VULVAL LICHEN SCLEROSUS: COMMUNITY CARE

Lichen sclerosus (LS)

Your patient has vulval and/or perianal LS. This chronic condition is associated with a 3.5-5% risk of malignant change (Vulval SCC). We recommend that, following treatment, patients are followed annually for signs of early malignant change. We encourage women to self-examine and report any changes. Patients are given written information on vulval self-examination.

For most patients we now advocate maintenance treatment long term with once or twice weekly steroid (usually Dermovate or Elocon ointments). We also advise long term use of emollients/soap substitutes such as Cetraben, Hydromol or Doublebase (Aqueous cream no longer recommended). Please see our discharge letter for individual recommendations.

Community care is suitable for women with well controlled disease (requiring less than 30g Dermovate ointment or equivalent in any 6 month period), those who find travel to a hospital clinic difficult or for those who express a preference for GP care. We propose that follow-up care should be carried out by the GP annually. In case your experience with this disease is limited we have produced this advice sheet. Please contact us if you have any concerns or questions.

Vulval appearances and symptoms to expect in LS

- Remember that many patients are post-menopausal and may need local oestrogen, particularly if they are experiencing dyspareunia, dryness or urinary frequency
- The disease can present either as a localised patchy problem, or involvement can be extensive affecting the entire vulva/perineum, typically extending to the perianal area.
- Plaques are usually white and generally thin and atrophic. Asymptomatic white changes do not necessarily require treatment, and these skin changes may not resolve with treatment.
- Purpura and haemorrhage are common features and may indicate active disease.
- Architectural change is common. Features include: anterior or posterior midline labial fusion with a contracted introitus, burying of the clitoral hood, and resorption of the labia minora.
- Fissures are common, but must be seen to heal within 3 weeks of daily potent topical steroid use (see below).
- Secondary infection with candida (which may be clinically atypical) and bacteria may cause worsening of symptoms. Please do a vulval swab and treat as appropriate.

What to look for

- Erosions, hyperkeratotic or fissured areas which do not respond to Dermovate ointment once daily for three weeks should be referred urgently for review at the vulval clinic.
- Nodule formation is a very suspicious sign and needs urgent referral. If a tumour is strongly suspected urgent referral via the 2 week wait to gynaecology/oncology is advised to avoid a delay in treatment.
- If LS is more active ie increased symptoms, pallor and purpura, then treat for 4-6 weeks with daily Dermovate and then restart maintenance treatment.
- LS is associated with other autoimmune diseases such as thyroid disease and pernicious anaemia. Please remain vigilant.
- Lubricants eg Astroglide, Sylk or Yes (oil-based may be more comfortable but should not be used with condoms) may be needed for intercourse. We recommend Amielle Comfort vaginal dilators when there is narrowing of the vaginal entrance that is causing symptoms such as dyspareunia.
- Please re-refer to Dermatology (or Uro-Gynaecology) if there is progressive, symptomatic narrowing of the vaginal introitus that is causing dyspareunia or altered urinary stream
- Vulvodynia and psychosexual issues may occur. The vulval clinic is able to advise on most cases of vulvodynia; referral to the pelvic pain clinic may also be appropriate

Original document

- Dr Susan Cooper Staff, Consultant Dermatologist
- Nurse Bernadette Miles-Marsh, Vulval Nurse Practitioner

Revisions

- Dr Rachael Jarrett
- Dr Stephanie Arnold
- Dr Inge Kreuser-Genis