

Macmillan Clinical Nurse Specialist Service for Brain & Central Nervous System Tumours

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This patient information is aimed at offering support for you and your relatives from the time you are first diagnosed.

How the service will help you:

- Provide ongoing advice and information.
- Give advice and information about radiotherapy, chemotherapy and any side effects.
- Give advice regarding seizures, steroids, fatigue, travel, wig information, financial concerns etc.
- Work closely with other healthcare professionals involved in your care and refer you to their services when required.
- Provide continuing support for you and your family during and after treatment acting as your key worker.

Key worker

Your key worker will be your main point of contact, giving support during and after your treatment.

If at any point a member of your local community team is more appropriate to be your key worker, then we can discuss this together.

It is not unusual for your key worker to change during your care pathway.

Your GP, District Nurse or Community Macmillan Nurse may be your key worker in the future.

Contact information

Macmillan Clinical Nurse Specialist for Neuro-Oncology and Sarcoma

Monday, Tuesday and Friday, 7.45am to 3.45pm (excluding bank holidays)

The Clinical Nurse Specialist covers all of the hospitals in the Lincolnshire area and is based at Lincoln County Hospital.

Telephone: 01522 572313

There is an answer-phone service where messages are checked daily. All messages will be returned though this may not always be on the same day.

Please always leave your name and contact telephone number.

If urgent advice is required please contact your GP.

Multi-disciplinary Team (MDT)

During your treatment and on follow-up your surveillance/interval scans may be discussed at the Neuro-Oncology MDT meetings.

The local team consists of:

Two Clinical Oncologists

Macmillan Neuro-Oncology Clinical Nurse Specialist

Cancer Care Co-ordinator

Frequently asked questions

Q: What is the procedure for me being able to drive?

A: This is dependent on your diagnosis and treatment. The DVLA must be informed immediately of your diagnosis and treatment you will be receiving. You may wish to cancel your car insurance temporarily.

Q: Can I drink alcohol?

A: Yes, in moderation, although if you are having seizures alcohol can induce them or have a sedating affect. You may be advised not to.

Q: Am I able to travel/go on holiday?

A: There are specialist companies who will provide insurance cover. You must NOT fly up to 6 weeks after surgery.

Useful Contacts

www.braintumour.org.uk Tel: 0845 4500 386

Macmillan Cancer Information + Support Centre, Lincoln County Hospital

Tel: 01522 573799

The Brain Tumour Foundation 'Ready Buddy Go'

Tel: 020 8336 2020. This is a support network with somebody in a similar situation.

www.epilepsy.org.uk - Seizure support

www.willowfoundation.co.uk - Special days out for patients and their families

www.honeyrosefoundation.co.uk

United Lincolnshire Hospitals NHS Trust has worked with AccessAble to create detailed Access Guides to facilities, wards and departments at our sites. www.accessable.co.uk/united-lincolnshire-hospitals-nhs-trust

United Lincolnshire Hospitals NHS Trust endeavours to ensure that the information given here is accurate and impartial.

If you require this information in another language, large print, audio (CD or tape) or braille, please email the Patient Information team at patient.information@ulh.nhs.uk