

Dermatofibrosarcoma protuberans (DFSP)

Signs and symptoms, treatment information and support

A Sarcoma UK Factsheet
produced by
the information
and support team

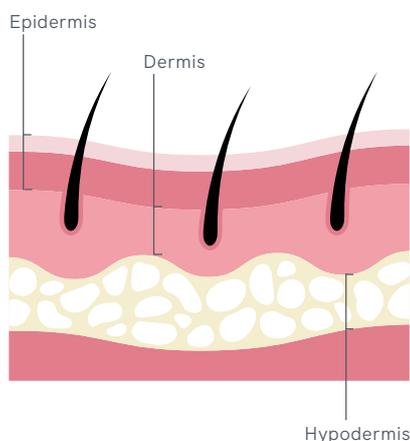
DFSP is a rare cancer found in the middle layer of the skin, called the dermis.



What is DFSP?

DFSP is most commonly found on the torso, but it can also appear on the arms, legs, head and neck. DFSP can affect people of all ages but it is most common in people between the ages of 20 and 50.

DFSP tends to grow slowly and only rarely spreads to other parts of the body. However, it is important to get correct treatment as soon as possible. Without correct treatment, DFSP can grow deep into the fat, muscle, and even bone making it more difficult to treat.



Signs and symptoms

DFSP can appear as:

- a slow growing, painless lump under the skin
- a scar or a deep seated pimple
- a lump with the skin over it feeling soft and indented
- pink to brown in colour and sometimes may appear in shades of purple

If DFSP is left for several years the DFSP can grow through the top layer of skin and develop into an ulcer.



Who will treat me?

People with DFSP should be referred to a specialist sarcoma multidisciplinary team (MDT) for diagnosis and treatment. An MDT is a group of experts from a wide range of health care professions who will work together to manage your case. Your MDT will include your key worker or clinical nurse specialist, surgeon and other healthcare professionals involved in your care. Your MDT will support you to ensure you get the right treatment.

People with DFSP can benefit from the expertise of skin cancer specialists and plastic surgeons. They can offer specialised treatments such as Mohs surgery to treat DFSP. There should be a formal relationship between the skin cancer

MDT and the sarcoma MDT to make sure to make sure your treatment is provided by clinicians with appropriate skills and experience.



What treatment is available?

Surgery

In most cases, surgery is used to treat DFSP. The surgeon will remove the tumour and will aim to take out an area of normal tissue around it too. This is known as taking a surgical margin. It allows any cancer cells that are not visible to the naked eye to be removed along with the tumour. This can reduce the risk of the cancer coming back.

Rarely there is a risk that taking a wide margin will cause significant cosmetic changes or affect how a part of the body works. In these cases the surgeon will not remove a margin of healthy tissue and a surgical technique called Mohs surgery is used.

Mohs surgery can be carried out by a surgeon who is part of a skin cancer MDT. It involves removing thin layers of cancerous skin one at a time. These layers are then examined for signs of cancer. The surgeon will continue to remove layers of skin until only cancer free skin remains. The aim of Mohs surgery is to remove the DFSP while doing minimum damage to the healthy tissue around it. It is often done under local anaesthetic so you can usually go home the same day.



Treatment in rarer cases

If DFSP cannot be removed safely through surgery then radiotherapy and chemotherapy can be used.

Radiotherapy

This treatment uses high-energy radiation beams to destroy cancer cells. Radiotherapy is used to treat DFSP that cannot be removed through surgery. Radiotherapy can also be used after surgery, to kill off any local cancer cells which remain in the area of the tumour.

Chemotherapy

This treatment uses anti-cancer drugs to destroy cancer cells. A drug called imatinib is sometimes used to treat people with DFSP that cannot be removed through surgery, or in rare cases where it has spread to another part of the body. Imatinib comes in the form of a tablet that you swallow with water after food. You may experience side effects such as tiredness and feeling sick. Your sarcoma clinical nurse specialist can help you manage your symptoms.



What happens after I have had my treatment?

After treatment, you will have regular follow-up appointments for several years. You should receive a follow-up schedule from your sarcoma clinical nurse specialist. The usual practice will include:

- A chance to discuss symptoms
- A physical examination to look for any signs of DFSP returning
- A chest x-ray to look out for any secondary cancers in the lungs

The majority of people recover well from DFSP.



What if my cancer comes back?

DFSP can sometimes come back in the same area where a previous tumour has been removed. This is called a recurrence. If DFSP does reappear, it is important to get treatment as quickly as possible. This could involve further surgery or radiotherapy. Your treatment will be assessed on an individual basis.

It is useful to check for recurrences yourself through self-examination. If you are worried about your DFSP returning contact your doctor or clinical nurse specialist. They may decide to bring forward the date of your follow up appointment to investigate your concerns.



What if my cancer spreads to another part of my body?

It is very rare for DFSP to spread to another part of the body. Treatment may involve surgery, radiotherapy or chemotherapy. This will be assessed on an individual basis.



What support is available?

Your feelings

There is no right or wrong way to feel or react to a diagnosis of DFSP. You may feel angry, sad or anxious about the future. You may also have concerns about how the news will affect your loved ones. You may find comfort in talking through your concerns with family members or friends.

Talking to us

Our Support Line offers practical and emotional support and advice to anyone affected by sarcoma.

- Our support line is independent and confidential
- We believe no question is a silly question
- We lend a listening ear
- We can point you in the right direction

You may also find it helpful to talk to your clinical nurse specialist or doctor about your diagnosis; they will be able to answer any questions you may have about your condition. They may also be able to put you in touch with a counsellor for additional support, providing you with a safe, confidential place to talk about your concerns. Your GP will have access to local counselling services who can provide support to people with cancer.

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