

NLCA Patient Questions to ask Healthcare Professionals

Navigating a lung cancer diagnosis and treatment can feel overwhelming. Below is a list of questions that it might be helpful to ask healthcare professionals involved in your care for lung cancer. Not every question will be relevant to all patients and carers, and some may not be relevant at a particular meeting. However, this is a good starting point for planning out the questions you wish to ask your medical team during consultations. You can take these questions along with you to consultations.

Information:

- What written information will I receive about the management of my cancer?
- Can I decide how much information I should receive about the management of my lung cancer?
- Can I bring a relative or friend to my consultations?
- When will someone explain to me what treatment options are available? Who will this be?
- Please can I have the contact details for relevant patient-support organisations?

Diagnosis:

- What type of lung cancer do I have?
- What stage is my lung cancer?
- Has my cancer already spread from my lungs? Is the cancer likely to spread in the future?
- What tests am I likely to have and what are they for?
- How long do the results of the tests take to come through?

Shared Decision-making:

- Can I talk about the approach we will take in making decisions about my care and discuss how my voice will be heard?
- Can we share decision-making so I am involved in deciding my care options?
- How does the cancer service encourage patients to be involved in their care planning?

Treatments:

- What treatments will I be offered?
- Are the treatments intended to cure my lung cancer?
- How might the treatments affect my fitness and quality of life?
- Will my treatments be in the same place or will I need to travel to other hospitals?
- How will we know if the treatment is working / has worked?
- How am I likely to recover after the treatment?
- Are there further treatments planned?
- What options are available if I can't (or choose not to) have cancer treatments like chemotherapy or radiotherapy?
- Are there any experimental or special-access drugs from pharmaceutical companies that might be available for me to try on a named patient/ compassionate basis?

Quality, Expertise and Outcomes:

- Which staff will be involved in my care?
- What experience does my healthcare team have in treating my specific type of lung cancer?
- Do you have a Lung Cancer Nurse Specialist I can contact anytime?
- If the Lung Cancer Nurse Specialist is unavailable, how do I leave a message, and will I be called back quickly?
- If the treatment centre doesn't have a Lung Cancer Nurse Specialist, who can I contact between consultations if I have any concerns?
- Do I have the right to ask for a second opinion?
- Can I be referred to a centre of excellence?

Scans for diagnosis, disease staging or monitoring reaction to treatments:

- What type of scans will I receive? What are the scans looking for?
- How often will I receive scans?
- How long after a scan will I be informed of the result? Do you know how I will receive this information?

Side Effects of treatment:

- What side effects might I experience?
- Who should I tell if I suffer severe side effects?
- Is there an out-of-hours service?
- Do I need to take active measures to avoid picking up viruses and infections (in other words, am I immuno-compromised)?

Quality of Life:

- How will I maintain my quality of life during my treatment so that I can live as normal as possible?
- Does this cancer service measure the quality of my life in any way, such as using Patient Reported Outcome Measures (sometimes called PROMs for short)?
- Who can I approach if I have emotional, social or financial problems during the management of my cancer?
- What can I do to get as fit and healthy as possible? Is any help available for this?
- Will I still be able to go to work?
- Can I go on holiday?

Progression:

- How will I know if my lung cancer progresses/spreads?
- If my cancer is mostly under control but some areas start growing again, will I be referred to a team that specialises in treating this kind of situation?
- If appropriate, will I be referred to another team if the cancer has spread to other organ/ part of the body (for example, a neuro-oncology team experienced in treating brain metastases?)

Supportive and palliative care:

- Should it be necessary, will I be given supportive and palliative care based on my individual needs?
- Can I be referred to the supportive and palliative care service anytime?
- Is the supportive and palliative care provided at home or in the hospital?

Research and Innovation:

- Is this cancer service active in cancer research, enrolling patients in clinical trials?
- Is there a study or clinical trial in which I could participate if I am eligible and choose to do so?
- Can I go to another hospital or centre if I wish to be involved in a specific clinical research project not offered at this hospital?

Please also add your own questions below:

The following organisations can provide you with further information and support:

<https://roycastle.org/>

<https://ruthstraussfoundation.com/>

<https://www.macmillan.org.uk/>

<https://www.maggies.org/>

Glossary

Diagnosis & Testing:

- Lung cancer – A type of cancer that starts in the lungs. It can be either *non-small cell lung cancer (NSCLC)* or *small cell lung cancer (SCLC)*, which behave differently.
- Cancer stage – A way of describing how much the cancer has grown or spread in the body, usually on a scale from 1 to 4.
- Metastasis – When cancer spreads from the lungs to other parts of the body, like the brain, bones, or liver.
- Scans – Medical imaging tests, like CT scans or PET scans that help doctors see inside the body to check for cancer or monitor treatment effects.
- Disease staging – The process of determining how far cancer has spread, which helps decide on the best treatment.

Treatment & Care:

- Chemotherapy – A treatment using strong drugs to kill cancer cells or stop them from growing.
- Radiotherapy (Radiation therapy) – A treatment that uses high-energy X-rays to target and kill cancer cells.
- Palliative and supportive care – a medical speciality that provides care focusing on relieving symptoms, side effects and improving quality of life for people with serious illnesses. It also includes end of life care.

Decision-Making & Quality of Care:

- Shared decision-making – A process where patients and doctors work together to decide on treatment based on medical facts and personal preferences.
- Lung Cancer Nurse Specialist – A nurse with expert knowledge in lung cancer who provides support, advice, and coordination of care.
- Centre of excellence – A hospital or medical centre that specialises in treating a specific type of cancer and has access to the latest treatments and research.

Side Effects & Quality of Life:

- Immuno-compromised – A weakened immune system, often caused by cancer treatments like chemotherapy, making it harder to fight infections.
- Patient-Reported Outcome Measures (PROMs) – Surveys or assessments where patients report on their own health, symptoms, and quality of life.

Progression & Advanced Disease:

- Oligo-progressive disease – When cancer is mostly controlled by treatment, but a few areas are starting to grow again.
- Brain metastases – When lung cancer spreads to the brain, which may require specialised treatment from a neuro-oncology team.

Research & New Treatments:

- Clinical trial – A research study that tests new treatments to see if they are safe and effective.
- Compassionate use / Named patient use – When a drug that is not yet widely available is given to a patient who has no other treatment options.

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