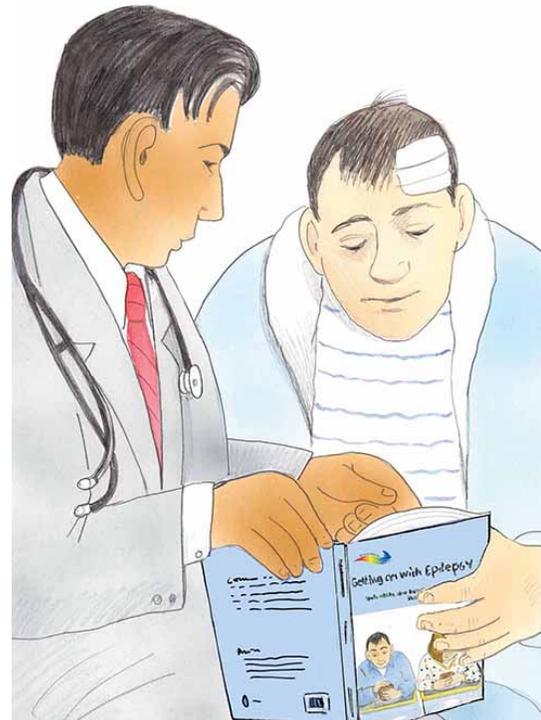


# Beyond Words creates wordless stories to:

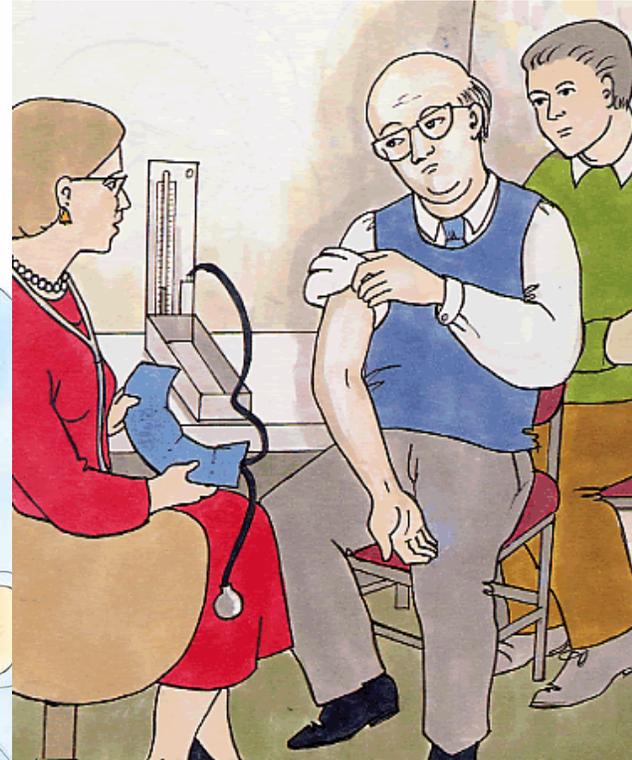
Check  
understanding



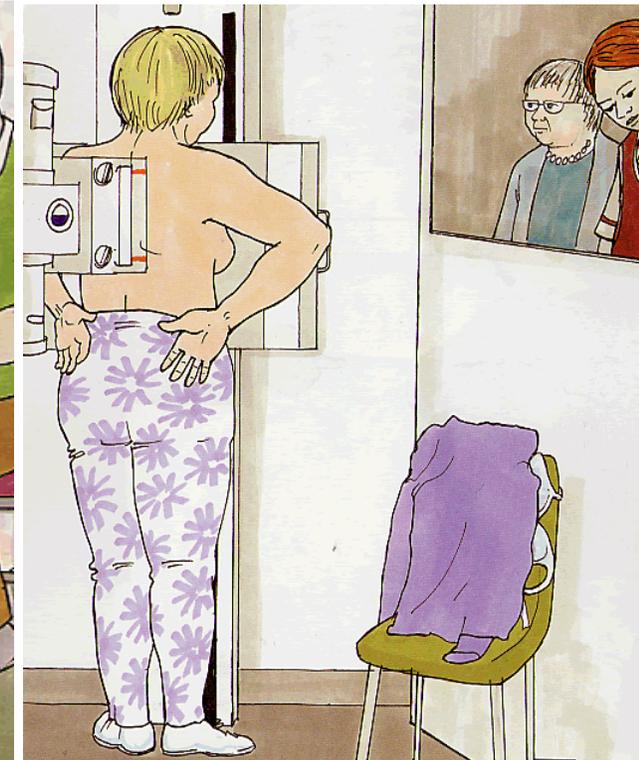
*Support decisions*

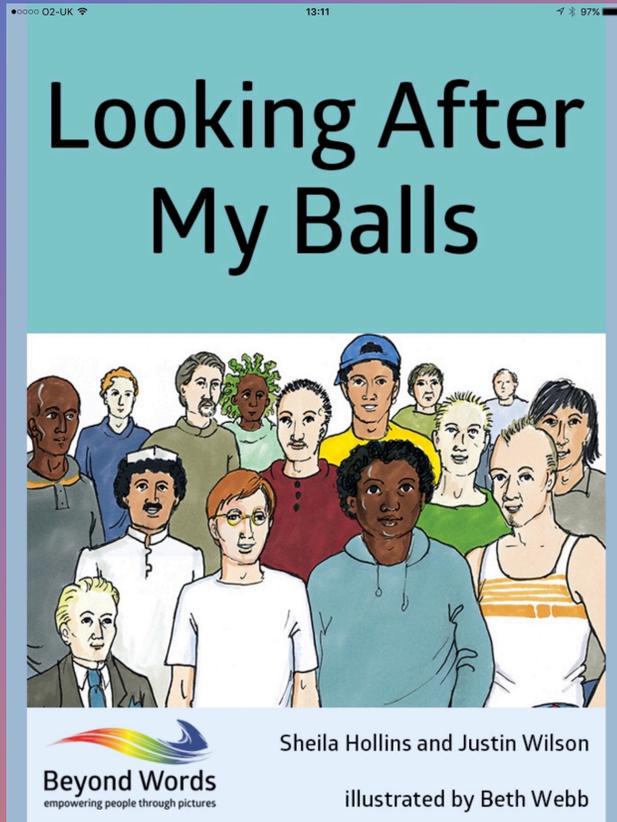


Share test results



Explain a  
procedure





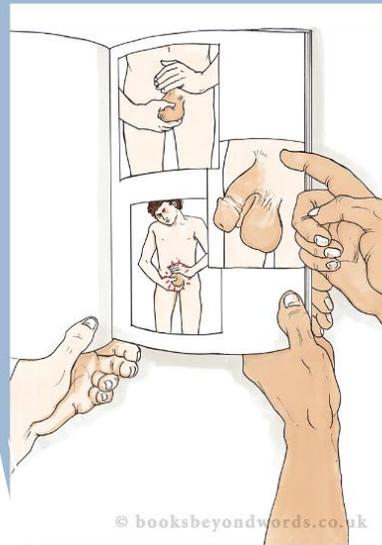
# Testicular Cancer Screening Study

- 37 randomised to a Pictorial leaflet group
- 36 randomised to a **teaching group**
- **age of participants**
  - **16 to 35 years**

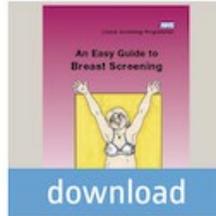
# Compared confidence in self checking and seeking help

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- Significantly improved confidence in ability to check and seek help:
  - initially by Teaching group participants
  - after six months also by those in the Leaflet group.
- 73% of the Teaching group and 61% of the Leaflet group reported testicular self-examination during the 6 months after the intervention.

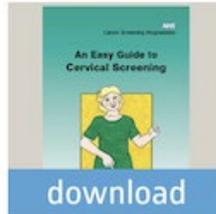


To support  
screening



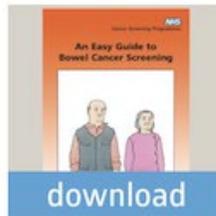
### An Easy Guide to Breast Screening

An Easy Guide to Breast Screening ... A free 8 page guide to breast screening ... Screening ... screening ...



### An Easy Guide to Cervical Screening

An Easy Guide to Cervical Screening ... Screening ... A free 8 page guide to cervical screening ... screening ...



### An Easy Guide to Bowel Cancer Screening

A free 16 page guide to bowel cancer screening ... Screening ... An Easy Guide to Bowel Cancer Screening ... screening ...

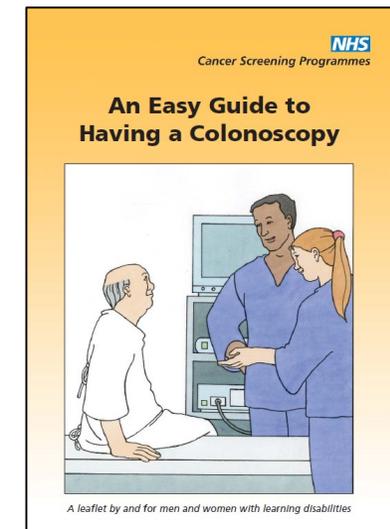
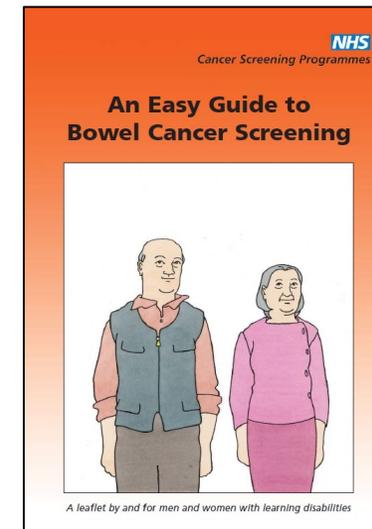
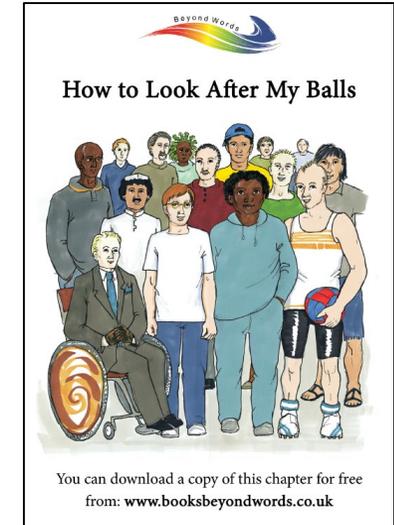
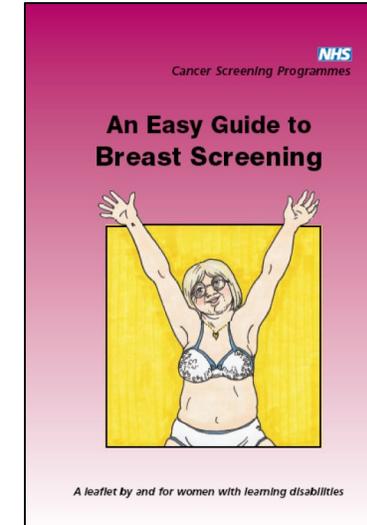
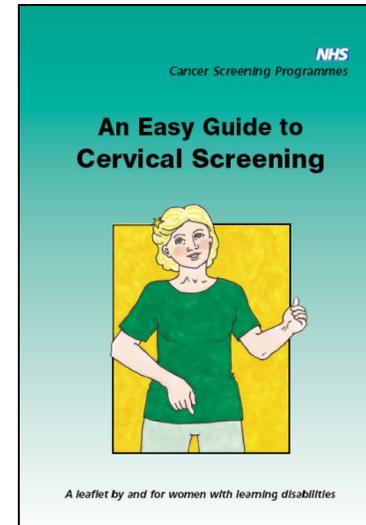
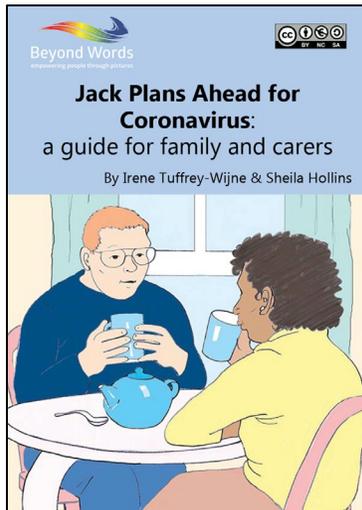
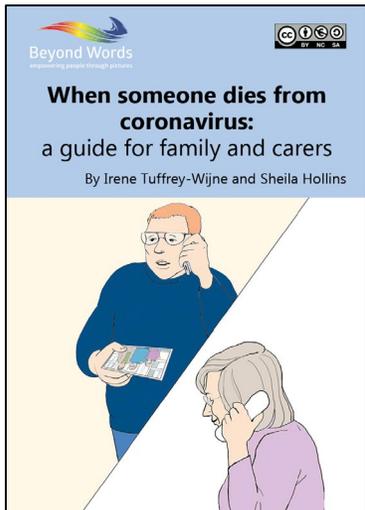
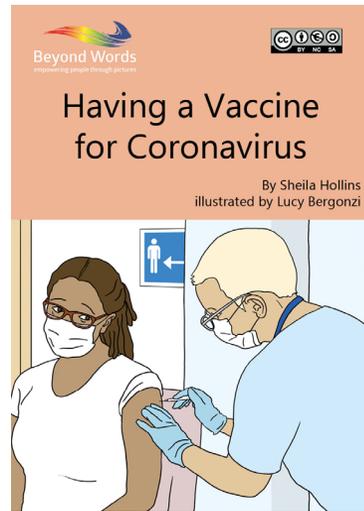
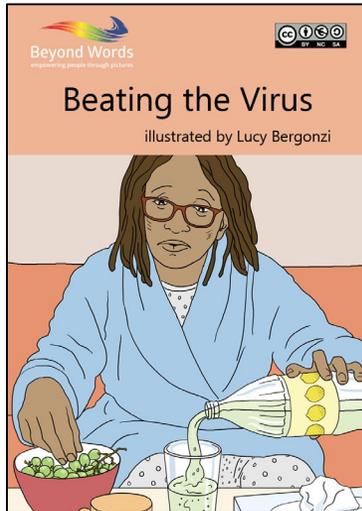
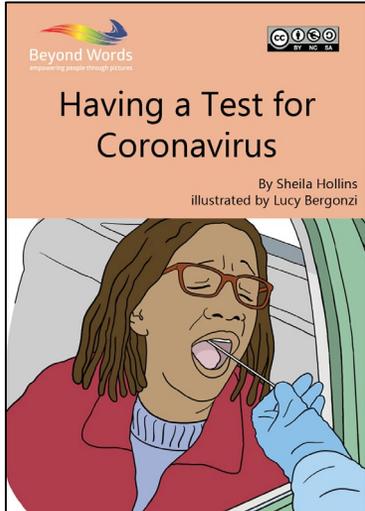


### Keeping Healthy 'Down Below'

cervical screening ... screening ...

Free resources to support people through the coronavirus pandemic:

[www.booksbeyondwords.co.uk/coping-with-coronavirus](http://www.booksbeyondwords.co.uk/coping-with-coronavirus)



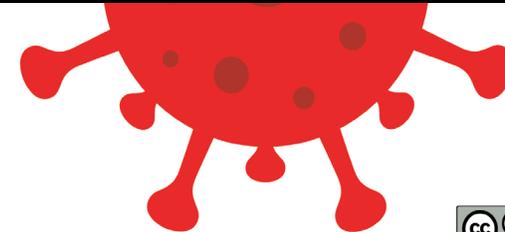
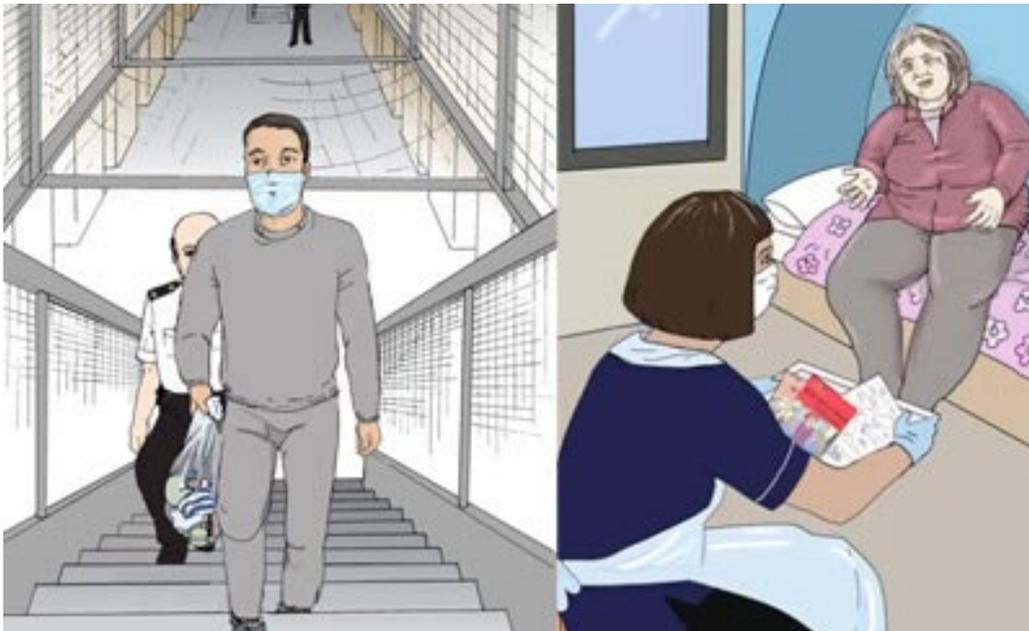
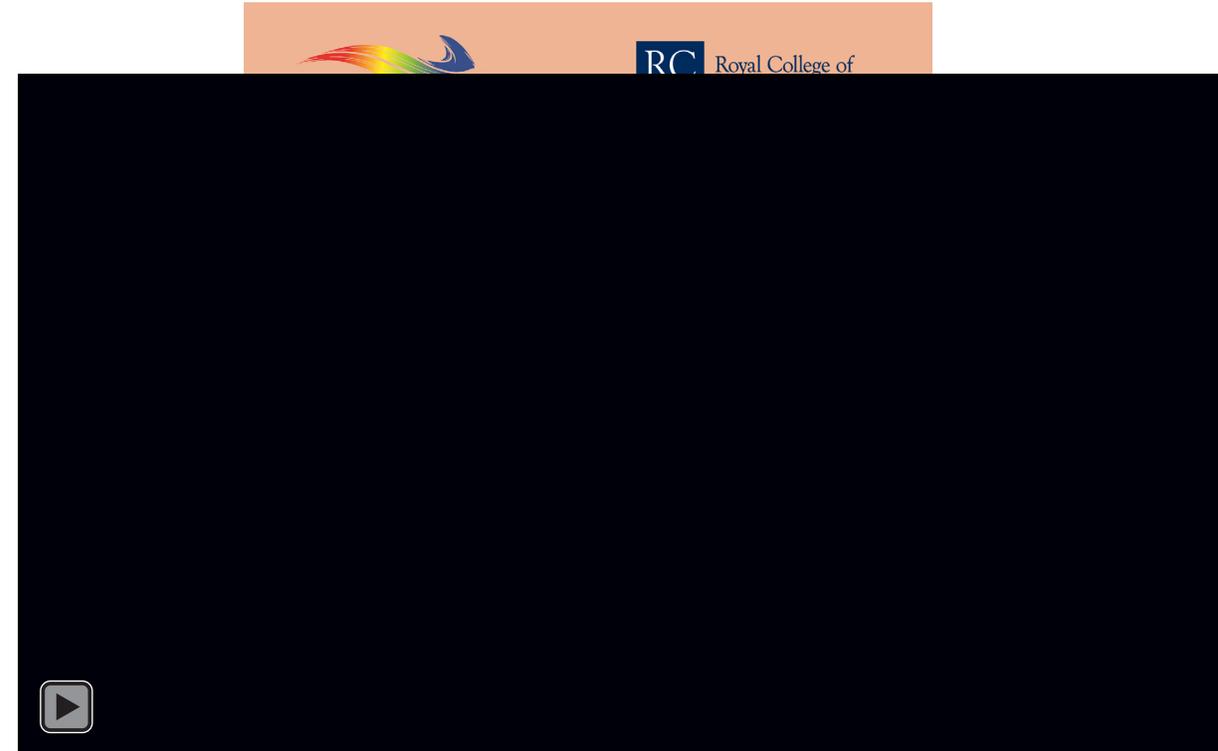
Download free screening leaflets from:  
[www.booksbeyondwords.co.uk/resources-dl](http://www.booksbeyondwords.co.uk/resources-dl)

# Coronavirus in secure settings

A story and 'toolkit' of materials for prisoners with learning and literacy difficulties

Way Out TV video story with voiceover

The RCGP are supporting this initiative and currently testing the resources in HMP Bedford



Many people **understand pictures better** than words

Quickly find a relevant health or social short story in the BWStoryApp

Choose a printed book on a health-related topic

Download free COVID-19 PDFs



**eBooks**

**Translations**

**Books Beyond Words** are for anyone who finds pictures easier to understand than words. The books use pictures to tell stories that help people understand and explore their own experiences. For more information and our online book shop please visit: [www.booksbeyondwords.co.uk](http://www.booksbeyondwords.co.uk)



**BW Story App**

visit: [www.booksbeyondwords.co.uk](http://www.booksbeyondwords.co.uk)

**Beyond Words Story App**

Picture stories to enrich the lives of the people you care about



## Read more here:

1. Hollins, S., Egerton, J. and Carpenter, B. (2017), Using wordless books to support clinical consultations *Journal of Mental Health Training, Education and Practice*. Emerald. DOI: <http://dx.doi.org/10.1108/jmhtep-03-2017-0022>)
2. Hurtado, B., Jones, L. and Burniston, F. (2014), “Is Easy Read information really easier to read?”, *Journal of Intellectual Disability Research*, Vol. 58 No. 9, pp. 822–829.
3. Mengoni, S.E., Gates, B., Parkes, G., Wellsted, D., Barton, G., Ring, H., Khoo, M.E., Monji-Patel, D., Friedli, K., Zia, A., Irvine, L. and Durand, M.-A. (2016) “Wordless intervention for people with epilepsy and learning disabilities (WIELD)”, *BMJ Open*, Vol. 6 (Available at: <http://bmjopen.bmj.com/content/bmjopen/6/11/e012993.full.pdf>; accessed: 25.3.17)
4. Nikolajeva, M. (2012), “Reading other people’s minds through word and image”, *Children’s Literature in Education*, Vol. 43 No. 3, pp. 273–291.
5. Schlochtermeyer, L.H., Kuchinke, L., Pehrs, C., Urton, K., Kappelhoff, H. and Jacobs, A.M. (2013), “Emotional picture and word processing”, *PLoS ONE*, Vol. 8 No. 2, pp. e55619. (Online at: <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0055619>; accessed: 26.3.17)
6. Hastings, R., Durand, M. and Begum, S. (2016), *The Books Beyond Words Manual for Professionals, Trainers, Researchers and Funders*, Books Beyond Words and University of Warwick, London. Available from: Beyond Words, City Lit, 1-10 Keeley Street, London, WC2B 4BA.

# Premature mortality research

- \*<https://www.gov.uk/government/news/people-with-learning-disabilities-had-higher-death-rate-from-covid-19>
- Heslop et al. (2020) Deaths from COVID19 reviewed as part of the LeDeR programme in England. <http://www.bristol.ac.uk/sps/leder/news/2020/leder-covid-19-reviews.html>
- HOLLINS, S., ATTARD, M.T., VON FRAUNHOFER, N., McGUIGAN, S. and SEDGWICK, P. (1998) Mortality in People with learning disability: risks, causes, and death certification findings in London. *Developmental Medicine & Child Neurology* 40, 50-56.
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- Perera et al (2020) , BJPsych Open (2020) 6, e123, 1–6. doi: 10.1192/bjo.2020.102 (analysis of 66 deaths of people with intellectual disabilities who died with COVID-19, identifying comorbidities, demographic and clinical factors)
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- Turk, Margaret A., Scott D. Landes, Margaret K. Formica and Katherine D. Goss. 2020. "Intellectual and Developmental Disability and Covid-19 Case-Fatality Trends: Trinetx Analysis." *Disability and Health Journal* 13(3):1-4. doi: 10.1016/j.dhjo.2020.100942. <https://www.sciencedirect.com/science/article/pii/S1936657420300674>
- McGUIGAN, S.M., HOLLINS, S. and ATTARD, M. (1995) Age-Specific Standardised Mortality Rates in People with Learning Disability. *Journal of Intellectual Disability Research* 39, 6, 527-531.