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Cervical Screening for Women with Learning Disabilities: Guidance for Healthcare professionals in Sussex.

Document control

This is a controlled document. The most recent release is held by PHE.Screening-ImmsSSAT@nhs.net.

This document will be reviewed every two years or sooner if there are changes to the national policy and guidance.

This document has been adapted from the Kent and Medway guidance document and the previous Sussex guidance document of August 2014.

Contents page

Introduction	Page 4
Need for Screening	Page 4
What is Cervical Screening	Page 4
What is a Learning Disability	Page 4-5
Cervical screening Pathway for Women with Learning Disabilities	Page 6
The Pre- Screening appointment	Page 7
Capacity to consent for Cervical Screening	Page 8
Best Interest Decisions	Page 9
Support from Learning Disability Services	Page 9
The Screening Appointment	Page 10
Results and Follow up	Page 10
Colposcopy Appointment	Page 10

Appendices

Appendix 1- Useful Links Page	Page 11
Appendix 2-Ceasing Best interest letter to PCSE	Page 12
Appendix 3- What happens after Cervical Screening	Page 13
Appendix 4- Learning Disability Liaison Services (acute) contacts	Page 14
Appendix 5- Further contacts and useful links	Page 15-17

Introduction

The aim of this document is to provide guidance and to describe good practice to ensure that women with Learning disabilities have the same rights of access as all other women to NHS Cervical Screening Programme (NHSCSP).

By providing a clear pathway this guidance aims to overcome some of the challenges women with learning disabilities face when accessing cervical screening services. It is aimed at the healthcare professionals involved in delivering the screening service, providing an algorithm to follow and some guidance on broader management of women with learning disabilities within the cervical screening pathway.

Need for screening

Disabled women are living longer and fuller lives and should have access to breast, bowel and cervical screening on the same basis as other women. Many women with [learning] disabilities cope well in society, either independently or with support from family or friends. Some, however, have multiple or more severe disabilities. This means that the breast, bowel and cervical screening programmes have to make sure that women have access to information about screening which is presented in a way which they can understand. Staff in the screening programmes must therefore adopt good practice to enable women who choose to attend for screening to be screened successfully (NHS CSP Cancer screening edition No 3 March 2016) [Appendix 1](#)

What is Cervical Screening

Cervical screening is **not** a test for cancer. It is a method of preventing cancer by detecting and treating early abnormalities which, if left untreated, could lead to cancer in a woman's cervix (the neck of the womb). The first stage in cervical screening is taking a sample using liquid based cytology (LBC).

A sample of cells is taken from the cervix for analysis. A doctor or nurse inserts an instrument (a speculum) to open the woman's vagina and uses a small soft brush to sweep around the cervix. Most women consider the procedure to be only mildly uncomfortable. Early detection and treatment can prevent 75 per cent of cancers developing but like other screening tests, it is not perfect. It may not always detect early cell changes that could lead to cancer.

What is a Learning Disability

Learning disability includes the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence)
- A reduced ability to cope independently (impaired social functioning)
- Which started before adulthood, with a lasting effect on development

(Valuing People, 2001)

An IQ of 69 or below is also used as an indicator of learning disability.

This does not tell you what kind of help and support someone needs or who they are – each person will be different and the impact of their disability on their lives will vary.

Mild (IQ range 50 – 69)

Many able to maintain good social relationships, independent in self care & domestic skills, basic reading & writing

Moderate (IQ range 35 – 49)

Likely marked developmental delays in childhood, most can learn some degree of independence in self care & adequate communication/academic skills. Will need varying degrees of support to live and work in the community

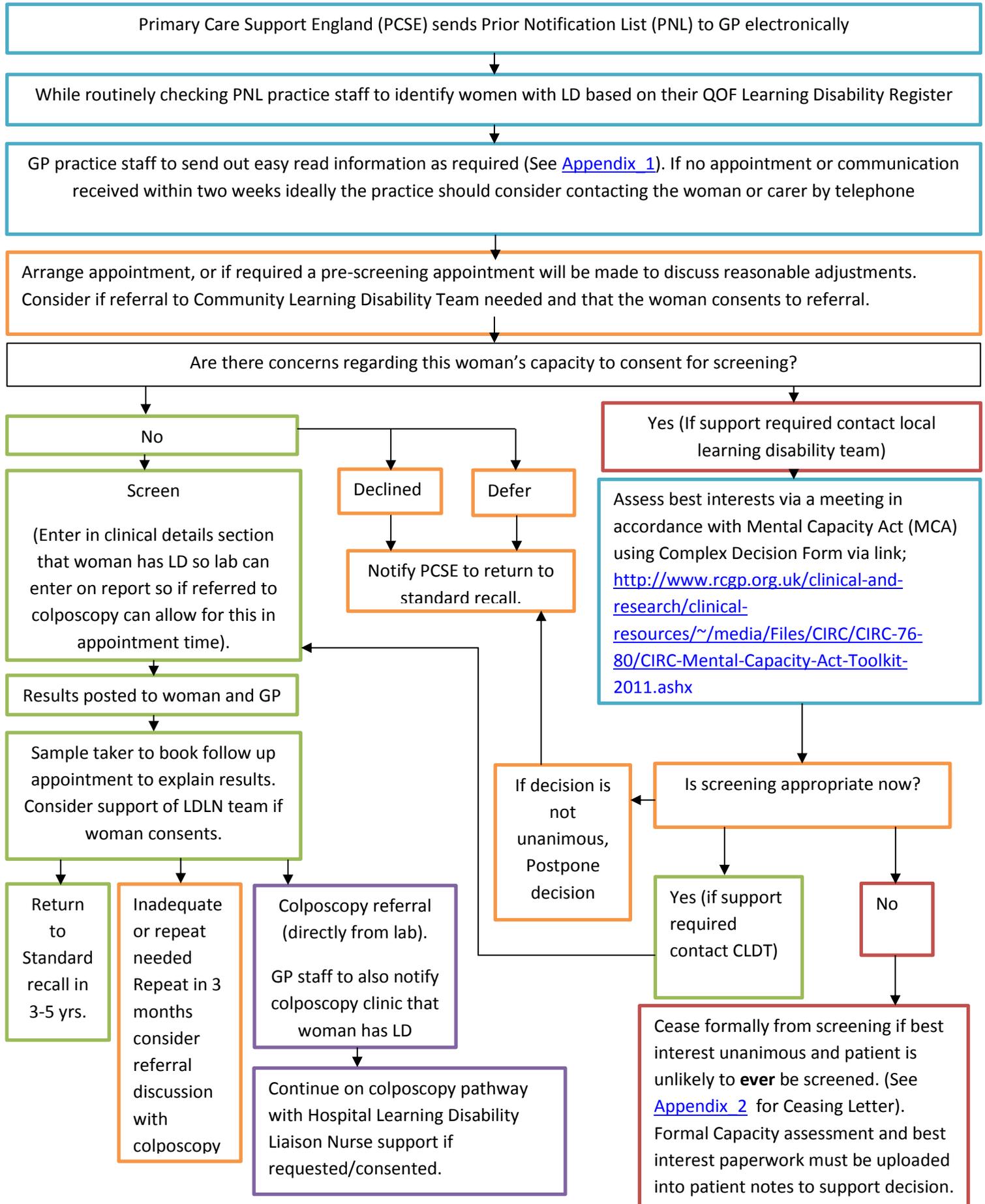
Severe (IQ range 20 – 34)

May have use of words or gestures for basic needs, likely to need support and supervision in all aspects of self care

Profound (IQ under 20)

Severe limitations in self care, continence, communication & mobility. Require full support to fulfil all daily living skills.

Cervical Screening Pathway For Women With Learning Disabilities (LD)



The invitation

Women between the ages of 24.5 and 64 years who are registered with a GP are invited by the Primary Care Support England (PCSE) to have a cervical screening test every three to five years. Women identified as eligible for cervical screening are sent a letter informing them that a cervical screening test is due and inviting them to make an appointment with their GP or alternatively with a community clinic. If the woman does not respond, she is sent a further letter by the PCSE.

GP surgeries are sent the prior notification list 10 weeks before the woman is due the test, and the invite is then sent six weeks prior to the test due date. The GP surgery should identify if the woman has a learning disability and should ensure that an easy read leaflet is sent to the woman. The easy read leaflet is available here.

<http://www.cancerscreening.nhs.uk/cervical/publications/easy-guide-cervical-screening.html>

People with Learning Disabilities often require Reasonable Adjustments to be made to enable them to access health care. This is supported in the Equality Act 2010. Reasonable adjustment can be many things, such as, longer appointment times, quiet waiting areas, easy read letters and information, additional support at appointments etc. Please see below for examples of how these can be implemented in practice and scenarios where they may be of helpful.

The pre-screening appointment

Fear and anxiety or a lack of information and preparation may contribute to non-attendance for cervical screening. Use the pre-screening appointment to talk through easy read information, allow the woman time to look at and handle equipment if she wants, give information to take away. However, for some women this may increase anxiety – always consider individual preferences. Explain options for having a friend or carer present during the screening appointment, or a chaperone from the practice.

The standard letter and leaflet about cervical screening may be difficult for a woman with a learning disability to understand. Use the easy read leaflet on cervical screening, and any other appropriate resources that the practice has access to, in order to support your discussion with the patient and/or her carer. Consider using 'The Smear Test Film' a health education film resource for women eligible for cervical screening (smear tests) who have mild and moderate learning disabilities useful. This film has been made by Public Health England in association with Jo's Cervical Cancer Trust. Please be aware that you may need to present and explain information on more than one occasion, and in a variety of ways. See [Appendix 1](#) for link, Smears Test Film by Jo's Trust.

Assumptions should be avoided regarding risk and sexual history – past histories may or may not be known. It cannot be assumed that someone is not or never has been sexually active. Women aged 24.5-64 should be included in recall unless exempted or ceased according to national guidance (primarily no cervix or informed choice), and where an individual lacks capacity a best interest decision should be made.

Poor attendance – women may not attend for arranged appointments, either through anxiety, or forgetting it has been arranged for example. Consider providing simple appointment cards indicating time and date of appointment, or ring or text the patient the day before appointments to remind them.

Standard appointment times may not be long enough to achieve successful cervical screening. The timing of appointments may also be a factor, as some women may struggle to tolerate busy waiting rooms and long waiting times, or have specific routines that are important to them. It is good practice to book a longer screening appointment, consider

scheduling at the start or end of clinic session – start of session reduces waiting time, end of session allows for more time to be taken without pressure of other waiting patients.

Sample takers should discuss with the woman at the pre-screening appointment any particular arrangements that need to be in place to discuss results of screening. It may be appropriate to arrange to follow up a result letter with an appointment or telephone call if the woman indicates she would like support to understand her results. This may include providing relevant contact details of the person to contact at the practice with any questions the woman and/or her carer may have about the result letter.

The sample taker may decide not to proceed to carry out the screening test if they think that preparation has not been adequate. The attendance on this occasion should be seen as part of the preparation process, and the woman should be given the opportunity for further explanation and consideration before making another appointment to have the screening test.

Capacity to consent for Cervical Screening

The following points should be considered when assessing a woman's capacity to consent to cervical screening:

1. Does the woman have a basic understanding of what cervical screening is, its purpose and why she has been invited? Has she seen a copy of the easy read leaflet?
2. Has she been invited for a routine cervical screen, or recalled for a follow up test after a previous one?
3. Does she understand that the test does not always find that something is wrong?
4. Does she understand that a positive test result will mean having more tests? *
5. Is she able to retain the information for long enough to make an effective decision?
6. Is she able to make a free choice (ie free from pressure from supporters or health professionals)?

Where there are concerns about capacity, this does not automatically mean a woman should be excluded from screening. No one, including carers, can give consent to a medical intervention on behalf of another adult. Capacity should always be determined on a decision specific basis. The Mental Capacity Act states that the presumption should be that an individual has capacity, and the professional should take reasonable steps to provide information and support a woman to make and communicate the decision herself. When it is felt that a woman lacks capacity, follow principles of the Mental Capacity Act to reach a best interest decision, including input from those who know her well e.g. GP, carer, family. Consider confidentiality issues when seeking the views of others. For medical treatment and examination it will be the responsibility of the clinician proposing and carrying out the treatment to ascertain capacity to make a decision regarding that specific procedure. All findings must be recorded in the medical notes.

**In some cases a woman may only be able to consent to one step of the screening pathway at a time. Therefore answering 'No' to this question should not necessarily preclude screening.*

Best interest decisions

If applicable a best interest meeting will need to take place with all relevant parties involved in the woman's care. This can be in person, by phone or via email if a face to face meeting is

not possible, a *Complex Decisions* form needs to be completed as a record of the meeting. This can be found within the Mental Capacity Act GP Toolkit see [Appendix 1](#) for link- The Mental Capacity Act (Capacity Assessment and Best Interest Documentation).

Completion of the form needs to:

- Be led by a clinician
- Be discussed with those involved in her care
- Document that the risk of cervical cancer has been discussed
- Acknowledge that if a woman may not have been sexually active, her risk may be reduced but it does not mean she is risk free
- Document any reasonable adjustments implemented to support the woman's understanding including use of easy read materials, discussions with the woman, desensitisation, etc
- Document any relevant history of successful or unsuccessful screening/gynaecological examinations and treatment – this can be helpful in considering likely compliance and potential for distress
- Document the decision reached, and detail what the least restrictive action is that will be taking e.g. attempt screening, do not attempt screening on this occasion & remain in recall
- Agreed and signed by all. A copy of the best interest meeting should be recorded into the patient notes.
- A decision to cease a woman from recall should only be taken if the best interest decision is unanimous and is the most appropriate and least restrictive option for her. [Appendix 2](#).

At the best interest meeting there should be discussion, agreement and a documented plan regarding appropriate actions, for example documenting any signs and symptoms of cervical cancer and/or any enhanced monitoring that can be carried out in the absence of cervical screening should it be decided that screening is not appropriate at that time. This will ensure heightened awareness is maintained and it is clear what process should be followed if symptoms of concern are identified. These signs and symptoms should then also be put into a health action plan that will be held by appropriate parties e.g. the woman, her family, carers, and the clinician, with a relevant review date agreed.

Further guidance on the Mental Capacity Act and links to the best interest forms can be found in [Appendix 1](#) - Further Guidance on the Mental Capacity Act.

Choosing to decline or defer Screening

Women with the capacity to consent who wish to decline or defer their cervical screening should be returned to standard recall by notifying PCSE. The woman should be made aware that she can decide to attend screening at any time during this recall interval and be screened. The best interest letter should **not** be completed in these circumstances.

Support from the Community Learning Disability Team

For many women with learning disability, sample takers can achieve successful screening through implementing reasonable adjustments. Support from a community learning disability nurse or health facilitator may be of additional benefit to some women. A learning disability nurse or health facilitator can have an important role in preparing a woman for having a cervical screening test and could work closely with the sample taker to ensure that women who attend for screening have an understanding of the screening process and how the test is taken.

The input available will vary according to individual need, and could range from specific advice for staff and carers, to more in depth work with an individual woman. Contact your local team for more information about the specific support and resources they may be able to provide – details in [Appendix 4](#) or [Appendix 5](#).

The screening appointment

Allow plenty of time for screening. Remind the patient of her right to have a chaperone during the appointment if she is not accompanied by a carer, and use appropriate communication to reassure her throughout the procedure. Behavioural cues should be observed, looking for indications that the woman is passively consenting, or that she is showing signs of distress. **A woman may withdraw her consent during the procedure; this could be verbal or behavioural. If a woman withdraws consent, stop the procedure immediately.** Where appropriate, discuss whether to arrange another attempt at screening, taking into account individual risk/history, and either arrange a further appointment or include in recall for three years' time. If screening does not take place and is to be postponed until next recall, it may be appropriate to provide carers with information about any changes in gynaecological health or symptoms of concern to be aware of. See [Appendix 1](#) for links to further information.

Results and further follow up

If screening is successful, explain what happens next – that the woman will receive a letter with her results within 2 weeks, and go over again any arrangements made at the pre-screening appointment about arranging to make an appointment to discuss the results. Provide the woman with a copy of the 'What happens after Cervical Screening' form for her to take away, see [Appendix 3](#). If they are referred to colposcopy the GP practice will need to notify the colposcopy coordinator that the woman has a learning disability and discuss any additional support that may be required such as a pre visit or any specific appointment requirements.

Follow up appointments may be needed depending on the result of the test. If the sample is reported as inadequate it will state a 3 month repeat test will be required and early discussion with colposcopy may be appropriate.

Colposcopy Appointment

In the event that a Colposcopy appointment is required the same considerations for the pre-screening and screening appointment should apply.

- Allow plenty of time for the appointment.
- Consider reasonable adjustments.
- Remind the patient of her right to have a chaperone during the appointment if she is not accompanied by a carer, and use appropriate communication to reassure her throughout the procedure.
- Behavioural cues should be observed, looking for indications that the woman is passively consenting, or that she is showing signs of distress.
- **A woman may withdraw her consent during the procedure; this could be verbal or behavioural.**
- **If a woman withdraws consent, stop the procedure immediately.**

Contact details of the Learning Disability Acute Hospital Liaison Nursing Service can be found in [Appendix 4](#).

Appendix 1

Useful Links Page

Easy read leaflet

<https://www.gov.uk/government/collections/cervical-screening-information-leaflets>

The smear test film by Jo's Trust

<http://www.jostrust.org.uk/videos/smear-test-film>

The Mental Capacity Act (Capacity Assessment and Best Interest Documentation)

<http://www.rcgp.org.uk/clinical-and-research/clinical-resources/-/media/Files/CIRC/CIRC-76-80/CIRC-Mental-Capacity-Act-Toolkit-2011.ashx>

Further Guidance on the Mental Capacity Act

<http://www.justice.gov.uk/guidance/protecting-the-vulnerable/mental-capacity-act/index.htm>

Cervical cancer symptom information

http://cancerawarenesstoolkit.com/assets/uploads/resources/Cervical_Cancer_Symptom_Sheet.pdf

Colposcopy and Programme Management Guidelines NHSCSP 20 3rd edition

<https://www.gov.uk/government/publications/cervical-screening-programme-and-colposcopy-management>

Appendix 2

Ceasing – Best Interest Letter to PCSE

Practice name
Address
Telephone/fax

[date]

Patient Name [insert woman's name]
Date of birth: {insert}
NHS number [insert]

The above named woman has been assessed not to have the capacity to understand and consent to cervical screening. After a best interest meeting conducted with invitation of all multidisciplinary team members involved in this woman's care, a unanimous decision was reached that it is not in this woman's best interest to undertake any further cervical screening. Please you could you cease this woman from the cervical screening recall register. A copy of the mental capacity and best interest decision has been placed in the patients notes.

I understand that this letter will be copied, one copy retained on file at PCSE Screening Department, one copy to be sent to the patient, and one returned to myself.

Yours sincerely

[insert name]
GP

Completed Letter to be returned to:-

Screening Manager, Primary Care Support England, PO Box 350, Darlington, DL1 9QN
Please note this letter may be updated and therefore the most recent letter should be used from the NHS website

What Happens After Cervical Screening?

Your name	
Date of your cervical screening	
Nurse who did your test	

You came to the practice for cervical screening today. This is sometimes called a smear test. This leaflet explains what happens now you have had your test.

	<p><u>A normal result</u> If your test result is normal you will get a letter telling you this. This means you will get asked to come for screening again in about 3 years time.</p>
	<p><u>Repeating the test</u> Sometimes a test has to be done again because the result is not clear. If your test has to be done again you will get a letter. The letter will tell you what you should do next.</p>
	<p><u>An abnormal result</u> If your test result is abnormal you will get a letter asking you to go for a special test called a colposcopy. A colposcopy means having a test to look more closely at your cervix. The letter will tell you what to do next.</p>

	<p>If you have any questions about the letter you get please ring the number on your letter. Or you can ask a practice nurse for more information.</p>
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Remember - you can speak to a practice nurse if you are ever worried about any changes with your periods or down below.

Photo Symbols images

Appendix 4

Learning Disability (Acute Hospital) Liaison Nurse – Sussex Locality Team Contacts

Brighton & Hove area

Contact by telephone on 01273 696955 ext 64975

Monday to Friday, normal office hours

West Sussex area

Contact via the Health Facilitation office 01403 227000 ext. 7341

Monday to Friday, normal office hours

East Sussex area

Contact by telephone on 01323 417400 ext. 4276 or 07876578366

Monday to Friday, normal office hours

Appendix 5

Health Facilitation - Contacts in Sussex (April 2016)

Health Facilitation as a role has been described in Valuing People (Dept of Health, 2001) and Valuing People Now (Dept of Health, 2009). Health Facilitation is seen as one of the ways to address the health inequalities experienced by the learning disability population.

It is defined at two levels – strategic health facilitation and one to one health facilitation. Strategic health facilitation focuses on the mainstream health services themselves, supporting services to develop and improve their provision for the learning disability population. One to one health facilitation is the support provided to an individual with a learning disability, to have their specific health needs met and managed.

Health Facilitators may be available in your area to fulfil the strategic functions, working with health services to improve the access and support they offer to people with a learning disability. Please be aware that the remit of the Health Facilitators may vary slightly in each area, so you will need to contact the lead for your area to discuss what they are able to offer in more detail. If you require support for an individual patient in relation to cervical screening, please see information on page 9/10 of the guidance 'Is support required from the Community Learning Disability Team' and proceed accordingly.

Brighton & Hove:

Natalie Winterton – Health Facilitator

Brighton & Hove Community Learning Disability Team

2nd floor West Wing, Bartholomew House, Bartholomew Square, Brighton, BN1 1JE

Tel: 01273 295550

E-mail: natalie.winterton@brighton-hove.gcsx.gov.uk

East Sussex:

No dedicated strategic health facilitation post at present – please contact your nearest community learning disability team for further information/advice. (April 2016)

West Sussex:

Corinne Nikolova

Clinical Service Manager - Learning Disabilities Health Facilitation

Sussex Community NHS Trust

Horsham Hospital

Hurst Rd

Horsham

West Sussex

Tel: 01403 227000 ext 7341

Mob: 07554334720

E-mail: corinne.nikolova@nhs.net

Community Learning Disability Teams

Brighton & Hove

Brighton & Hove Community Learning Disability Team
2nd floor West Wing Bartholomew House, Bartholomew Square, Brighton, BN1 1JE
Tel: 01273 295550

East Sussex

Eastbourne Downs & Weald -
Bellbrook Centre, Bell Lane, Uckfield, East Sussex, TN22 1QL
Tel: 01273 336555

Hastings & Rother -

Cavendish House, Breeds Place, Hastings, East Sussex, TN34 3AA
Tel: 01424 726551

West Sussex

Worthing - Integrated Team Coastal
Centenary House, Durrington Lane, Worthing, West Sussex, BN13 2QB
Tel: 0330 222 7778

Chichester - Integrated Team Western

Durban House, Durban Road, Bognor Regis, West Sussex, PO22 9RE
Tel: 0330 222 7888

Horsham - Integrated Team Northern

County Hall North, Chart Way, Horsham, West Sussex, RH12 1XH
Tel: 01403 229129 or 033 02228600

Public Health screening leads

Surrey & Sussex Screening & Immunisation Area Team,
Public Health England, York House, 18-20 Massetts Road, Horley, Surrey RH5 7DE

Dr Max Kammerling - Consultant in Public Health Medicine
Screening & Immunisation Lead
E-mail: m.kammerling@nhs.net
Direct Tel: via PA: 01293 778804, or 01138 254769

Jenni Thomas- Screening and Immunisation Manager
E-mail: jenni.thomas1@nhs.net
Tel: 01138 254694

Sarah Tomkinson – Screening & Immunisation Coordinator
E-mail: sarah.tomkinson@nhs.net
Tel: 01138 248122

Cervical Screening call recall

Generic email: PCSE.enquiries@nhs.net
Screening email: PCSE.screening-leeds@nhs.net
Phone: 0333 014 2884
Web: pcse.england.nhs.uk/
PO Box: Primary Care Support England, PO Box 350, Darlington, DL1 9QN

Health Promotion in Sussex

Brighton Health Promotion Library

The Library, Audrey Emerton Building, The Royal Sussex County Hospital, Eastern Road, Brighton, BN2 5BE

Tel: 01273 523300

Web: <http://www.bsuh.nhs.uk/work-and-learn/library-services/public-health/>

A full library service on health improvement and related topics – has a selection of resources available to borrow specifically targeted at the learning disability population.

West Sussex Health Promotion Resource Centre

North Walls

County Hall

Chichester

West Sussex

PO19 1RQ

Tel: 0330 22 28696

Web: https://www.westsussex.gov.uk/social-care-and-health/social-care-and-health-information-for-professionals/public-health-information-for-professionals/#order-health-promotion-resources_tab

The Resource Centre provides access to teaching materials, leaflets and posters on a variety of topics for different target groups

East Sussex Health Promotion Library & Resources

Please see the East Sussex County Council web site for information about the health promotion library, details of resources available to borrow, joining information and contact details:

<http://www.eastsussex.gov.uk/socialcare/providers/resources/healthpromotion/form.htm>

IMCA Service

Independent Mental Capacity Advocates

The Sussex-wide IMCA service is provided by POhWER:

Tel – 0300 456 2370

Fax – 0300 456 2365

Web: www.pohwer.net

E-mail: pohwer@pohwer.net

All referral paperwork can be downloaded direct from the web site.

Useful Web Sites

Books Beyond Words

<https://www.booksbeyondwords.co.uk/>

Series of books developed for use with people with a learning disability, including 'Keeping Healthy Down Below' & 'Looking After My Breasts'

Easy Health

<http://www.easyhealth.org.uk>

Provides over 500 accessible health leaflets and video clips. Most are free and can be downloaded and printed direct from website. Links to useful organisations. Provides easy read information on consent, going to health appointments including GP, dentist, hospital and how to take your medicine. Hospital / Care passport information.

Jo's Trust

This is a charity who are encouraging women to cervical screening. They offer a range of promotional material but have also made video's which are accessible on their website. 'The Smear Test' film - <http://www.jostrust.org.uk/about-cervical-cancer/cervical-screening-smear-test-and-abnormal-cells/women-learning-disabilities>

The Elfrida Society

<http://www.elfrida.com/index.html>

Charity based in London – has developed a range of health & health related leaflets. Cost of publications detailed on web site.

National Health Service Cancer Screening Programme

<http://www.cancerscreening.nhs.uk/>

Information about the breast, bowel and cervical cancer screening programmes and the prostate cancer risk management programme.

FAIR

<http://www.fairadvice.org.uk/health-publications.php>

An organisation that produces a range of booklets, interactive CD-ROMs on healthy living, including cervical screening (costs detailed on web site)

MacMillan Cancer Support

<http://www.macmillan.org.uk/information-and-support/resources-and-publications/other-formats/easy-read.html>

A series of easy read books and leaflets about cancer prevention, screening, investigations, diagnosis, treatment, end of life, bereavement. Three easy read books for people with a learning disability and three equivalent versions for carers/support staff. These books and the leaflets are free resources.

GMC - Learning Disabilities site

<http://www.gmc-uk.org/learningdisabilities/default.aspx>

Interactive online learning identifying the issues related to treating patients with a learning disability including consent

RCGP - Learning Disability Resources

<http://www.rcgp.org.uk/clinical-and-research/clinical-resources/learning-disabilities.aspx>

Information for General Practitioners on caring for people with a learning disability – includes Mental Capacity Act Toolkit

RCN - Learning Disability section

http://www.rcn.org.uk/development/practice/social_inclusion/learning_disabilities

Information for nurses on caring for people with a learning disability – includes good practices examples, links to guidance and policy

Surrey Health Action

<http://www.surreyhealthaction.org>

Provides easy read information on a wide range of health issues.

Free access to easy read letter templates for health service's including GP, dentist and hospital appointments . Health Action Planning templates. Annual Health Check information and Health Check tools. Information on local Community Teams for People with Learning Disabilities.

Royal college of general practitioners

<http://www.rcgp.org.uk>

These resources are designed to support GPs and the primary healthcare team to care for people with a learning disability and to encourage equal access to healthcare.

Access to the step by step guide for GP practices. Annual Health Checks for people with a learning disability. Access to further training in learning disability awareness and health issues. Provides Mental Capacity Act toolkit for GP's and primary care staff.

Improving Health and Lives

<http://www.improvinghealthandlives.org.uk>

IHAL (Improving Health And Lives) website was created following several reports into the failings in meeting the healthcare needs of people with learning disabilities. The website includes Further information on reasonable adjustments

Links to relevant reports into the healthcare for people with learning disabilities.