PATIENT INFORMATION LEAFLET

PORT WINE STAINS



WHAT ARE THE AIMS OF THIS LEAFLET?

This leaflet has been written to help you understand more about port wine stains. It tells you what this condition is, what causes it, what can be done about it, and where you can find out more about it.

WHAT IS A PORT WINE STAIN?

A port wine stain is a 'vascular birthmark' caused by abnormal development of the tiny blood vessels (called capillaries) under the skin. This results in a red or purple mark, often referred to as the colour of port wine. Although most port wine stains are present at birth, in a few cases that these have developed later in life ('acquired port wine stain').

WHAT CAUSES PORT WINE STAINS?

The change in the blood vessels is caused by a mutation (change in a gene) occurring early in pregnancy while the baby is developing in the womb. This change in the gene is not inherited (passed on from one generation to the next) and is not known to be related to anything that happened during pregnancy.

Acquired port wine stains are rare, but may appear without a known cause, as part of an illness or in previously inflamed or injured skin.

ARE PORT WINE STAINS HEREDITARY?

Port wine stains do not often run in families; however, they are relatively common, affecting about 1 in 300 babies and both genders equally. Port wine stains are not contagious or cancerous.

WHAT DO PORT WINE STAINS FEEL AND LOOK LIKE?

Port wine stains vary in size, some are small, while others can be quite large.

Uncomplicated port wine stains do not usually cause any physical symptoms. However, their appearance may impact the quality of life of the affected individual and their family.

Eczema can develop over a port wine stain, which may then become itchy or sore.

Port wine stains can appear anywhere on the body. Commonly (in about 65 out of 100 people)port wine stains are found on the head and the neck.

- Rarely a port wine stains may lead to complications such as glaucoma (increased pressure in the eye). In such cases, a referral to an eye-specialist may be required.
- In other rare cases, port wine stains are observed as part systemic syndromes, for example:
 - A port wine stain on the upper face or scalp can be linked to abnormalities within the brain (called Sturge-Weber syndrome). This can be investigated by neurology specialists.
 - A port wine stain on the central back overlying the spine can be linked to an underlying spine defect called spina bifida (Latin for 'split spine').
 - Klippel-Trenaunay syndrome occurs when there is enlargement of the limb affected by the port wine stain, which may also develop



enlarged deeper varicose-type veins.

The appearance of a port wine stain tends to change during the course of life. A flat faint red, purple or pink mark is usually seen at birth, which may become temporarily darker when the baby cries, has a temperature or is teething. Although the port wine stain usually does not get any larger, it does grow in proportion with the child.

Port wine stains often turn darker red or purple in adults and the skin becomes thicker. Lumps can form (a cobblestone-like appearance), which may bleed readily. The lip or nose, if involved, may in some people become slightly swollen.

Generally, port wine stains tend not to cross over the midline. This means that a port-wine stain can be found on either the left or right side of the body, but they can occasionally be found on both sides.

HOW IS A PORT WINE STAIN DIAGNOSED?

A dermatologist can diagnose port wine stain by taking a history about the skin changes and looking at the appearance of the skin.

However, when there is uncertainty about the diagnosis or whether underlying tissues may be affected, an ultrasound scan may be performed.

CAN PORT WINE STAINS BE CURED?

Port wine stains do not go away on their own because they are permanent birthmarks. However, with treatment they may become far less noticeable.

HOW CAN A PORT WINE STAIN BE TREATED?

Treatment of port wine stains depends on their location and size.

Various lasers are in use for treatment of port wine stains and may be available on the NHS. Early treatment is possibly more effective, as the baby's skin is thinner, and the port wine stain may be smaller.

Laser treatment is a safe and effective method for fading port wine stain birthmarks by shrinking and closing the blood vessels, making them significantly less noticeable. However, even after successful early treatment, any remaining areas of port wine stain may darken again later in life.

The Pulsed Dye Laser is the most commonly used laser. It emits a beam of special light, which reacts with the red colour in blood. Adults do not usually require an anaesthetic, apart from cooling the skin. Children may need a general anaesthetic due to discomfort when laser is applied to the skin, but also because they must stay still throughout a treatment. The treatment causes immediate dark bruising, and the skin will be more sensitive to rubbing. Other possible temporary side effects include blistering and crusting. Scarring is rare. A course of laser treatment is usually required, with a few months between repeated treatments. The aim of treatment is to make the port wine stain paler, as it is often not possible to make it fade completely. If the port wine stain has developed bleeding areas, these can be successfully treated by laser.

If the area affected is on the face or hands, a high-factor sunscreen will need to be applied to the area being treated throughout the entire course of treatment. The specialist carrying out the laser treatment will provide guidance on skin care.

NHS funding for laser treatment may vary by area and age. Patients with large facial port wine stains may be considered for exceptional funding, and children with large facial birthmarks are typically funded. A dermatologist will be able to inform you further on what treatments are available in your local area.

Skin camouflage is a type of specialised, waterresistant makeup that can conceal various skin conditions, including scars, birthmarks, vitiligo, tattoos and others. You can get a prescription for a special type of camouflage makeup that covers up the birthmark. Typically, the product is formulated to match your skin tone closely. The charity 'Changing Faces' may offer camouflage advice in your area (see below for further information).

WHERE CAN I GET MORE INFORMATION ABOUT PORT WINE STAINS?

Patient support groups providing information:

Birthmark Support Group

Tel: 07825 855 888

Email: info@birthmarksupportgroup.org.ukW eb: www.birthmarksupportgroup.org.uk/

Changing Faces

Email: info@changingfaces.org.uk Web: www.changingfaces.org.uk

Web links to other relevant sources:

www.dermnetnz.org/vascular/vascular-malformation.html

patient.info/doctor/port-wine-stain-pro

Jargon Buster:

www.skinhealthinfo.org.uk/support-resources/jargon-buster/

Please note that the British Association of Dermatologists (BAD) provides web links to additional resources to help people access a range of information about their treatment or skin condition. The views expressed in these external resources may not be shared by the BAD or its members. The BAD has no control of and does not endorse the content of external links This leaflet aims to provide accurate information about the subject and is a consensus of the views held by representatives of the British Association of Dermatologists: individual patient circumstances may differ, which might alter both the advice and course of therapy given to you by your doctor.

This leaflet has been assessed for readability by the British Association of Dermatologists' Patient Information Lay Review Panel

BRITISH ASSOCIATION OF DERMATOLOGISTS

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