

SELF-MONITORING FOR MALIGNANCY IN NF1 TUMOURS



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Most tumours associated with NF1 are benign (non-cancerous) skin tumours, which grow slowly over time and do not become malignant (cancerous).

Neurofibromas are the most common type of tumour associated with NF1. The two major types of neurofibromas are:

Dermal neurofibromas which are small, harmless growths, that appear on the skin. They can be painful, itchy, or tender when touched, but they have little to no potential of becoming cancerous.

Plexiform neurofibromas are larger tumours that develop inside the body and can wrap around nerves, blood vessels and other structures. They can be deep inside the body or close to the surface of the skin. Plexiform neurofibromas can cause pain, numbness, weakness, disfigurement, or no symptoms at all. However, these tumours do have a small chance of becoming malignant

If your plexiform neurofibroma is increasingly painful or rapidly grows (significantly more than its normal growth pattern), or new neurological symptoms occur, you should see the doctor as soon as possible.

What is malignancy and how does it relate to NF?

The word “malignancy” describes the presence of cancerous cells that can spread to other parts of the body (metastasize) or destroy tissues. Malignant cells can grow rapidly and out of control.

Malignant Peripheral Nerve Sheath Tumours

Malignant peripheral nerve sheath tumours (MPNST) are a rare type of tumour associated with NF1 that usually develops from a plexiform neurofibroma. This cancer grows in the soft tissues of the body, such as muscle, fat, ligaments, blood vessels, or nerves. MPNST can grow quickly and may spread to other parts of the body. Some people with MPNST do not have symptoms at first. Later, when the tumor gets larger, symptoms can include pain or weakness.

What Signs and Symptoms Should I Watch For?

Changes or worsening of pain and rapid growth characteristics in a pre-existing tumour are usually the first sign of malignancy and should be reported to your doctor immediately.

OTHER SIGNS AND SYMPTOMS TO WATCH FOR:

- the tumour developing a harder texture or exterior
- new neurological symptoms such as weakness, numbness, tingling
- bowel or bladder problems
- weight loss or night sweats
- Swallowing difficulty
- Breathing issues
- new symptoms coming from any affected organ

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

Malignant peripheral nerve sheath tumours are rare, so your doctor may investigate more common causes for your symptoms first.

If you have any persistent symptoms that worry you, contact your doctor. Remember that early detection of cancer improves outcomes.

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