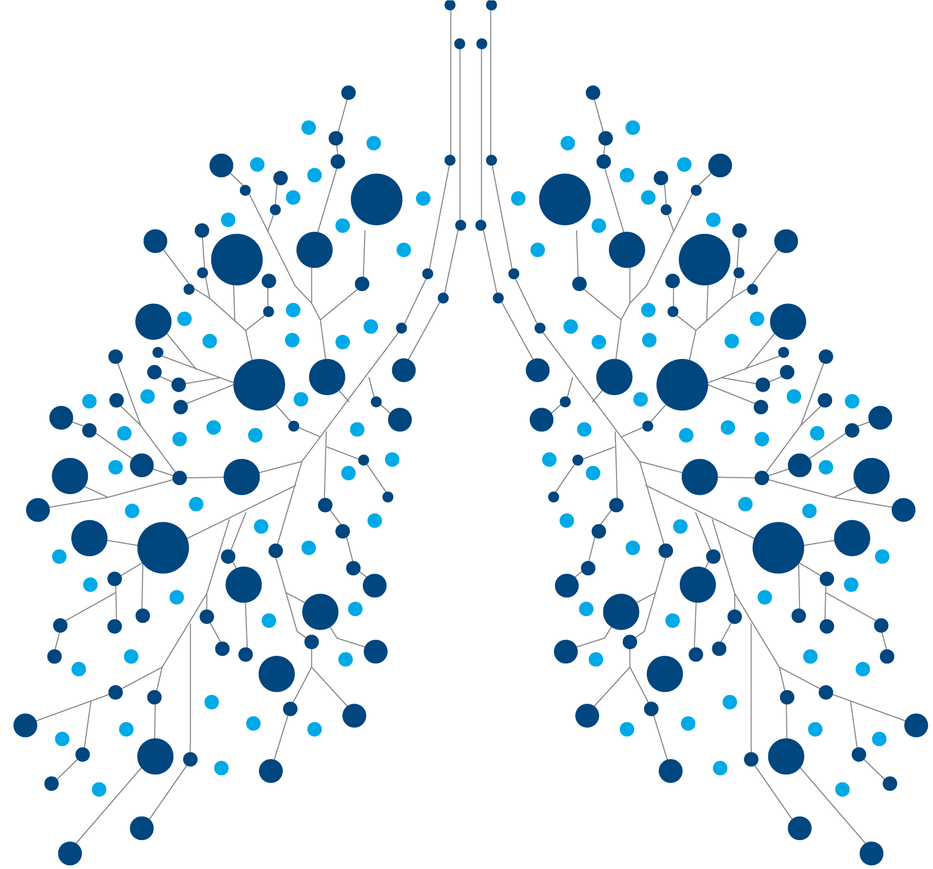


Lung Cancer Patient Guidebook

Coping with lung cancer

ABOUT THIS GUIDEBOOK

This Guidebook was developed to help you navigate through the vast amount of information available on lung cancer and direct you to reliable and helpful sources that can enable you to ask questions and have more open discussions with your doctor.

Throughout the Guidebook, there are questions to help you initiate discussions with your healthcare team and clarify any concerns you may have.

WHAT IS LUNG CANCER?

It is normal for cells in the body to grow and divide to make new cells. However, when this process is dysregulated, cancer may occur.

Lung cancer results from the transformation of normal cells to lung cancer cells in the lungs. Some genetic mutations called driver mutations are known to play a role in the transformation of normal to lung cancer cells.[1]

Some symptoms of lung cancer may include:[2-5]

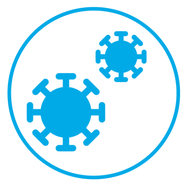
Fatigue

Persistent new cough (>8 weeks)

Shortness of breath

Coughing up blood

Worsening chronic cough



Repeated respiratory infections

Having these symptoms may or may not be a sign of lung cancer.
If your symptoms get worse or persist, consult your doctor immediately.

WHAT IS LUNG CANCER?

Cancer can be primary and/or secondary. If cancer starts from the lung, it is called primary lung cancer. Cancer can spread from a primary site (where the cancer started) to the lung through a process called metastasis, resulting in secondary lung cancer.[6]

This Guidebook focuses on NSCLC, as it is the most common form of lung cancer. However, many of the resources provided will be useful for people living with any form of lung cancer.

2 Types of Lung Cancer

Non-Small Cell Lung Cancer (NSCLC)

80-85%

of lung cancers[7,8]

Adenocarcinoma[3,9]
- Most common
- Forms from the cells that line the alveoli and make mucus

Squamous cell carcinoma[3,9]
- Lines the bronchi

Large cell carcinoma[3,9]
- Forms from any large cells that are throughout the airways

Each type of NSCLC grows and spreads differently. It is important to know which type of cancer you have because it will affect your treatment options.

Small Cell Lung Cancer (SCLC)

10-15%

of lung cancers[8]

Also called oat cell cancer[8]

Grows and spreads faster than NSCLC[8]

Further reading and support

Lung Foundation Australia:

https://lungfoundation.com.au/patients-carers/conditions/lung-cancer/overview/

Cancer Council Victoria:

https://www.cancervic.org.au/cancer-information/types-of-cancer/lung_cancer/lung-cancer-overview.html

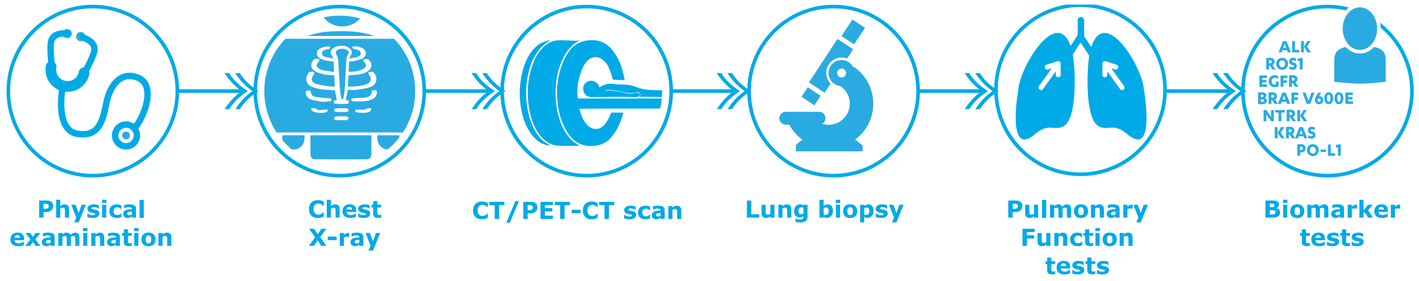
Better Health Channel:

https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/lung-cancer

TESTS FOR LUNG CANCER

A wide range of tests may be performed to confirm the diagnosis of lung cancer.

The first test is usually imaging to investigate abnormal symptoms, followed by a biopsy if a tumour is suspected on an X-ray or Computed tomography (CT) scan.[10]



Imaging

Imaging is a way of taking a picture of the inside of your body to investigate whether there is cancer and how far it has progressed. Different imaging options include:[9]

- Chest X-rays
- CT scan
- PET-CT scan

Biopsy

A biopsy involves removing a bit of the potential cancer tissue for testing.

Biomarker tests

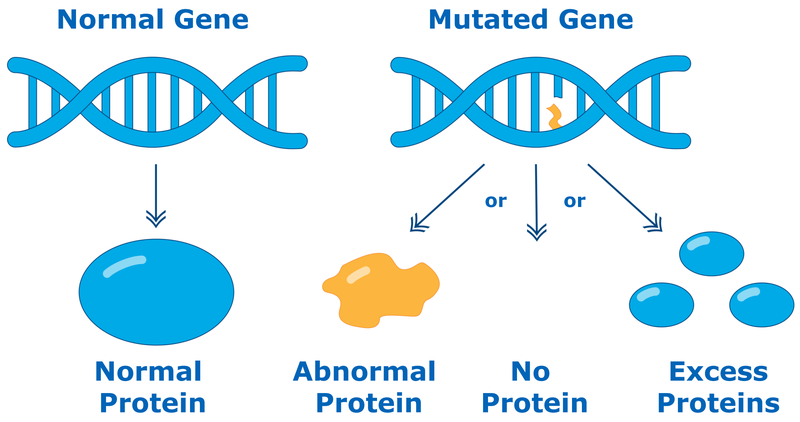
The main biomarkers tested for in non-small cell lung cancer (NSCLC) are targetable driver (genetic) mutations and immune system biomarkers. Finding out which biomarkers you have is an important step in making sure you get the right treatment, as specific driver mutations are targeted by respective treatment options.[11]

TESTS FOR LUNG CANCER

Biomarker Tests

Testing for driver mutations

Inside the cells in our body is a complex structure called DNA. This structure contains all the instructions our body needs to develop, function, and survive. Sometimes, your DNA may change and cause cancer. This change is called a 'driver mutation'.[12]



Driver mutations that have been identified in NSCLC include EGFR, KRAS, ROS, and ALK mutations, among others.[1] Identifying the type of mutation through biomarker testing may help your doctor determine the best course of treatment.

There are several different types of biomarker tests that you can ask your doctor about. Next-generation sequencing (NGS) is a comprehensive method that can be used to look for multiple driver mutations at the same time. Another type of test is the polymerase chain reaction (PCR), which looks for the specific driver mutations of interest by your doctor and is used if NGS is inaccessible.[11,13] The more comprehensive method is NGS and is recommended if available.

Testing for immune system biomarkers

Proteins on the surface of cancer cells can prevent them from being detected by a patient's immune system.[14] In lung cancer, doctors often test for immune system biomarkers such as PD-L1. Testing for the protein PD-L1 can help your doctor determine if you are eligible for treatments such as immunotherapy.

Key questions to ask your doctor

- What tests do you recommend for my condition and why?
- What will the test(s) involve, and how do I prepare for testing?
- Where can I be tested? How long will the tests take?
- How much will the test(s) cost? Will my insurance cover these?
- How soon can I obtain the results and who will explain the results to me?
- What are the next steps following the tests?

Further reading and support

Cancer Council Victoria:
https://www.cancervic.org.au/cancer-information/types-of-cancer/lung_cancer/diagnosing_lung_cancer.html

NCCN guide on NSCLC: Pg 20-28
https://www.nccn.org/patients/guidelines/content/PDF/lung-early-stage-patient.pdf#page=20

EGFR, Epidermal Growth Factor Receptor; KRAS, Kirsten Rat Sarcoma Virus; ROS, Reactive Oxygen Species; ALK, Anaplastic Lymphoma Kinase.

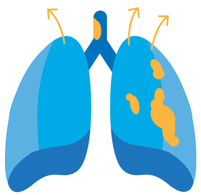
STAGES OF LUNG CANCER (NSCLC)

When you are diagnosed with lung cancer, your doctor will need to determine what stage your cancer is by determining the size of the cancerous tumour, and how much it has spread in the body. This allows your doctor to decide on the best treatment for your cancer.[15] Non-small cell lung cancer is staged using the TNM system.[16]

TNM stands for tumour, node, and metastases. Staging is based on three key pieces of information:[16]

1. Size and extent of the primary tumour
2. Spread to nearby lymph nodes
3. Spread to other parts of the body

Description of what each stage in lung cancer means:

STAGE 0	STAGE I	STAGE II	STAGE III	STAGE IV
				
In stage 0, this means that there are abnormal cancer cells in the airways, but these have not grown or spread into lung tissue.	Stage I, early-stage lung cancer, refers to the presence of a small tumour in the lung but without any involvement of the lymph nodes or spread to any other part of the body.	In stage II, there is a bigger tumour in the lung, which may or may not have spread to the nearby lymph nodes, is also often referred to as early-stage lung cancer.	In stage III, also known as locally advanced lung cancer, the tumour has further grown and cancer has spread to your lymph nodes and the middle of your chest.	Stage IV, refers to a tumour of any size with definite involvement of the lymph nodes and spread to one or more other organs in the body such as the brain, liver, kidney, adrenal gland, and bone. Once the cancer has spread to other parts of the body, it is often called metastatic lung cancer.

Key questions to ask your doctor

- What stage is my tumour?
- How far has my disease spread and which other body parts have been affected?
- Has my tumour been tested for molecular biomarkers?
- What does this mean for my treatment?

Further reading and support

Lung Foundation Australia:
https://lungfoundation.com.au/patients-carers/conditions/lung-cancer/stages/

Cancer Australia:
https://www.canceraustralia.gov.au/affected-cancer/cancer-types/lung-cancer/how-lung-cancer-diagnosed

NCCN guide on NSCLC: Pg. 28-33
https://www.nccn.org/patients/guidelines/content/PDF/lung-early-stage-patient.pdf#page=28d

FACTORS THAT IMPACT TREATMENT CHOICE

The type of treatment recommended for you will depend on several factors such as:

- The type of lung cancer
- The number of primary lung tumours
- The stage of the lung cancer
- Your overall health status
- Types of biomarkers identified

While your healthcare team will make treatment recommendations, it is important that you share what's important to you, such as upcoming life events, time away from work, cost of treatments, etc., as those may influence treatment options. If there is any aspect of the treatment recommendation that you do not understand or are uncomfortable with, ask for clarification or a second opinion.

Key questions to ask your doctor

- Why are you recommending this treatment option over others?
- Are there other treatment options you aren't recommending? Why?
- What happens if I choose no treatment?

TYPES OF TREATMENT

Local treatment: In early-stage and locally advanced lung cancer, local treatment options can be used to either remove the cancer via surgery or to shrink the primary tumour.[9]

TREATMENT	WHAT IS IT?	POTENTIAL SIDE EFFECTS
SURGERY[9,17]	Goal is to remove all the cancer from the body. The type of surgery will depend on the size and location of your tumour, and how well your lungs function. **3 types of surgery:**  **Wedge or segment resection:** Removes a small part of the lung. **Lobectomy:** Removes an entire lung lobe containing the tumour. **Pneumonectomy:** Removes one of the two lungs.	Pain, numbness around the surgical area, infection, swelling, and scars
RADIATION THERAPY[9,18]	Use of **high-energy X-rays** to damage the DNA of lung cancer cells causing them to stop multiplying.	Fatigue, skin changes/problems, hair loss, shortness of breath, nausea/vomiting
CHEMORADIATION[9,19,20]	**Combination** of chemotherapy and radiation therapy. Chemotherapy uses drugs to kill cancer cells. Drugs travel through the bloodstream to attack cancer cells.	Fatigue, weakness, infection, nausea, breathlessness

Further reading and support

Lung Foundation Australia:
https://lungfoundation.com.au/patients-carers/conditions/lung-cancer/treatment/

Cancer Council NSW:
https://www.cancercouncil.com.au/lung-cancer/treatment/surgery/

NCCN guide on NSCLC: Pg 39-53
https://www.nccn.org/patients/guidelines/content/PDF/lung-early-stage-patient.pdf#page=39

Cancer Council NSW:
https://www.cancercouncil.com.au/lung-cancer/treatment/radiotherapy/

Cancer Australia:
https://www.canceraustralia.gov.au/cancer-types/lung-cancer/treatment

TYPES OF TREATMENT

Systemic treatment: Refers to treatment agents that travel through your bloodstream all over the body to attack cancer cells wherever they may be.[20]

TREATMENT	HOW DOES IT WORK?	HOW IS IT GIVEN?	POTENTIAL SIDE EFFECTS
CHEMOTHERAPY[21, 22]	• Kills cancer cells by **destroying DNA**. • Can also be given before surgery to shrink tumours or after surgery to prevent cancer from returning.	• Orally as tablets/capsules or IV (intravenously) • Given in cycles every 21 or 28 days	Nausea, fatigue, mouth ulcers, infections, and hair loss
TARGETED THERAPY[23-25]	• Testing is required to identify the genes and proteins present in the tumour. Uses drugs to **target specific genes and proteins** that contribute to cancer cell growth and survival. • Limits the damage to healthy cells.	• Orally as capsules, shot under the skin (subcutaneous) or IV (intravenously) • Depending on how it is administered, may be taken every day/week, several times a week or once a month	Dependent on target - sensitivity to light, skin rash, elevated liver enzymes, diarrhoea, heart rhythm changes
IMMUNOTHERAPY[26-28]	• Use of medicines to **stimulate your immune system** to directly target, find, and kill cancer cells	• IV (intravenously) • Infusions need to be repeated every few weeks	Fatigue, nausea, diarrhoea, loss of appetite, joint or muscle pain, and changes to the skin

Key questions to ask your doctor

- My priorities are _____. What treatment options would you recommend for me?
- How many cycles of treatment do I need? How many days of treatment within a cycle? How do I prepare to start treatment?
- Can the disease be controlled for the long-term?
- How much do the treatments cost? Are these covered by insurance?
- Is there a treatment option that is available in self-pay?
- What treatment side effects do I need to watch out for?
- Can I stop treatment anytime? What happens if I stop treatment?

Further reading and support

Cancer Council NSW – Chemotherapy:
https://www.cancercouncil.com.au/lung-cancer/treatment/chemotherapy/

Cancer Council NSW - Immunotherapy:
https://www.cancercouncil.com.au/lung-cancer/treatment/immunotherapy/

Cancer Council NSW – Targeted Therapy:
https://www.cancercouncil.com.au/lung-cancer/treatment/targeted-therapy/

NCCN guide on NSCLC: Pg 51-53
https://www.nccn.org/patients/guidelines/content/PDF/lung-early-stage-patient.pdf#page=51

MANAGING TREATMENT

Managing side effects

All cancer treatments have the risk of causing unwanted side effects, which could range from mild to serious.

Many of these side effects often disappear as soon as the treatment is completed. However, it is important to let your doctor know about any side effects as soon as you experience them or are worried about them. It is better to identify and address them at a mild stage rather than waiting until they become severe.

Monitoring and maintenance

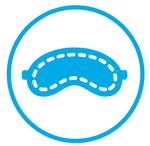
Once you complete the course of treatments prescribed by your doctor, you will be expected to attend follow-up appointments where regular tests such as chest X-rays and/or CT scans may be carried out to confirm that there are no more tumours and recurrent cancer.[29] During the follow-up appointments, your doctor will also look out for any complications or late side effects related to treatment(s) that you may have received.

Things to take note of

Cancer treatments may make you feel tired and emotional. It is important to get as much support as you need and take good care of yourself.[30]

If you smoke, it is crucial that you stop as soon as you can during and after treatment as smoking can increase the risk of cancer reoccurrence.[30]

Eat a healthy diet and exercise often to stay active. Start exercising slowly and gradually build up as you begin to feel stronger. [30]



Get as much rest as you can to let your body slowly recover.[30]

Key questions to ask your doctor

- What can I do to prevent or relieve the side effects?

Further reading and support

Cancer Council NSW:

https://www.cancercouncil.com.au/cancer-information/managing-cancer-side-effects/

Cancer Council NSW:

https://www.cancercouncil.com.au/lung-cancer/after-cancer-treatment/

Better Health Channel:

https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/lung-cancer#living-with-advanced-lung-cancer

MANAGING TREATMENT

What's next if the treatment isn't working?

While taking the initial course of treatments, your doctor will evaluate you closely to determine if your symptoms are getting better, and if your tumour size is smaller; if there does not seem to be an improvement during the initial course of treatment, your doctor will investigate why and potentially prescribe a different type of treatment.

In cases where the cancer returns or progresses, your doctor may offer a new treatment that will depend on the extent of the recurrence.[29,31]

Palliative treatment

If the cancer is advanced when it is first diagnosed or comes back after treatment, your doctor may discuss palliative treatment for any symptoms caused by cancer. Palliative treatment aims to manage symptoms without trying to treat the cancer.[29,31] It is used to improve your quality of life and make sure you feel comfortable as much as possible.

Key questions to ask your doctor

- How do I know if the treatment is working or not? What do I do if the treatment is not working?
- What are the effects of the treatment on me being able to continue working or studying?
- How often do I need to return for check-ups after my treatment? What tests would I need to do again after the treatment?
- Would you recommend palliative treatment to me? Why?
- Do I get to decide when to transition to palliative treatment?

Further reading and support

Lung Foundation Australia:

https://lungfoundation.com.au/patients-carers/support-services/support-and-palliative-care/

Cancer Council NSW:

https://www.cancercouncil.com.au/lung-cancer/after-cancer-treatment/

https://www.cancercouncil.com.au/cancer-information/advanced-cancer/palliative-care/

Better Health Channel:

https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/lung-cancer#living-with-advanced-lung-cancer

MANAGING TREATMENT

Clinical trials

Clinical trials are studies that help doctors find new ways to improve treatments and quality of life of people with certain diseases.[32]

Clinical trials are the final step in a long process that begins with research in a lab. Before any new treatment is used by patients enrolled in clinical trials, researchers work for many years to understand its effects on cancer cells in the lab and in animals. They also try to figure out the side effects it may cause.[32] It is important to know that even if a new treatment has benefits, it may not work for everyone.[33]

Ask your doctor about any clinical trials that may be appropriate for you and your cancer. Your doctor will let you know if the clinical trial may work for you, discuss your eligibility for the trial with you, and point you in the direction of where you can access further information.

Key questions to ask your doctor

- How does the treatment I would receive in this trial compare with the other treatment choices?
- How does this clinical trial work? What are the treatments being assessed?
- How will I know if the treatment is working? Can I get other treatments if this isn't working?

Further reading and support

Cancer Australia Clinical Trial Finder:
https://www.australiancancertrials.gov.au/

LIVING WITH LUNG CANCER

Caring for your mental health

The diagnosis of lung cancer can be devastating for you and your loved ones. You may find it stressful to manage the symptoms of cancer, the side effects of treatments, or the financial costs of care. The diagnosis may also affect your sense of self. You may worry about what other people will think or how they'll respond to your diagnosis.[34] It is important that you take care of your mental health during this time.

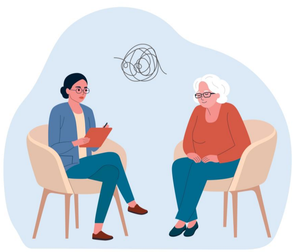
Tips for managing your mental health

Take an active role in your treatment journey. Understanding the ins and outs of your lung cancer treatment can benefit you and give you a greater sense of control.[34] While your healthcare team does the best they can during this time, don't be afraid to ask questions and voice your concerns.[35]

Find support groups. Even with loved ones supporting you, the experience of living with cancer can be isolating.[37] You may find it helpful to connect with other people who are diagnosed with lung cancer,[34] through support groups such as Lung Foundation Australia.

Lean on your support team. Being diagnosed with cancer is hard to cope with. Common feelings during this time can include anxiety, anger, distress, or feeling depressed.[36] It is important that you have sources of support during this time, which can come from your family members, close friends, volunteers, or support groups.

Engage in pleasurable pastimes. Engaging in activities and/or hobbies that you enjoy may take your mind off challenging thoughts and feelings and reduce your stress.[34]



Seek professional counseling. If you are struggling with your mental health, let your doctor know. They may refer you to a psychologist, social worker, or other mental health professionals who specialise in supporting people with cancer.[34]

Take care of your body. A consistent routine of sleeping well, exercising, and eating a balanced diet can also be a strong ally of overall mental health.[37]

LIVING WITH LUNG CANCER

Mental health support links

Lung Foundation Australia:
https://lungfoundation.com.au/patients-carers/after-your-diagnosis-title/mental-health

Lung Foundation Australia Social Work Service:
https://lungfoundation.com.au/find-a-service/lung-cancer-social-work-service/?service-card=6

Lung Foundation Peer Support:
https://lungfoundation.com.au/patients-carers/support-services/peer-support/

Cancer Council Support Services:
https://www.cancer.org.au/support-and-services/cancer-council-13-11-20

Cancer Council Counselling:
https://www.cancercouncil.com.au/get-support/cancer-counselling/

Cancer Council Workshops and forum:
https://www.cancer.org.au/support-and-services/workshops-and-forums

Key questions to ask your doctor

- What are the symptoms of mental distress that I should look out for?
- Where can I access psychosocial support to help me better manage my condition physically and emotionally?
- Is there an activity or hobby you recommend to help cope with the stress that has worked for your other patients?
- When should I start considering professional mental health support?

MY NOTES

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GLOSSARY[38,39]

1. **Alveoli**: Tiny air sacs at the end of the bronchioles (tiny branches of air tubes in the lungs). The alveoli are where the lungs and the blood exchange oxygen and carbon dioxide during the process of breathing in and breathing out.
2. **Bronchi**: The large air passages that lead from the trachea (windpipe) to the lungs.
3. **Biomarker**: A biological molecule found in blood, other body fluids, or tissues that is a sign of a normal or abnormal process, or of a condition or disease. A biomarker may be used to see how well the body responds to a treatment for a disease or condition. Also called a molecular marker and signature molecule.
4. **Biomarker testing:** A laboratory method that uses a sample of tissue, blood, or other body fluid to check for certain genes, proteins, or other molecules that may be a sign of a disease or condition, such as cancer.
5. **Carcinoma:** Cancer that begins in the skin or in tissues that line or cover internal organs.
6. **CT-scan:** A procedure that uses a computer linked to an X-ray machine to make a series of detailed pictures of areas inside the body. The pictures are taken from different angles and are used to create 3-dimensional (3-D) views of tissues and organs. A dye may be injected into a vein or swallowed to help the tissues and organs show up more clearly.
7. **DNA (deoxyribonucleic acid):** The molecules inside cells that carry genetic information and pass it from one generation to the next.
8. **Driver mutation:** A term used to describe changes in the DNA sequence of genes that cause cells to become cancer cells and grow and spread in the body.
9. **Dysregulation:** a condition where a process in the body is not controlled in the way that it normally should be.
10. **Gene:** The functional and physical unit of heredity passed from parent to offspring. Genes are pieces of DNA, and most genes contain the information for making a specific protein.
11. **Lymph node:** A small bean-shaped structure that is part of the body's immune system. Lymph nodes filter substances that travel through the lymphatic fluid, and they contain lymphocytes (white blood cells) that help the body fight infection and disease.
12. **Metastases:** The spread of cancer cells from the place where they first formed to another part of the body. In metastasis, cancer cells break away from the original (primary) tumor, travel through the blood or lymph system, and form a new tumor in other organs or tissues of the body.
13. **Mucus:** A thick, slippery fluid made by the membranes that line certain organs of the body, including the nose, mouth, throat, and vagina.
14. **Mutation**: Any change in the DNA sequence of a cell. Mutations may be caused by mistakes during cell division, or they may be caused by exposure to DNA-damaging agents in the environment. Mutations can be harmful, beneficial, or have no effect.
15. **Next-generation sequencing:** A term that describes methods used in the lab to learn the order of building blocks (called nucleotides) for millions of DNA or RNA fragments at the same time. Computers are used to piece together the fragments in order to sequence a person or other organism's entire DNA, large segments of DNA or RNA, or the DNA in specific types of cells from a sample of tissue. NGS can also identify changes in certain areas of the genome or in specific genes.

GLOSSARY[39,40]

16. **Palliative treatment:** Treatment given to help relieve the symptoms and reduce the suffering caused by cancer or other life-threatening diseases. Palliative therapy may help a person feel more comfortable, but it does not treat or cure the disease.
17. **PET-CT scan:** A procedure that combines the pictures from a positron emission tomography (PET) scan and a computed tomography (CT) scan. The PET and CT scans are done at the same time with the same machine. The combined scans give more detailed pictures of areas inside the body than either scan gives by itself.
18. **Polymerase chain reaction:** A laboratory method used to make many copies of a specific piece of DNA from a sample that contains very tiny amounts of that DNA. PCR allows these pieces of DNA to be amplified so they can be detected. PCR may be used to look for certain changes in a gene or chromosome, which may help find and diagnose a genetic condition or a disease, such as cancer.
19. **Recurrence:** the fact of happening again.[s]
20. **Sputum:** Mucus and other matter brought up from the lungs by coughing.
21. **Tumour:** An abnormal mass of tissue that forms when cells grow and divide more than they should or do not die when they should. Tumors may be benign (not cancer) or malignant (cancer).

Further reading and support

National Cancer Institute – Cancer Terms:
https://www.cancer.gov/publications/dictionaries/cancer-terms

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