ROY CASTLE
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Genomic testing in lung cancer

A guide for people with lung cancer and their loved ones

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What is genomic testing?

A genomic test checks cancer cells for important genetic changes (variants). Testing lung cancer in this way is a vital early step in making sure you or your loved one starts on the best treatment plan.

Some genetic variants are passed down through families (inherited or hereditary variants)… The genetic variants which can cause lung cancer are not usually inherited. They are changes that happen during your lifetime and are called *acquired* variants.

"Although I initially received chemotherapy, I received targeted therapy after I got the results of my genomic test." - **Sally**

"I was first diagnosed with a tumour in the brain, but a scan showed that I had lung cancer. My genomic test showed that my cancer was ALK positive, so I was put on a targeted treatment." - **Andy**

"I had surgery to remove a mass in my lung. I didn't know I was tested at the time, but my genomic test revealed my cancer didn't carry a variant that had a targeted treatment." - **Brian**

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of all patients with non-small cell lung cancer have at least one variant that has a targeted treatment[1,2]; every patient should have their sample tested to ensure opportunity for treatments are not missed.

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The 2021 GLCC Patient Experience Survey suggested that around one third of 54 patients asked were either not offered a genomic test or were unsure whether they had been tested for one.[3]

Why should you ask your clinical team about genomic testing?

- Genetic changes can be found in your tissue, blood, or other body fluids. They can give your clinical team more information on what is causing your cancer to grow and spread.[4]
- When a genomic test is done, your clinical team are looking to see which genetic changes your cancer has – these are called variants.
- Because there are many different types of non-small cell lung cancer, genomic testing at the time of diagnosis can be a critical first step in helping your clinical team in offering your treatment options.

There are genetic changes found in lung cancer. These changes can be found in molecules, genes, proteins or characteristics found in the tumour cells.

Genomic testing, also called "genetic", "molecular" testing is designed to find these changes.

What does genomic testing involve?

01. Testing
Your clinical team will collect some tissue from your tumour in a procedure called a biopsy. If a tissue biopsy cannot be performed, your clinical team may take a blood sample.

02. Analysis
Your biopsy will be sent to a laboratory for analysis and a report will be sent to your clinical team. This can take days to weeks, but you may want to ask your clinical team when to expect the results. The National Lung Cancer Optimum pathway recommends test results should be available within 10 days for newly diagnosed.[5]

03. Reporting
Your clinical team will explain the results of the test and discuss implications for your treatment, if any, including whether a targeted therapy may be an option available to you.

Changes in genetics and proteins found in lung cancer patients include EFGR, ALK, MET, ROS1, BRAF, RET, NTRK1, KRASG12C, PD-L1 and HER2.

This is a growing list as new changes are still being discovered. Speak with your clinical team for more information.

What can genetic variants mean for your treatment?

- Your treatment options may change depending on whether or not your tumour has a targetable variant, what that variant is, or your personal circumstances.
- If your tumour tests positive for a variant, you may be placed on therapy that is already approved, or you may be eligible for a current or future clinical trial.[6]
- Each targeted therapy treats a particular variant. If your lung cancer does not have a variant that currently has an available treatment, speak to your oncologist about your treatment options.

What should you ask your clinical team?

You have the right to information about your cancer and treatment from your clinical team, including information about genomic testing.

Questions you may wish to ask:

- Is there a plan to test my cancer cells for genetic variants? If so when will this be done?
- If you aren't doing a genomic test, what is the reason?
- Have you done genomic testing on my cancer sample?
- When will I get the results of my genomic testing?
- What were the results of my genomic test?
- What do the results of my genomic test mean for my treatment?

Guide for loved ones

This is complicated! Immediately after diagnosis your loved one may not be in the best state of mind to ask questions or take information in, but the earlier you engage in conversations about genomic testing the better.

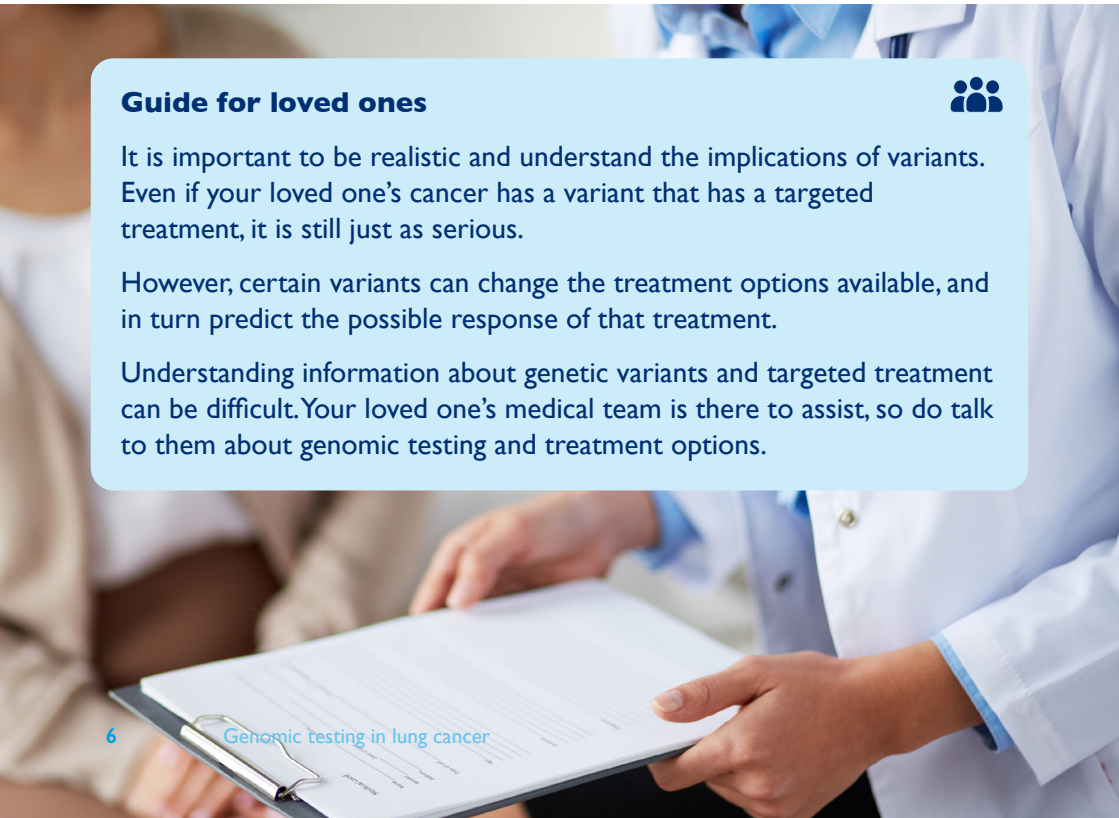
So, with your loved one's permission, why don't you ask their clinical team instead – do they plan to do genomic testing, and if so, when?

What does genomic testing mean for you?

Genomic testing can be an important part of shaping your treatment. Some types of non-small cell lung cancer can be treated with targeted therapies.

Your treatment will depend on a number of factors. This will include your general health, other medical conditions as well as any genetic variants. A targeted treatment might not be the best option for your cancer. Every person, and every cancer, is different.

That is why it is so important to have a conversation with your clinical team.



Guide for loved ones

It is important to be realistic and understand the implications of variants. Even if your loved one's cancer has a variant that has a targeted treatment, it is still just as serious.

However, certain variants can change the treatment options available, and in turn predict the possible response of that treatment.

Understanding information about genetic variants and targeted treatment can be difficult. Your loved one's medical team is there to assist, so do talk to them about genomic testing and treatment options.

What happens once you've started treatment?

Targeted therapies are used to treat some lung cancers. They work by targeting a specific change in or around the cancer cells that is helping them to grow. Targeted therapies may be given as tablets, with or after other types of treatment.

If you are given targeted therapy, you may want to ask your clinical team how long the therapy is expected to work for and what changes in symptoms you should look out for. The targeted therapy may stop working, so you may want to ask how you tell if the therapy has stopped working, and what happens next.

It can take some time to see how targeted treatments are working, though you may become aware of changes in symptoms more quickly. You can experience side effects, so speak to your clinical team about any concerns you have.

You will have regular follow-up appointments during your treatment. Your clinician may do blood tests to see if the treatment is affecting your body. If your cancer is responding to the targeted therapy, then treatment will continue, as long as you're coping with any side effects and want to continue.

Your visits are a good time to ask your clinical team questions and talk about any changes or problems you notice. It can be useful to write down the questions you want to ask before your visit.

References:

1. Baumgart M. Am J Hematol Oncol. 2015;11:10-13.
2. Xiao Y, Liu P, Wei J, Zhang X, Guo J and Lin Y, Recent progress in targeted therapy for non-small cell lung cancer. Front. Pharmacol. 2023;14.
3. Global Lung Cancer Coalition. COVID-19 pandemic: the impact on lung cancer patients. https://www.lungcancercoalition.org/wp-content/uploads/2021/08/GLCC.-Patient-experience-survey-2021.-Report-for-the-UK.-27.07.21-edited-1.pdf
4. National Cancer Institute. Tumor Markers. https://www.cancer.gov/about-cancer/diagnosis-staging/diagnosis/tumor-markers-fact-sheet. Accessed January, 2024.
5. https://www.roycastle.org/app/uploads/2020/09/National-Optimal-Lung-Cancer-Pathway-3.0.pptx
6. Li MM, Datto M, Duncavage EJ, et al. J Mol Diagn. 2017;19:4-23.

Here are some trusted support organisations that have further information on genomic testing, targeted treatments, and living with lung cancer. Your hospital may also run a local support group.

Lung cancer support organisations

Roy Castle Lung Cancer Foundation
www.roycastle.org

ALK Positive Lung Cancer UK
www.alkpositive.org.uk

EFGR Positive UK
www.egfrpositive.org.uk

EFGR Resisters
www.egfrcancer.org/

ROS1ders
https://www.theros1ders.org/

MET Crusaders
https://metcrusaders.org/

RET Positive
www.retpositive.org/

Exon 20 Group
www.exon20group.org/

NHS
www.nhs.uk/conditions/lung-cancer

General support organisations

Cancer Research UK
www.cancerresearchuk.org

Macmillan Cancer Support
www.macmillan.org.uk

Guide for loved ones

We understand your loved one is going to be your priority right now, but it's important that you also look after yourself, have support, and know where to seek advice.

Macmillan Cancer Support – www.macmillan.org.uk/cancer information-and-support/supporting-someone

Maggie's – www.maggies.org/cancer-support/supporting-someone-cancer/support-adult-carers/

Mind – www.mind.org.uk/information-support/helping-someone-else/carers-friends-family-coping-support/

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