Malignant Peripheral Nerve Sheath Tumour (MPNST)
Information for patients
What is a malignant peripheral nerve sheath tumour (MPNST)?

A malignant peripheral nerve sheath tumour (MPNST) is a rare malignant (cancerous) tumour which can develop in the protective linings (nerve sheaths) of the nerves in the body. It can arise in any part of the body, but is most common in the arms, legs and trunk.

Malignant peripheral nerve sheath tumour can cause pain and weakness in the affected area and can also appear as a lump. It can occur in any age group but is most common between the ages of 20 to 50.

Diagnosis

We will confirm your diagnosis once we have carried out ultrasound and MRI scans (imaging) and we have the histology (results) from the biopsy taken from the tumour, if this is needed. The MPNST will also be ‘graded’, depending on how fast it is growing and how likely it is to spread to other parts of the body.

As with all cancers, malignant peripheral nerve sheath tumours can spread (metastasise) to other parts of the body. We will check for this very quickly after your diagnosis by taking CT or PET CT scans. This type of tumour can spread to the lungs, so we will closely monitor your chest with X-rays at each clinic appointment during your follow-up. We may also take further CT scans if we feel these are needed.
Treatment options

The usual treatment for MPNST is surgery to remove the tumour. Chemotherapy can be used in certain situations and we will discuss this with you if we feel it is a suitable option. We will decide on the best treatment for you depending on a number of factors. These include:

• the position, size and grade of the tumour
• whether it has spread to other parts of your body
• your general health and wellbeing.

Follow-up

Once the tumour has been removed, you will remain under the care of the sarcoma team for your follow-up. This will include clinic appointments at the following times:

• once every 3 months from surgery, until 2 years after your surgery
• once every 6 months between years 2-5 after your surgery
• once a year between years 5-10 after your surgery.

Further information

Macmillan: Types of soft tissue sarcoma
http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Softtissuesarcomas/Aboutsofttissuesarcomas/Typesofsofttissuesarcoma.aspx

Sarcoma UK: What is sarcoma?
http://sarcoma.org.uk/what-is-sarcoma

Cancer Research UK: Types of soft tissue sarcoma
http://www.cancerresearchuk.org/about-cancer/type/sarcoma/about/types-of-soft-tissue-sarcomas#lipo
If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call 01865 221 473 or email PALSJR@ouh.nhs.uk

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OMI 12240P