

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 and advice for patients

Macmillan Clinical Nurse Specialist (Neuro-Oncology)

- **Hours:** Monday to Friday, 8.00am to 4.00pm (except bank holidays)
- The Clinical Nurse Specialist (CNS) service covers all hospitals across Lincolnshire and is based at Lincoln County Hospital
- **Telephone:** 01522 572313

An answerphone service is available, and messages are checked daily. All calls will be returned; however, this may not always be on the same day. Patients are reminded to clearly leave their name and contact telephone number when leaving a message.

If patients require advice and have left a message for the specialist nurse but have not yet received a response, they may wish to contact their GP in the meantime.

Urgent Advice and Oncology Support (Patients on Treatment)

Patients currently receiving treatment who require urgent advice or assessment should use the following contact details, depending on the time of day:

Oncology Assessment Unit

- **Telephone:** 01522 307841
- **Hours:** Monday to Friday, 8.00am to 6.00pm

Waddington Ward (Out of Hours Support and bank holidays)

- **When:** After 6.00pm on weekdays and throughout weekends
- **Telephone:**
 - 01522 572255
 - 01522 307199
 - 01522 307198

The Bostonian, Pilgrim Hospital (Boston)

- **Telephone:** 01205 446148

Patients Not Currently Receiving Treatment

Patients who are not currently receiving treatment and require medical advice should contact their GP as the first point of care.

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 effect. 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

Lincolnshire Brain Tumour Support Group: 07341467109

Website; www.lbtsg.co.uk

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

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If you require this information in another language or alternative format, please email the Patient Information team at ulth.patient.information@nhs.net