



# Dermatofibrosarcoma Protuberans (DFSP)

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## What is this booklet about?

This booklet is designed to give you information about dermatofibrosarcoma protuberans and how it may be treated. We hope it will answer some of the questions that you or those who care for you may have. It is not meant to replace the discussion between you and your doctor but helps you to understand more about what is discussed.

If you have further questions please contact your Clinical Nurse Specialist (CNS). You should have been given the details of your CNS but if not, please ask your doctor's secretary to provide them.

## What is dermatofibrosarcoma protuberans (DFSP)?

DFSP is a rare type of cancer that occurs in the skin. It develops in the dermis, which is our second layer of skin. The exact cause of it is unknown.

## How common is DFSP?

DFSP is a rare type of cancer. For every one million people, about five to eight will develop DFSP. It most commonly affects people in their 20s, 30s, and 40s. Men and women are equally affected.

While this type of skin cancer tends to grow slowly, it may sometimes be aggressive. DFSP may grow deeply into the skin and may grow into the fat, muscle, and bone. However, DFSP rarely spreads to other parts of the body. This gives DFSP a very high survival rate.

As it is a rare cancer, local hospitals will send affected patients to a specialist centre that has knowledge and expertise in treating and managing DFSP. Queen Elizabeth Hospital Birmingham is one such specialist centre.

## What are the signs and symptoms?

DFSP causes reddish brown or skin-coloured growths in the skin that eventually grow into bulging masses that may become tender and bleed. However, in many cases, there is no sign of discomfort or pain. The most common location is the trunk, but other parts of the body can be affected. Whilst DFSP rarely spreads to other parts of the body it may frequently return in the original site if not treated appropriately.

## How is DFSP diagnosed?

To test a patient for DFSP, the doctor takes a small sample of the affected skin, called a biopsy, and sends it to a laboratory for study under a microscope. This is the only way to confirm the diagnosis.

## How is DFSP treated?

Treatment is important as DFSP can grow deeply into the skin. Standard treatment is surgery. A process called Moh's micrographic surgery (also known as Moh's) is used. As each layer of tissue is removed it is examined under a microscope until all cancerous tissue has been removed. This provides the most accurate method of ensuring all cancer cells have been removed and reducing the chances of the cancer returning. You will be given a separate information sheet about this type of surgery.

For the majority of people treated with Moh's surgery they will have no further problems. However, in the rare cases where DFSP is not treated with Moh's surgery, it may spread to other parts of the body and it may be fatal.

## What happens after surgery?

You will be asked to attend follow up appointments within the Dermatology Department every six months for three years after your surgery, however it is important to know that most people treated with Moh's surgery will have no further problems. This appointment will usually be at the Queen Elizabeth Hospital Birmingham.

## What are the alternatives?

Your doctor will discuss any alternative options with you.

## The role of your CNS

Your CNS (sometimes called a key worker) is an experienced skin oncology nurse who works with the other members of the team to provide specialist medical and psychological care to people with DFSP and their families.

The role of your CNS is to co-ordinate any investigations, treatment and follow-up care during your cancer journey. She/he is there to clarify any information, discuss matters that are important to you, provide emotional support and refer to other professionals if required. It is very important that you are able to have your questions answered and concerns discussed and your CNS will make every effort to ensure this.

You will be given a contact telephone number for the CNS so that you are able to contact her/him, should you have any worries or need further information when at home.

**It may help to write down questions as you think of them so that you have them ready. It may also help to bring someone with you when you attend your outpatient appointments.**

## Local sources of further information:

You can visit any of the health/cancer information centres listed below:

### University Hospitals Birmingham NHS Foundation Trust

1. The Patrick Room, Cancer Centre Heritage Building, Queen Elizabeth Hospital, Birmingham B15 2TH  
Tel: 0121 371 3539 / 3537

2. Health Information Centre Birmingham Heartlands Hospital Bordesley Green Birmingham, B9 5SS  
Tel: 0121 424 2280

3. Patient Information Centre Good Hope Hospital, Rectory Road Sutton Coldfield, B75 7RR  
Tel: 0121 424 9946

### Sandwell and West Birmingham Hospitals NHS Trust

The Courtyard Centre, Sandwell General Hospital (Main Reception) Lyndon, West Bromwich, B71 4HJ  
Tel: 0121 507 3792

Walsall PACT (Patient Advisory Cancer Team)  
Tel: 0800 783 9050

## About this information

This guide is provided for general information only and is not a substitute for professional medical advice. Every effort is taken to ensure that this information is accurate and consistent with current knowledge and practice at the time of publication. We are constantly striving to improve the quality of our information. If you have a suggestion about how this information can be improved, please contact us via our website.

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**Dermatology**  
**Queen Elizabeth Hospital Birmingham**  
Mindelsohn Way, Edgbaston, Birmingham B15 2GW  
Telephone: 0121 627 2000

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