



How can I support my loved one with lung cancer?

Trusted Information Creator Patient Information Forum

This booklet has been written for people supporting a loved one through lung cancer diagnosis and treatment.

It is a general guide containing questions that may help you. Information can be found from other sources, including your lung cancer nurse.

This booklet has been fully funded and developed by MSD, with input from Roy Castle Lung Cancer Foundation

Supporting someone with lung cancer

Your loved one has had some tests, which have found cancer.

DIAGNOSIS:

Your loved one has been diagnosed with lung cancer.



- Are you able to help them get to their next appointments?
- Would it help you to talk to someone about the lung cancer diagnosis?
- There are patient support groups that can help you to support them.

A group of lung cancer specialists called a multidisciplinary team (MDT) talk about the treatment and care options for your loved one.



- What are the treatment and care options available to them?
- Have you met the lung cancer nurse, and asked any questions you have?
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There may now be some different options to talk about. They may start treatment, join a clinical trial, have surgery, or start pain management care.



- Your loved one may want to talk to you about their treatment. Is there more information you need for these conversations?
- Are you able to help them get to their appointments?
- Is there any support you need during their treatment?
- You could have a 'carers assessment' (see the 'What is a carer' section) to find out what help you need.

TREATMENT OPTIONS:

If they have treatment and/or surgery, there will be follow-up appointments to discuss how they are feeling, how well the treatment is going, and the risk of their cancer coming back.



- You/your loved one could make some notes during these appointments.
- Have you noticed any side effects from their treatment?
- Is there any support you need during their treatment, for example helping them with their side effects?
- Do you need any emotional support with these conversations?

Your loved one may be asked if they would like to join a clinical trial.



- Your loved one may want to talk to you about clinical trials.
- Is there more information you need for these conversations?

Your loved one may start care to help manage their pain and other symptoms.



- Is there any more support you or your loved one needs during symptom management care?
- What questions do you have?



Navigating lung cancer as a patient

You have had some tests, which have found cancer.

DIAGNOSIS:

You have been diagnosed with lung cancer.



- Are you able to get to your next appointments?
- Would it help you to talk to someone about your lung cancer diagnosis?
- There are patient support groups that can help you.

A group of lung cancer specialists called a multidisciplinary team (MDT) talk about the treatment and care options for you.



- Have you met your lung cancer nurse?
- Do you have all the information about your next appointments?

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There may now be some different options to talk about. You may start treatment, join a clinical trial, have surgery, or start pain management care.



- Do you need more information about any of the options?
- Are you able to get to your next appointments?
- Is there any support you need during your treatment?



TREATMENT OPTIONS:

If you have treatment and/or surgery, there will be follow-up appointments to discuss how you are feeling, how well the treatment is going, and the risk of your cancer coming back.



- You/someone else could make some notes during these appointments.
- Do you have any side effects?
- How much energy do you have and how hungry are you?
- Do you need any emotional support with these conversations?
- Do you have any other questions?

You may be asked if you would like to join a clinical trial.



- Do you understand what a clinical trial is?
- Have you asked any questions you have about clinical trials?

You may start care to help manage your pain and other symptoms.



- Is there any more support you need during symptom management care?
- What questions do you have?



Important words and their meanings

Clinical trials

Clinical trials are a type of medical research involving people that tries to understand the safety and effectiveness of a treatment.

Supportive care

This is care that helps your loved one and the people supporting them to cope with lung cancer and any treatment.¹

Palliative care

The supportive care given when your loved one's lung cancer is advanced and a cure is not possible.¹

Advanced

When your loved one's cancer has spread to other parts of the lung or to other parts of the body.



Multidisciplinary team (MDT)

This is a team of healthcare professionals that work together to plan the best care for your loved one.²

A lung cancer MDT may include a:

Surgeon A doctor who does operations, surgery, on the lungs.

Medical or Clinical Oncologist (cancer doctor)

A doctor who treats cancer using anti-cancer medicines, or radiotherapy.

Pathologist

A doctor who looks at samples of lung tissue under a microscope to diagnose lung cancer.

Lung cancer nurse specialist (LCNS)

A nurse who gives information about lung cancer and support during treatment.

Radiologist

A doctor who looks at scans and x-rays to diagnose lung cancer.

There may be other healthcare professionals involved in your loved ones MDT.





What is a carer?

You may hear yourself being referred to as a carer as you support your loved one with their lung cancer.

Many people that are carers do not see themselves as carers, and this can mean they do not access some of the support available to them.³

According to the NHS,⁴ a carer is anyone, including children and adults, who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid, and it can range from helping with everyday tasks to giving emotional support.

It may be helpful to identify as a carer in order to access support, such as a **carer's assessment**. This is a free assessment that can see what might help make your life easier when caring for someone. To request one, contact adult social services at your local council, or trust in Northern Ireland, and ask for a carer's assessment.



Taking notes

You or your loved one may find it helpful to make notes during and between their appointments. This could include some of the information below:

- Any questions.
- The name and phone number for the lung cancer nurse and any other healthcare professionals you speak to regularly.
- Details about the next appointment who it's with, what time it is and where it is.
- Anything you want to talk about at the next appointment.
- Any changes in your loved one's eating habits or tiredness, and any other side effects they have experienced.







Roy Castle Lung Cancer Foundation is the charity that gives help and hope to people affected by lung cancer.

We offer lung cancer help and support to anyone who has been affected by the disease. From the latest lung cancer information to a dedicated forum and free Ask the Nurse helpline, we're here to help.

If you have a question, need emotional support or just want to chat about lung cancer, call us now free on 0800 358 7200, or email lungcancerhelp@roycastle.org.

For more information, call our Lung Cancer Information and Support Services: 0333 323 7200 (option 2) or visit our website: www.roycastle.org



Information and Support Services 524-528, Baltic Chambers, 50 Wellington St, Glasgow G2 6HJ Email: **info@roycastle.org**

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References

Please be aware that all external hyperlinks will take you to an external website.

1 Roy Castle Lung Cancer Foundation. Managing your Lung Cancer Diagnosis. 2020; Available from: https://www.roycastle.org/app/ uploads/2021/01/Managing-Your-LC-Diagnosis-Online-Jan-2021.pdf [Accessed June 2024]

2 Macmillan. Your multidisciplinary team (MDT). Macmillan Cancer Support; 2022; Available from: https://www.macmillan.org.uk/cancerinformation-and-support/treatment/your-treatment-options/yourmultidisciplinary-team-mdt [Accessed June 2024]

3 Carers UK. Identification. 2022; Available from: https://www. carersuk.org/policy-and-research/our-areas-of-policy-work/ identification/ [Accessed June 2024]

4 NHS England. Who is considered a carer? Available from: https:// www.england.nhs.uk/commissioning/comm-carers/carers/ [Accessed June 2024]









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