



Supporting Cancer Screening for People with Learning Disabilities

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eQUALITY

for people with learning disabilities

Megan Pannell (Health Equalities Nurse)



My Role: Health Equalities Nurse

Reduce health inequalities
experienced by people with learning
disabilities

- Improve access to national screening programmes (breast, bowel and cervical)
- Support reasonable adjustments and advocacy
- Work with carers, primary care, and screening services
- Promote early detection and informed decision-making

Why Cancer Screening Matters

People with learning disabilities experience poorer cancer outcomes

- Later diagnosis leads to reduced treatment options
- Screening helps detect cancer early or prevent cancer developing
- Carers play a key role in access, understanding, and attendance

Breast Cancer Screening (NHS)

Who: Women aged 50–70
(some areas extending to 47–
73)

- How often: Every 3 years
- Method: Mammogram (X-ray of the breasts)
- Invitation sent automatically via GP registration
- Reasonable adjustments can be requested

Bowel Cancer Screening (NHS)

Who: Adults aged 50–74

- How often: Every 2 years
- Method: Home FIT (poo test)
- Test kit sent by post
- Support may be needed to understand and complete the test

Cervical Screening (NHS)

Who: Women and people with a cervix aged 25–64

- Every 5 years. If someone is on a 3 year recall, that will stay but go onto every 5 from then on
- Method: Cervical sample (smear test)
- HPV primary screening

Carers' Role in Supporting Screening

Encourage attendance and explain the purpose of screening

- Support understanding using accessible information
- Help with appointments, transport, and preparation
- Advocate for reasonable adjustments
- Provide emotional reassurance before and after appointments

Managing Refusal to Be Screened

- Explore reasons for refusal (fear, pain, misunderstanding, trauma)
- Ensure information is accessible and repeated if needed
- Allow time. Consent is an ongoing process
- Do not coerce or force screening
- Record decisions clearly

Mental Capacity & Best Interest Decisions

- Assume capacity unless proven otherwise
- Capacity is decision-specific and time-specific
- Provide all practicable support to enable decision-making
- If no capacity, follow best interest process
- Carers provide evidence but do not make the decision alone

Protective Factors When Screening Is Refused or Not Possible

- Symptom awareness and early reporting
- Regular health checks and GP reviews
- Healthy lifestyle support
- Clear escalation pathways if symptoms appear
- Good documentation and communication
- Recording when visual checks are taking place
- Continue to encourage if refusing and make it a regular topic of conversation

Bowel Cancer – Symptoms to Be Aware Of

- Persistent change in bowel habit
- Blood in poo or bleeding from bottom
- Ongoing tummy pain or bloating
- Unexplained weight loss
- Unexplained tiredness or anaemia

Know the symptoms of bowel cancer



Bleeding from your bottom



Blood in your poo



A change in how often you poo, or regularly having diarrhoea or constipation



Losing weight but you're not sure why



Feeling very tired all the time but you're not sure why



A pain or lump in your tummy

If you have any of these symptoms, talk to your GP and ask about an at-home test.

Links for guides on bowel screening

- [Bowel Screening Guide](#)
- <https://youtu.be/qzJ71-OY3t4>
- [Bowel cancer screening – An easy read guide](#)

Breast Cancer – Symptoms to Be Aware Of

- New lump or thickening in breast or armpit
- Change in size or shape of breast
- Skin changes (dimpling, redness, rash)
- Nipple discharge or inversion
- Persistent breast pain

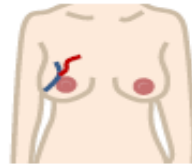
Breast Cancer – Easy Read Checklist



Doing a visual breast check



If the nipple becomes inverted (pulled in) or changes its position or shape.



New or growing vein.



A swelling in the armpit or around the collar bone.



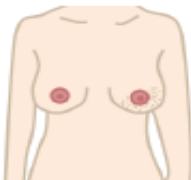
A Change in shape or size of breast.



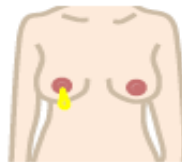
Constant pain in your breast or your armpit.



Redness or heat rash on the skin and/or around the nipple.



A change in the texture of the skin such as puckering or dimpling (like the skin of an orange)



Discharge (liquid) from one or both of the nipples.



A lump or a thickening that looks different from the rest of the breast tissue.

Any changes need to be checked with your GP

Links for breast checking guides

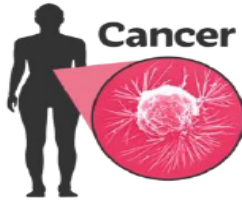
- [Breast Checking Guide
Breast Screening For Women
aged 50-71](#)
- [An Easy Guide to Breast S
creening -
2021 updated .pdf](#)

Cervical Cancer – Symptoms to Be Aware Of

- Bleeding between periods or after sex
- Post-menopausal bleeding
- Unusual vaginal discharge
- Pain during sex
- Persistent pelvic pain

Cervical Cancer – Easy Read Checklist

Symptoms of Cervical Cancer



When you have changes to your cervix these can be treated by the doctor before they become cervical cancer.



If they are left and become cancer, you may not get symptoms or feel unwell until it has spread and is more difficult to treat



This is why it is important to go to your cervical screening or 'smear test' when you are asked to.



Whether you decide to go or decide not to go for the screening it is still very important to look out for ANY signs and symptoms that MAY be cervical cancer so you can get the right treatment before it spreads too far.

Symptoms of Cervical Cancer

The most common symptoms of cervical cancer are:



Bleeding from your vagina that is not your period or time of the month



Pain or discomfort during sex



Discharge from your vagina that you may find in your underwear



Pain in the area between your hips



These symptoms of Cervical Cancer can also be a symptoms of other things which are not cervical cancer.



Don't worry, but it is really important that you DO book to see your doctor as possible so they can check it out for you.

Links for cervical screening guides

- [Cervical Screening for women age 25-64](#)
- [CSP05 easy guide to cervical screening July 25.pdf](#)

Accessing Support When Screening Is Difficult

- GP reasonable adjustment flag
- Learning Disability Nurses
- Screening services for alternative appointments or desensitisation visits
- Health Equalities Nurse support –
healthqualitynursing@hertfordshire.gov.uk
- Hertfordshire's LD My Health Website has all the information on how to access support
[How to stay healthy | Learning disabilities | Hertfordshire County Council](#)

References

NHS England – Cancer
Screening Programmes

Public Health England
Screening Guidance

Mental Capacity Act 2005

NICE Guidance on Learning
Disabilities and Cancer Care

NHS Accessible Information
Standard

The HCPA Resource Library

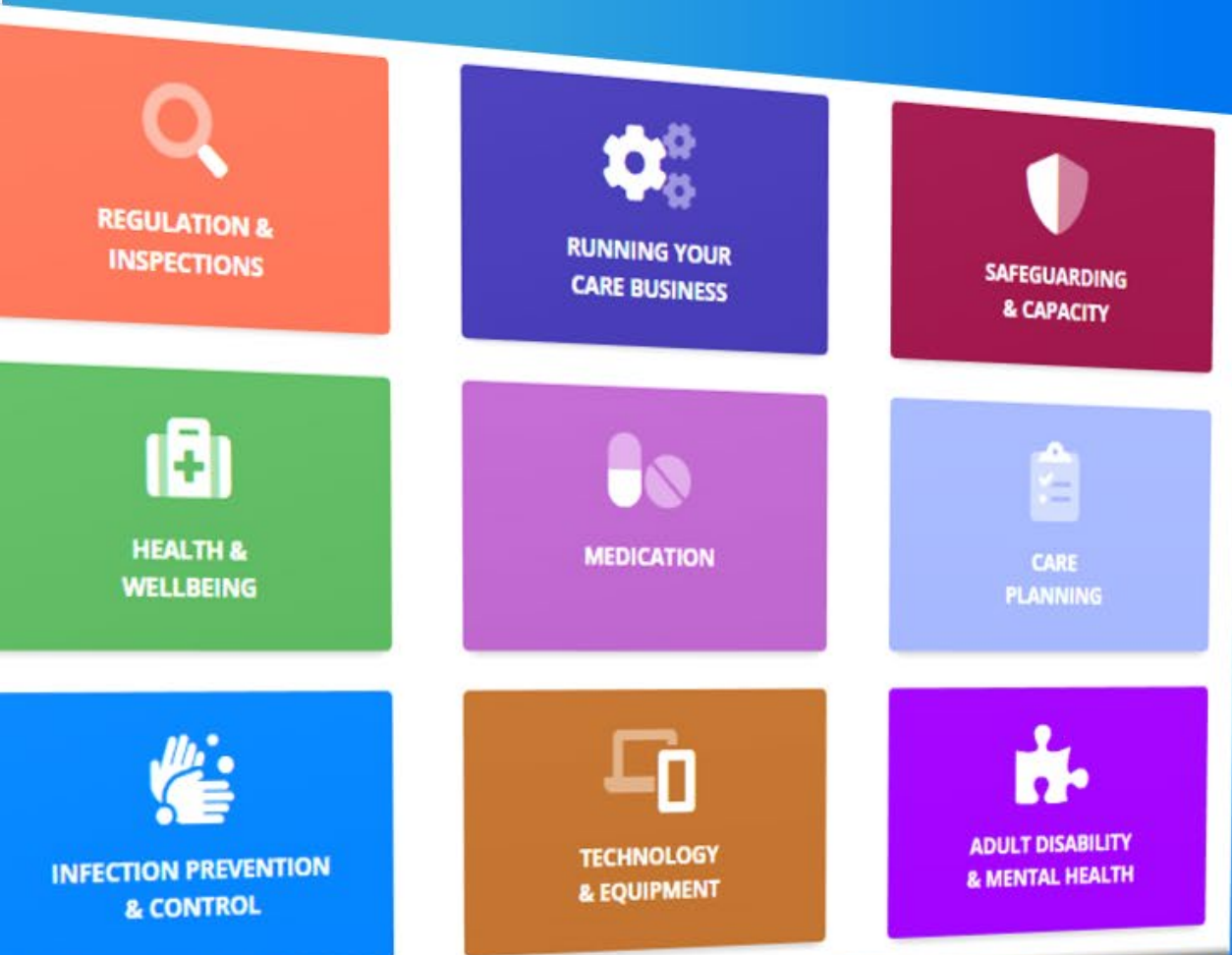
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