

Your Mesothelioma Key Worker

Cancer Services

Information for patients

Produced: Jan 2024

Review: Jan 2027

Leaflet number: 544 Version:8

Introduction

You have been given this leaflet because you or a close relative has been diagnosed with mesothelioma. It explains the role of the Leicester-based Mesothelioma Clinical Nurse Specialist (MCNS).

Role of key worker

To ensure that patients with cancer and their families have appropriate support and information all patients have a named healthcare professional they can contact. This person is called a **key worker**. Your key worker will be available from diagnosis, through treatment and beyond.

Your key worker will change from time to time because your care takes place in a variety of settings, including hospital and at home, as well as in different parts of the country.

You should always know who your key worker is and how to contact them. Please ask your consultant or a member of the nursing team if you are not told who your key worker is.

Your key worker will work with you in the following ways:

- They are a central point of contact for support and information for you and your family.
- They will assess your needs and ensure that you are involved in decisions about your care as much as possible.
- They will ensure that you are referred to and receive different services as needed.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

Who is my key worker?

Leicester, Leicestershire and Rutland

When it has been confirmed that you have Mesothelioma you will be introduced to your MCNS. Before this has been confirmed you may have met other nurse specialists. Your MCNS will discuss any concerns and questions you might have and continue to support you through your care and treatment. The MCNS will be your key worker and you will be able to contact them for advice and support.



Louise Nelson



Laura Smith

Mesothelioma Clinical Nurse Specialists, Leicester

Rest of the UK

If you do not live locally you will be given contact details for the MCNS and they will be able to support you while you are having treatment in Leicester, however if you have further treatment or care at your local hospital your key worker will become the nurse specialist you see at that hospital.

The Leicester MCNS team will remain available for disease specific advice and support especially if you need to be referred back for further treatment or a clinical trial.

What is a Holistic Needs Assessment (HNA)?

This is a chance for you to think about your concerns and discuss possible solutions with your key worker. It gives you the time to explore what resources, help and support are available.

Please ask your key worker for a Holistic Needs Assessment if you think that this would be helpful for you.

When will you meet your Mesothelioma CNS?

You will meet your MCNS when you attend for a clinic appointment either with the Pleural Team, the Oncology Team or maybe while you are in hospital on one of our wards. If the MCNS is not available when you attend clinic you will be given their contact details

Surveillance

There are times when it is best to monitor your disease rather than have any treatment immediately. During this time you will have a CT scan and clinic appointments every 3 months.

If you feel unwell, develop new symptoms or just want support or advice, please contact your MCNS who will be able to help and if necessary change appointments to suit your needs.

During treatment

If you are having Immunotherapy or chemotherapy, this treatment will initially take place on the Chemotherapy Suite at the Leicester Royal Infirmary. Before your treatment starts you will be given information and advice and details for how to contact the chemotherapy team when needed.

Clinical Trials

People who have Mesothelioma may be offered the opportunity to have treatment by taking part in a clinical trial. Treatment that may be suitable for you as part of a clinical trial will be discussed with you at your clinic appointments. We have a dedicated clinical trial team based in the Hope Trial Centre at the Leicester Royal Infirmary. If you agree to take part in a clinical trial you will be given the contact details of the Research Nurse looking after you.

Further information about clinical trials in Mesothelioma can be obtained from

www.mesothelioma.uk.com

www.cancerresearchuk.org

www.clinicaltrials.gov

or, by downloading the Mesothelioma UK Clinical trials app from the QR code found on the mesothelioma UK web site www.mesothelioma.uk.com

Completing treatment

When you have completed a course of treatment / clinical trial you will enter a period of rehabilitation and monitoring and your hospital appointments will be less frequent. Please contact the MCNS in Leicester or your local lung cancer or Mesothelioma UK nurse if you have any concerns during this time.

Symptom control

It is important that you tell your GP, hospital doctor or MCNS if you have symptoms so that we can help you control them. We sometimes suggest you are referred to palliative care services in your area. They specialise in controlling symptoms such as pain. By involving them alongside our team, we aim to maximise your quality of life. This can also mean you more likely to remain eligible for clinical trials.

Contact details

If you have an urgent concern please use the emergency number given to you by your treatment centre.

Clinics - The Mesothelioma CNS are present in clinics at the Glenfield Hospital on a Tuesday and a Wednesday at the Leicester Royal Infirmary.

MCNS contact details

Office telephone: 0116 250 2615 Non-urgent messages can be left on an answerphone and will be actioned on Tuesday's Wednesday's and Friday's email address is mesocns@uhl-tr.nhs.uk

If you are admitted to hospital for any reason please let your MCNS know.

Support Groups

There are 2 support groups available for people living with Mesothelioma.

The East Midlands Mesothelioma Support group open to all those living in the East Midlands affected by Mesothelioma. The group meets monthly on a Friday morning and offers information about all aspects of Mesothelioma with an invited speaker each month followed by lunch and the opportunity to meet and socialise with others in a similar situation.

MELU (Mesothelioma & Lung cancer) Luncheon Club open to all those affected by Mesothelioma who live in Leicestershire or are having treatment or follow up at the Leicester

Hospitals. The group meet monthly on a Thursday and participate in a social activity followed by lunch.

Please speak to your Mesothelioma CNS if you would like more information or wish to attend either or both groups

HOPE course

This is an online self- management course designed to help you with the emotional impact of a cancer diagnosis. It is delivered over a six-week period.

For further information please contact the Macmillan Information and Support Centre. Telephone: 0116 2586189.

Vita Health Group

Your local NHS talking therapies service. Offers a range of short-term psychological therapies. You can refer yourself:

www.vitahealthgroup.co.uk

Other useful contacts

Professor Fennell's secretary

Telephone: 0116 258 7632

CT Scan appointments

If you do not receive an expected appointment for a CT scan please telephone the Direct Booking Line on 0116 258 8765. Choose Option 3 (CT). Have your hospital number ready (begins with the letter S).

Mesothelioma UK

This national charity is an excellent resource for information about all aspects of mesothelioma, including details of clinical trials available across the UK.

Helpline: 0800 169 2409.

Website: www.mesothelioma.uk.com

Email: info@mesothelioma.uk.com

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل
જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।

Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk