



Terminology guide

Be ready for your next appointment

You might find that speaking to your healthcare professional at appointments can feel like learning a new language. There are lots of words that you might not understand at first, but it's okay to ask your doctor to repeat themselves or stop and define exactly what they mean.

We have put together this quick and handy guide to help you prepare for appointments ahead of time. Take some time to learn the meanings of the words so that when your doctor uses them, you have a better idea of what your doctor is saying.



Momentsthatcount.co.uk

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MOMENTS *that* COUNT

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Advanced:

Cancer that is unlikely to be cured but maybe controlled with treatment. The cancer may have spread from where it first started to nearby tissue, lymph nodes, or other parts of the body. Treatment may be given to help shrink the tumour, slow the growth of cancer cells, or relieve symptoms. You might also hear the terms 'secondary' or 'metastatic'.¹

Biomarker:

A substance found in blood, urine, or body tissue that can give doctors useful information about a cancer.^{2,3} Biomarkers are molecules that indicate normal or abnormal process taking place in your body and may be a sign of an underlying condition or disease. Various types of molecules, such as DNA (genes), proteins or hormones, can serve as biomarkers, since they all indicate something about your health.³

Complete response:

The disappearance of all signs of cancer in response to treatment. This does not always mean the cancer has been cured. Also called complete remission.⁴

De novo metastatic breast cancer:

Breast cancer that wasn't detected until it had spread to another part of the body. "De novo" means from the beginning.⁵

Disease free survival:

In cancer, the length of time after primary treatment for a cancer ends that the patient survives without any signs or symptoms of that cancer. In a clinical trial, measuring the disease-free survival is one way to see how well a new treatment works. Also called DFS, relapse-free survival, and RFS.⁶

DNA:

DNA stands for Deoxyribonucleic Acid. They are the molecules inside cells that carry genetic information and pass it from one generation to the next.⁷

ECG (electrocardiogram):

An electrocardiogram (ECG) is a simple test that can be used to check your heart's rhythm and electrical activity. Sensors attached to the skin are used to detect the electrical signals produced by your heart each time it beats. These signals are recorded by a machine and are looked at by a doctor to see if they're unusual. An ECG may be requested by a heart specialist (cardiologist) or any doctor who thinks you might have a problem with your heart, including your GP.⁸ Your clinician may want to take your baseline ECG before starting you on medication. This is to see if the medication presents any changes to your result.

Endocrine (hormone) therapy:

Treatment that adds, blocks, or removes hormones. For certain conditions (such as diabetes or menopause), hormones are given to adjust low hormone levels. Hormones can also cause certain cancers (such as prostate and breast cancer) to grow. To slow or stop the growth of cancer, synthetic hormones or other drugs may be given to block the body's natural hormones, or surgery is used to remove the gland that makes a certain hormone. Also called hormonal therapy, hormone therapy, and hormone treatment.⁹

Event free survival:

In cancer, the length of time after primary treatment for a cancer ends that the patient remains free of certain complications or events that the treatment was intended to prevent or delay. These events may include the return of the cancer or the onset of certain symptoms, such as bone pain from cancer that has spread to the bone. In a clinical trial, measuring the event-free survival is one way to see how well a new treatment works. Also called EFS.¹⁰

Fatigue:

Extreme tiredness and an inability to function due to a lack of energy.¹¹

Gene:

Pieces of DNA that contain information for making a specific protein.¹²

HER2+/human epidermal growth factor receptor 2-positive:

Describes cells that have a protein called HER2 on their surface. In normal cells, HER2 helps control cell growth. Cancer cells that make too much HER2 may grow more quickly and are more likely to spread to other parts of the body. Checking to see if a cancer is HER2 positive may help plan treatment, which may include drugs that kill HER2-positive cancer cells. Cancers that may be HER2 positive include breast, bladder, pancreatic, ovarian, and stomach cancers. Also called c-erbB-2 positive and human epidermal growth factor receptor 2-positive.¹³

HER2-/human epidermal growth factor receptor 2-negative:

Describes cells that have a small amount or none of a protein called HER2 on their surface. In normal cells, HER2 helps control cell growth. Cancer cells that are HER2 negative may grow more slowly and are less likely to recur (come back) or spread to other parts of the body than cancer cells that have a large amount of HER2 on their surface. Checking to see if a cancer is HER2 negative may help plan treatment. Cancers that may be HER2 negative include breast, bladder, ovarian, pancreatic, and stomach cancers. Also called human epidermal growth factor receptor 2-negative.¹⁴

HR+/hormone receptor-positive:

Describes cells that have a group of proteins that bind to a specific hormone. For example, some breast cancer cells have receptors for the hormones oestrogen or progesterone. These cells are hormone receptor-positive and they need oestrogen or progesterone to grow. This can affect how the cancer is treated. Knowing if the cancer is hormone receptor-positive may help plan treatment.¹⁵

HR-/hormone receptor-negative:

Describes cells that do not have a group of proteins that bind to a specific hormone. For example, some breast cancer cells do not have receptors for the hormones oestrogen or progesterone. These cells are hormone receptor-negative and they do not need oestrogen or progesterone to grow. This can affect how the cancer is treated. Knowing if the cancer is hormone receptor-negative may help plan treatment.¹⁶

Hormones:

Substances in the body that control certain cells or organs.¹⁷ Oestrogen²⁴ and progesterone²⁶ are examples of hormones.

Immune system:

A complex network of cells, tissues, organs, and the substances they make that helps the body fight infections and other diseases. The immune system includes white blood cells and organs and tissues of the lymph system, such as the thymus, spleen, tonsils, lymph nodes, lymph vessels, and bone marrow.¹⁸

Malignant:

Malignant tumours are cancerous. Cells that are malignant grow uncontrollably and can invade nearby tissue and spread to other parts of the body.¹⁹

Menopause:

Menopause is when your periods stop due to lower hormone levels. This usually happens between the ages of 45 and 55. It can sometimes happen earlier naturally or for reasons such as surgery to remove the ovaries (oophorectomy) or the uterus (hysterectomy), cancer treatments like chemotherapy, or a genetic reason. Sometimes the reason is unknown.²⁰

Mutation:

Any change in the DNA sequence of a cell. Mutations can have a positive effect, a negative effect, or no effect. Some mutations may lead to cancer or other diseases.²¹

Objective response rate:

The percentage of people in a study or treatment group who have a partial response or complete response to the treatment within a certain period of time. A partial response is a decrease in the size of a tumor or in the amount of cancer in the body, and a complete response is the disappearance of all signs of cancer in the body. In a clinical trial, measuring the objective response rate is one way to see how well a new treatment works. Also called ORR.²²

Oestrogen:

A type of hormone made by the body that helps develop and maintain female sex characteristics.²⁴

Overall survival:

The length of time from either the date of diagnosis or the start of treatment for a disease, such as cancer, that patients diagnosed with the disease are still alive. In a clinical trial, measuring the overall survival is one way to see how well a new treatment works. Also called OS.²³

Primary:

Primary breast cancer is breast cancer that has not spread beyond the breast or the lymph nodes under the arm.²⁵

Progesterone:

A type of hormone made by the body that plays a role in the menstrual cycle and pregnancy. Progesterone can also be made in the laboratory. It may be used as a type of birth control and to treat menstrual disorders, infertility, symptoms of menopause, and other conditions.²⁶

Progression:

In medicine, the course of a disease, such as cancer, as it becomes worse or spreads in the body.²⁷

Progression-free survival:

The length of time during and after the treatment of a disease, such as cancer, that a patient lives with the disease but it does not get worse. In a clinical trial, measuring the progression-free survival is one way to see how well a new treatment works. Also called PFS.²⁸

Quality of life (QoL):

Quality of life (QoL) is a concept which aims to capture the well-being, whether of a population or individual, regarding both positive and negative elements within the entirety of their existence at a specific point in time. For example, common facets of QoL include personal health (physical, mental, and spiritual), relationships, education status, work environment, social status, wealth, a sense of security and safety, freedom, autonomy in decision-making, social-belonging and their physical surroundings.²⁹

Recur/recurrent:

When cancer comes back after it is treated. It may come back to the same place as the original (primary) tumour or to another place in the body.³⁰

Secondary breast cancer:

The name for breast cancer that has spread to other parts of the body, such as the bones, the liver, lungs or brain. It can also be referred to as stage 4 or metastatic breast cancer.³¹

Stage:

This describes the extent of cancer within the body and is usually represented by a number and/or letter.^{31, 32}

Targeted therapy:

A type of treatment that uses drugs or other substances to find and attack specific types of cancer cells with less harm to normal cells.³³

Time to progression:

The length of time from the date of diagnosis or the start of treatment for a disease until the disease starts to get worse or spread to other parts of the body. In a clinical trial, measuring the time to progression is one way to see how well a new treatment works. Also called TTP.³⁴

TNBC / Triple-negative breast cancer:

A type of breast cancer in which the tumour cells do not have oestrogen receptors (ER), progesterone receptors (PR), or large amounts of HER2/neu protein on their surface. Knowing whether breast cancer is triple negative is important in planning treatment. Also called ER-negative PR-negative HER2/neu-negative breast cancer and TNBC.³⁵

Tumour:

An abnormal mass of tissue that forms when cells divide more than they should or do not die when they should. Tumours may be benign (not cancer), or malignant (cancer).³⁶

Reporting of side effects

If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at <https://yellowcard.mhra.gov.uk/>

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