

CUTANEOUS NEUROFIBROMAS IN NF1



**Tumour
Foundation
of BC**

What are neurofibromas and cutaneous neurofibromas?

A **neurofibroma** is a non-cancerous (benign) tumour that grows on nerves. This growth is made up of nerve tissue, along with blood vessels and other types of cells. When a neurofibroma grows on the nerves in the skin, it is referred to as a cutaneous neurofibroma or a subcutaneous neurofibroma if it is under the skin.

What are Cutaneous Neurofibromas?

Cutaneous and subcutaneous neurofibromas, also called **dermal neurofibromas**, are the most common types of neurofibromas in NF1. They can appear as rubbery lumps on the skin, or as bumps that you can feel just below the surface of the skin. The number of fibromas that someone with NF1 has varies from person to person and can also change as a person ages. Some people may only have a few neurofibromas while others may have hundreds. These neurofibromas are not expected to become cancerous and do not usually cause severe medical problems. Sometimes they can cause discomfort, such as mild pain or itchiness, and they may occasionally bleed.

What is a Plexiform Neurofibroma?

A **plexiform neurofibroma** can occur anywhere in the body and can affect a network of nerves that serve a specific area of the body. These rare tumours can also affect muscles and connective tissues. When these tumours grow near the skin, they can become large enough to cause a deformity (a change in the normal shape of the tissue). Most plexiform neurofibromas do not cause any serious medical problems. However, if they grow very large, they can put pressure on nerves and organs, leading to pain or weakness. Plexiform neurofibromas have the potential to become cancerous and should be monitored by a doctor regularly.

Patient with cutaneous neurofibromas on arm



Patient with plexiform neurofibroma on face



TAKING CARE OF YOUR SKIN WITH CUTANEOUS NEUROFIBROMAS:

It is important to keep the skin as healthy as possible, as good skin care can decrease inflammation, itching and pain.

1. **Avoid using wash cloths or irritating skin care products, such as exfoliators.**
2. **Use fragrance-free gentle soap.**
3. **Moisturize the skin daily with thick ointments or creams that are fragrance free. Examples: Aveeno, Dove sensitive skin, CeraVe.**
4. **Use sun protection daily, such as broad spectrum SPF sunscreen and longer clothing.**
5. **For itchiness not relieved by gentle skin care alone, please consult with your doctor for possible topical or oral medications.**

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MANAGEMENT OF CUTANEOUS NEUROFIBROMAS:

Cutaneous neurofibromas are non-cancerous and do not need to be treated unless they are painful, significantly itchy, interfere with daily living, or negatively affecting your self-image.

TREATMENT OPTIONS FOR CUTANEOUS NEUROFIBROMAS:

SURGERY

This is the most used treatment option for the removal of large tumours (greater than 4 cm). Surgery will require recovery time, the use of sutures, and the need for close monitoring for signs and symptoms of infection. Anaesthesia will be required.

LASER

This option is most used for removing smaller tumour (less than 2 cm each), as multiple bumps can be removed at once and recovery is quick. This procedure could result in scarring.

ELECTRODESSICATION

With this procedure, an electrical current is applied to the neurofibromas through a needle point tip. This procedure is less invasive than the surgical removal methods, and it allows the specialist to treat large numbers of neurofibromas at a single time. This option is for the removal of multiple tiny bumps, over 100 bumps can be removed, usually less than 5mm in size each. This can result in scarring as well.

If you would like to pursue treatment for your cutaneous fibromas, please book an appointment with your health care provider to be referred to a physician that has experience with NF (such as a plastic surgeon or surgical dermatologist), or ask for a referral to the NF Virtual Clinic provided by the Tumour Foundation of BC.

Please note: In British Columbia, unless the cutaneous fibromas are causing pain you may be responsible for the cost of removal.

Presently there are no proven methods to prevent neurofibromas from occurring, however, exciting new research is underway for developing new medications and treatment options for treating NF1 cutaneous fibromas.

Self-Monitoring Cutaneous Neurofibromas

Cutaneous neurofibromas are non-cancerous, do not cause serious health issues, and are slow-growing. Taking photos of your skin can help you easily track changes and identify new growths.

However, if you experience a rapidly growing fibroma, or a lump that is changing in texture or shape, or one that becomes painful, it is important to seek medical attention from your physician or health care provider right away.

REMEMBER TO GET **HELP** FROM YOUR DOCTOR IF YOU HAVE THE FOLLOWING SYMPTOMS:

Hard texture of the tumour

Enlarging rapidly

Limb weakness, numbness, clumsiness

Persistent or night time pain

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