

Immunotherapy for lung cancer



Introduction

If you or someone you care for has lung cancer and immunotherapy is a treatment option for you, then it's almost certain that you will have a lot of questions.

We have written this booklet in partnership with lung cancer experts and people affected by lung cancer so that it is as accurate and relevant as possible. It will help you understand more about your cancer so you can make positive, informed decisions about your care and treatment.

Use this booklet along with information provided by your healthcare team.

Remember that most healthcare professionals are usually only too happy to answer questions and help you with things that may be unclear or causing you concern.

We hope that this booklet answers most of your questions about immunotherapy. If you would still like to talk to someone about lung cancer, call our free and confidential **Ask the nurse** service on: **0800 358 7200** or email: lungcancerhelp@roycastle.org



How treatments and other healthcare services are provided is likely to be affected by the coronavirus (COVID-19) pandemic. Your medical team will make sure you know about any national or local variations to what is described in this booklet. They will work in ways to keep you safe while getting the best possible service.



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Immunotherapy for lung cancer

What is immunotherapy?

Immunotherapy is a drug treatment used for some types of cancer, including some lung cancers. Immunotherapy is often shortened to IO (*immuno-oncology*). While some drugs are used to kill cancer cells (chemotherapy, for example), immunotherapy drugs help the body's immune system find, attack and destroy cancer cells.

If you want to know about your immune system and how immunotherapy works in some detail, keep reading. If not, turn to page 8.

About your immune system

The immune system helps protect us from infections and disease, and part of its job is to stop bacteria and viruses that can make us unwell. It is made up of different cells, tissues and organs that work together to keep our bodies as healthy as possible:

- white blood cells – these circulate around the body in blood and lymph vessels on the lookout for unwanted or damaged cells
- lymph glands – also called lymph nodes, these are normally pea-sized lumps of tissue that contain white blood cells and are found throughout the body
- spleen – this organ sits next to the stomach and filters old or damaged red blood cells from the blood and can release white blood cells when needed
- thymus – this glandular tissue releases hormones and develops and stores T-cells, and becomes smaller and less active in adulthood

Most of the time, our immune system comfortably handles any challenges our body faces. It can produce *antibodies* that help fight disease and can remain in our bodies ready to fight off future similar challenges. This is an *acquired immune response*.

Vaccination also helps your body's immune system to be prepared for viruses by prompting your immune system to produce virus-specific antibodies before being exposed to the virus.



Lymphocytes are a type of white blood cell that develop from stem cells in the bone marrow. Some remain in the bone marrow and are known as B-lymphocytes (*B-cells*). Others move to the thymus and develop into T-lymphocytes (*T-cells*).

Cells in our bodies use proteins on their surface to “communicate” with other cells. Damaged cells have specific proteins (*antigens*) on their surface that identify them as being damaged. These antigens trigger T-cells to destroy the damaged cells and alert other white blood cells that may join in the attack.

What about cancer?

Cancer starts when cells become damaged and begin to grow and multiply without normal controls. These abnormal cells may continue to increase in number because:

- although the immune system recognises the cancer cells, it is not strong enough to kill them
- cancer cells send signals to the immune system not to attack them, overriding the normal antigen/T-cell messages
- cancer cells “hide” from the immune system

Over time, when left unchecked, these cancer cells can grow together to form a lump, or *tumour*, in solid cancers such as lung cancer.

How does immunotherapy work?

Immunotherapy helps your immune system fight cancer. T-cells respond to specific proteins on the surface of other cells that tell them what to do. Healthy cells have proteins on their surface that tell T-cells to ignore them. Unhealthy cells don't have these proteins, so the T-cells know to kill them.

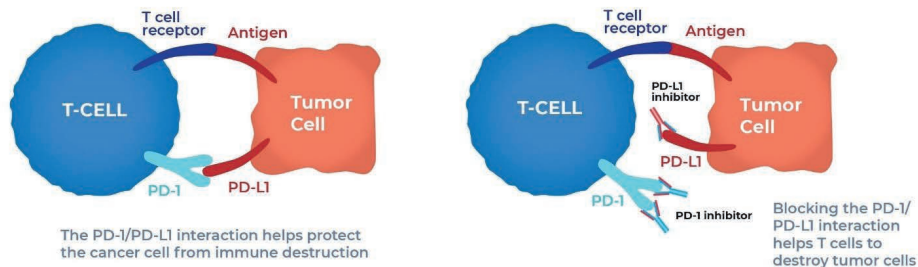
While cancer cells would ideally be killed by the immune system's T-cells, some of them have proteins that make them appear like healthy cells so *the T-cells don't kill them*.

One of these cancer-cell proteins is called PD-L1 (*programmed cell death ligand 1*). When this protein connects with a T-cell protein called PD-1 (*programmed cell death protein 1*), it convinces the T-cells that it's a healthy cell, *not* a cancer cell, and so avoids being destroyed.

The connection between the PD-1 and PD-L1 proteins is called an *immune checkpoint*. This checkpoint is known to stop the immune system's T-cells doing their job of destroying cancer cells.

Immunotherapy drugs block, or *inhibit*, this checkpoint and so your body's own T-cells can once again connect with and kill the cancer cells. These immunotherapy drugs are called *checkpoint inhibitors*.

The PD-1/PD-L1 Checkpoint



Credit: Lung Cancer Alliance

Checkpoint inhibitors work in a similar way to antibodies. Current immunotherapy drugs are called *monoclonal* antibodies (MABs). “Mono” relates to the fact that the drug is made up of a single type of protein, and “clonal” simply means that protein is copied, or *cloned*, in the laboratory many times.

The MABs target the PD-1 protein on the T-cell or the PD-L1 protein on the cancer cell.

This is complex information and you don't need to know it to receive immunotherapy. Ask your medical team about the things you don't understand and they will try to explain it so that it makes sense to you.

Treating lung cancer with immunotherapy

How do doctors choose immunotherapy?

As with any treatment for cancer, decisions about using immunotherapy are based on knowing the type of lung cancer you have, and if it is in one place or it has spread. You will most likely have already had several tests to find this out including an X-ray, CT scan and a tissue sample (*biopsy*).



For more information about tests for lung cancer and lung cancer types, please see the *Managing your lung cancer diagnosis* booklet in our *Lung cancer – Answering your questions* pack. See page 2 to find out how to get a copy.

A biopsy will tell doctors which of the two main types of lung cancer you have, described by how the cancer cells look under the microscope:

- small cell lung cancer (SCLC), and
- non-small cell lung cancer (NSCLC)

NSCLC makes up most of the cases of lung cancer (around 87% in the UK).

Immunotherapy drugs can be used to treat some types of locally advanced or advanced NSCLC. SCLC has fewer immunotherapy options though treatments are under development. Some people with previously untreated extensive stage SCLC may be able to have an immunotherapy treatment in combination with chemotherapy.

Doctors can't accurately predict who will respond to immunotherapy or how well, but evidence shows that it may give longer-term positive results for around one in five people.

For some people, immunotherapy can be effective for several years. It can still be a good treatment option even if its effectiveness isn't as long.

All biopsies should also be tested for specific changes, called *mutations*, in the genes of the cancer cells. If your biopsy shows that your cancer has these mutations, you would be offered a targeted therapy before immunotherapy. Less than 15% of people with NSCLC are found to have mutations (including EGFR, ALK and ROS1) that have targeted therapy treatment options.



The biopsy can be also checked for one of the proteins on the cancer cells – PD-L1. The levels of this protein can help doctors decide if they will offer you immunotherapy.

At the time of your diagnosis, a group of healthcare professionals, known as a *multidisciplinary team* (MDT), will talk about your case to work out the best treatment and care options for you. From then on, the doctor in charge of your care will normally be the person who considers your treatment options and speaks to you about what may be best for you.

Who will be in my MDT?

Your team will vary depending on where you are getting your treatment, and you may not meet all of them. An MDT will often include:

- a lung cancer nurse specialist
- a chest physician (respiratory consultant)
- an oncologist (cancer doctor) specialising in lung cancer
- a thoracic (chest) surgeon
- a radiologist
- a pathologist

Why am I being offered immunotherapy?

Your MDT or cancer doctor will have considered the results any scans and X-rays and other tests you may have had that show the size and location of the cancer, and your general health and medical history.

They will have decided that immunotherapy is a suitable treatment for you, either on its own or in combination with chemotherapy. Some of the more likely options, along with some possible side effects, are described on pages 13 and 14.



They will use the results of all your tests to *stage* your lung cancer.

Staging is a way of describing the size and any spread of cancer and is an important factor in deciding on the best treatment for you. This process will be done when you are first diagnosed, and again after treatments to measure any response or to see if your cancer has progressed.

I was very ill. Stage 4. Time was running out and chemotherapy had failed. I felt that, at 53, I was far too young to give up, plus I had a 14-year-old child who still needed me. It was an easy decision to make to have immunotherapy. It gave me hope.”

Pamela

Staging for lung cancer is complicated, but your doctors will explain it as it applies to you.

Doctors classify four stages of lung cancer based on what's known as the TNM system*. In this system, T (followed by a number 1 to 4) refers to the size of the tumour, N (followed by a number 0 to 3) refers to any spread of the cancer to lymph nodes, and M (followed by 0, 1a, 1b or 1c) refers to any spread of the cancer to other parts of the body (*metastasis*).

The combination of numbers and letters means the extent of a person's lung cancer can then be generally grouped into one of the four stages:

- Stage 1 (including subgroups 1A1, 1A2, 1A3 and 1B) means the cancer is small and in one area of the lung (*localised*).
- Stage 2 or 3 (including subgroups 2A, 2B, 3A, 3B and 3C) cancers are larger and may have spread into surrounding tissues. There may be cancer cells in the lymph nodes (*locally advanced*).
- Stage 4 (including subgroups 4A and 4B) means the cancer has spread to another part of the body (*secondary or metastatic cancer*).

*Based on the International Association for the Study of Lung Cancer's 8th Edition of the TNM Classification for Lung Cancer (www.iaslc.org)

As with other lung cancer treatments, your doctor will also look at your general wellbeing and how you are managing everyday life. This will help them work out what is known as your *performance status* (PS). This is a very important factor when deciding on the best treatment options for you.

The activities they will consider will include how you manage independently to do things like getting dressed, eating, and bathing as well as more complex tasks such as cleaning the house and holding down a job. The most commonly used PS scale ranges from 0 to 4, with 0 being fully able to do things and with no symptoms, and 4 being bedridden.

People with poorer PS, that is if a doctor assesses them as PS 2, 3 or 4, can find it harder to tolerate some cancer treatments. They may have more side effects and see less overall benefit. Performance status can change over time. Your PS may worsen as your cancer progresses. It can also get worse because of a build-up of adverse side effects of treatments. Your PS may also improve if your cancer-related symptoms reduce as your cancer responds to treatment. A physiotherapist or occupational therapist may also be able to help you improve your PS.

Some health conditions can make it less likely that your doctors will be able to offer you immunotherapy. These may include liver or kidney disease, if you have had an organ transplant, or if you have an autoimmune condition such as HIV. Your cancer doctor will speak to you if you have an existing health condition that may make immunotherapy less effective or even harmful.

Immunotherapy seems to have stabilised my condition. It has given me confidence to think of my cancer not as a “terminal condition” but as a long term manageable condition and to enjoy life.

Tony

What if I don't want to have any treatment?

If your doctors are offering, even recommending, immunotherapy as a treatment for you, it will be because they believe it may have benefits for you and be worthwhile. However, the decision to go ahead with it or not is entirely yours.

If you decide against treatment now, your medical team will respect your decision. However, your cancer doctor and lung cancer nurse specialist will talk to you about how your fitness or performance status may be affected as your cancer grows.

This could mean some of your current treatment options, including immunotherapy, may no longer be available to you as your doctor may not consider your health strong enough to handle the treatment.

Which immunotherapy drugs can be used?

There are currently* are four main lung cancer immunotherapy drugs available as a standard treatment on the NHS. Each drug has both a drug name and a brand or trade name:

- nivolumab (Opdivo®)
- pembrolizumab (Keytruda®)
- atezolizumab (Tecentriq®)
- durvalumab (Imfinzi®)

These are all monoclonal antibodies that are PD-1/PD-L1 checkpoint inhibitors. These drugs may be used to treat some NSCLC. Nivolumab and pembrolizumab target and block the PD-1 protein on the T-cell, and atezolizumab and durvalumab target and block the PD-L1 protein on the cancer cell.

Blocking these proteins allows the body's immune system to attack and destroy cancer cells.

You may have an immunotherapy drug on its own or in combination with chemotherapy. There are many treatment options depending on the type of lung cancer you have, how advanced it is and what other treatments you have already had. Your cancer doctor will speak to you about the treatment they are offering you. Some treatment may not be suitable for you.

Immunotherapy drugs can be used as your first treatment, known as first-line treatment. This could be an option if tests on your biopsy showed a high level of the protein PD-L1. It may also be used as first-line treatment in combination with chemotherapy. Others are used after another drug treatment and would be called a second-line or third-line treatment, for example.

Durvalumab can sometimes be given as an additional (*adjuvant*) treatment for a year after combined chemotherapy and radiotherapy when the person's lung cancer is under control.

Atezolizumab, in combination with carboplatin and etoposide (chemotherapy drugs), may also be used to treat some people with previously untreated, extensive-stage small cell lung cancer, who also have a PS of 0 or 1.

Not all immunotherapy drugs licensed to treat non-small cell lung cancer are currently available as a standard treatment on the NHS. When a new drug gains a European licence, it is available to buy and use as a treatment in the UK.

However, NHS doctors are only allowed to use drugs as standard treatment approved by either the National Institute for Health and Care Excellence (NICE) for use in England, Wales and Northern Ireland, or the Scottish Medicines Consortium (SMC) for use in Scotland, or are pending a decision by NICE about routine commissioning (England).

For example, immunotherapy has been licensed as a treatment for some people after having lung surgery (also an adjuvant treatment) and is in the process of gaining full approval from NICE and the SMC.

NICE and the SMC look at a combination of how well a drug works and the cost of using the drug. They then compare it to other available drugs used for the same health problem.

This can lead to variations in the availability of these drugs on the NHS, depending on which country in the UK you live in and whether or not they have been approved for use on the NHS.

Research is also underway to find out if there is benefit to having immunotherapy before lung surgery or combined chemoradiotherapy (*neo-adjuvant* treatment).

A drug may also be available through the Early Access to Medicines Scheme or as part of a clinical trial. Some drugs may also be available through compassionate use paid for through the Cancer Drugs Fund.

Your consultant will explain this if it applies to you. This is a way for doctors to offer treatments under development (as yet without NICE or SMC approval) to some people with no other treatment options or not able to take part in a clinical trial.

The up-to-date approvals for treatments and those that are in the process of getting approval are online at:

- www.scottishmedicines.org.uk/medicines-advice
- www.nice.org.uk/guidance

Receiving immunotherapy treatment

Where will I go for immunotherapy treatment?

Immunotherapy is a *systemic* cancer treatment that you will receive through an intravenous infusion (*drip*), like chemotherapy. It is usually an outpatient treatment in a chemotherapy day unit, and it is likely to be chemotherapy nurses and other staff who look after you on the day.

Nivolumab and durvalumab are given every two weeks, but sometimes every four weeks to reduce hospital visits. Atezolizumab can be given every three or four weeks, and pembrolizumab every three or six weeks. Your healthcare team will speak to you about your treatment plan.

Chemotherapy day unit

Most chemotherapy day units are open Monday to Friday. You can usually make an appointment time to suit both you and the unit.

TOP TIP

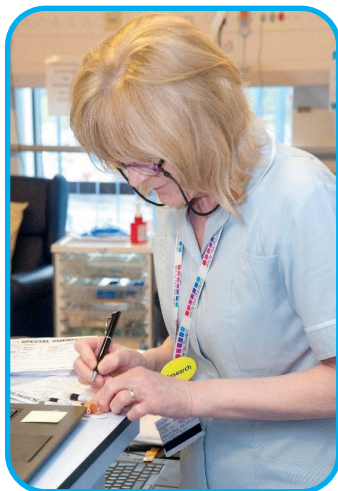
A hand-held electric fan may help to keep you cool and breathe more easily if the treatment area is stuffy.

How often will I need to go for treatment?

This depends on the immunotherapy drug.

Nivolumab and durvalumab are given every two weeks. Atezolizumab is given every three weeks and pembrolizumab every three or six weeks. Your healthcare team will speak to you about your treatment plan.

Treatment normally takes around 90 minutes.



What happens on the day of my treatment?

When you arrive for your appointment, you will be welcomed by a chemotherapy nurse, who will go over your personal details. They will then take your height and weight to work out your body mass index (BMI), an important way of helping to monitor how well you are doing during your treatment and may be used to calculate the amount of immunotherapy drugs you need.

Your blood will be checked before treatment, and regularly during and after treatment, to see if your white blood cells (cells that fight infection), haemoglobin (cells that carry oxygen), and platelets (cells that clot the blood) are normal. This is called your *blood count*.

The blood sample will also check if your blood biochemistry (kidney and liver function) is within normal limits.

If your blood count is too low, you might get a blood transfusion, drug dose reduction, or delay in your treatment. Your temperature and blood pressure will also be checked so the nurse can be sure you are well enough to get your treatment.

While receiving your immunotherapy, you will likely be in an armchair or reclining chair, or sitting propped up on a hospital bed.

Though immunotherapy treatment may not take as long as some chemotherapy, it can still help to take something to keep you occupied during it, such as a book, magazine or portable music player with earphones. There will be other people receiving immunotherapy and chemotherapy at the same time as you, so there is often a chance to chat with them if you wish.

Can I bring a relative or friend with me?

It is usually the case that you can bring a relative or friend with you, particularly to your first hospital appointment. They may be able to sit with you and keep you company while you receive your immunotherapy. Each treatment centre is different, so check with your own chemotherapy day unit before your appointment if someone can come with you. Infection control measures introduced as a result of the COVID-19 may also affect this.

However, each treatment centre is different, and some just don't have the space to have people accompanied at every visit.

I am frightened of needles – what should I do?

It is not unusual to be frightened of needles and nursing staff have many ways of helping people to feel less anxious. Tell them if you are feeling nervous before you start your treatment. There are also creams available to numb your skin so you hardly feel anything.

You can also have immunotherapy and other drugs and fluids through a PICC line. PICC stands for *peripherally inserted central catheter*. The line goes into a vein in your arm, under local anaesthetic. A doctor or nurse can put it in during an outpatient appointment. PICC lines can be left in for several months so you won't be facing the prospect of a needle each time you go for treatment.

Can I drive after receiving immunotherapy?

Immunotherapy affects people in different ways. Some people feel all right and able to drive after receiving immunotherapy. Others may experience some side effects and not be able to drive straight away. It is best not to drive to your first immunotherapy appointment and see how you feel after receiving treatment. If you need help with travelling, your lung cancer nurse specialist or immunotherapy nurse may be able to help to arrange transport for you.

Important information about driving

The DVLA has some strict guidelines about driving relating to lung cancer. These guidelines are in place because the DVLA considers lung cancer to represent a high risk of cancer spreading to affect the central nervous system (CNS) or brain. This could make someone less safe to be in control of a vehicle.

Car or motorcycle licence

You must tell the DVLA if any of the following apply to you:

- problems develop with your nervous system or brain (*metastases*)
- your doctor says you might not be fit to drive
- you are restricted to certain types of vehicles or vehicles that have been adapted for you
- your medication causes you side effects that could affect your driving

Speak to your doctor to find out if your lung cancer causes other symptoms that will affect your driving, or if you must tell the DVLA about them. Driving after surgery is restricted until your doctor says it is safe for you to drive.

Bus, coach or lorry licence

You must tell the DVLA if you have lung cancer. The outcome for these licence types is likely to be that you will not be allowed to drive. You may be able to get your licence back if specific criteria about your lung cancer after your treatment ends are met.

If any of these conditions apply to you, you can tell the DVLA about this online here: www.gov.uk/report-driving-medical-condition

Find out more information at: www.gov.uk/lung-cancer-and-driving

Can I take other medicines or herbal remedies while getting immunotherapy?

Some other medicines can be harmful to take at the same time as immunotherapy.

Tell your cancer doctor or lung cancer nurse specialist about any other medicines you take. This includes prescription medicine, over-the-counter medicines, vitamins and herbal supplements.

Your cancer doctor may change the dose of your other medicines or choose different ones while you are on immunotherapy.

Can I have tetanus, flu or other vaccinations?

Receiving immunotherapy treatment does not necessarily stop you from having a vaccination. Everyone's situation is different, however, and you will need to get the advice of your cancer doctor before going ahead.



How long will I be on immunotherapy?

This will depend on your unique health situation. Your treatment may stop if your cancer stops responding to it and starts to get worse again, or you have adverse side effects that make it unwise to continue treatment. At this point, your doctors will talk to you about any other available treatment and care options.

The duration of most current immunotherapy drug treatments is restricted even if your lung cancer appears to be under control. Depending on the drug, there is likely to be a maximum number of treatments (for example, 26 treatments for durvalumab) or a maximum length of time you may be on it (for example, 24 months for nivolumab, pembrolizumab and atezolizumab). If you are receiving first-line atezolizumab for metastatic NSCLC, this time limit does not apply.

Your treatment may be stopped earlier for other reasons, such as side effects.

These limits are in place because there is no clear evidence that continuing the treatment will have any benefit compared to stopping after the time limit or number of treatments. This is also weighed up against the ongoing cost of providing this drug.

Your medical team will give you information about your treatment that will include details of how long it may last.

*I stopped immunotherapy after 12 months.
I am fine with it.*

*It makes sense to me that the nature of the drugs
is likely by now to have taught my immune system
to change its behaviour and to attack the cancer cells.*

Tony

What side effects can I expect with immunotherapy?

When being treated with immunotherapy, your immune system will become more active. This can cause side effects such as:

- fatigue (tiredness)
- flu-like symptoms
- rashes
- diarrhoea
- inflammation (in your lungs, liver, kidneys, thyroid or pituitary gland)

While the side effects can often be milder than what you may expect from chemotherapy, some people can experience severe immune-related side effects, but the more serious side effects occur less often.

Side effects of checkpoint inhibitor treatment typically appear within a few weeks or months of starting treatment. However, they can arise at any time during treatment – as early as days after the first infusion, but sometimes as long as a year after treatment has finished.

Immunotherapy drugs work by removing the brakes on the body's immune system. This means the immune system can sometimes start attacking different parts of the body as well as the cancer. This can cause serious or even life-threatening problems in the lungs, intestines, liver, hormone making glands, kidneys, or other organs.

It's very important to report any new side effects to your health care team promptly. If serious side effects do occur, your immunotherapy treatment may need to be stopped. You may also be treated with high doses of corticosteroids to suppress your immune system.

If you are on immunotherapy and notice side effects or other changes, speak to your doctor or lung cancer nurse.

*I am fortunate to have, as yet, manageable side effects.
Itching all over at times – antihistamines.*

*Some rashes – steroid cream. Tiredness the first few
days. I find that drinking plenty of water
before and after treatment also helps.*

Tony

You will be given a dedicated treatment helpline contact number to phone if you experience difficulties with side effects. This number should be used at times when it may be difficult to contact your lung cancer nurse specialist or cancer doctor, such as during the night or at weekends.

There is space on page 33 for you to write down the phone numbers.

Clinical trials

Clinical trials are an essential part of medical research. They are a way of finding out if new treatments are better than current best practice.

Progress in medicine depends on people wanting to take part in trials so that their own situation may help generate new knowledge about the potential benefits and/or risks of newly developed drugs or treatment approaches.

People take part in clinical trials for different reasons. You may:

- hope that a new experimental treatment will be better than treatment you would otherwise be offered
- want to be part of “cutting edge” medicine
- hope that others may benefit from the knowledge gained from how the treatment works for you

On some clinical trials, your condition may be monitored more regularly than with standard care. This may include more blood tests, CT scans or other cancer tests. You may also spend more time with your doctor or nurse.

This could mean that any changes in your health, related to the treatment you are having or not, are picked up and acted upon earlier than if you were not in a trial. Trials recruit a group of people, some of whom receive the new treatment and the others receive the current best available treatment. People are randomly allocated to one group or the other, so you may not have any control over whether you receive the new treatment.

The drug trial or research study on a new treatment may be done to check if it is safe or which drug dose is best. It may also be carried out to find if the new option is better than what is currently offered. It may be the same, or it may be worse. Drugs tested in trials may not be made available to everyone on the NHS after the trial, though people already getting the drug may continue to receive it for as long as it is effective.

Ask your cancer doctor about any clinical trials. Getting into a trial is often based on being able to meet some very specific criteria. Your cancer doctor will be able to tell you if you are eligible for a trial and where it is taking place.



If you would like to check what clinical trials are available, visit:

- UK Clinical Trials Gateway –
www.bepartofresearch.nihr.ac.uk
- Cancer Research UK –
www.cancerresearchuk.org/about-cancer/find-a-clinical-trial

Why is immunotherapy time limited?

We know that people can become anxious, even angry, when their treatment comes to an end after whatever limit is reached even though it appears to be still working. To some, it can seem unfair and leave them feeling vulnerable and afraid their cancer may come back.

However, by its very nature, immunotherapy is designed to set your body up to have ongoing defences against further cancer by priming your immune system – creating an *acquired immune response*. Pharmaceutical and medical professionals consider the current limits to be optimal for achieving that.

Immunotherapy is still a relatively new treatment for many cancers, including lung cancer. While evidence about how these drugs work over time is growing, the number of people receiving immunotherapy as a treatment is still quite low.

The drugs have only relatively recently become available as treatments on the NHS and so research based on those people living beyond the end of their treatment is therefore still limited.

We would like to see further research into the benefits or otherwise of extending the treatment periods for immunotherapy drugs so that people can feel confident that they are getting the best possible treatment and care, even if that involves time-limited drug treatment.

In the meantime, your doctors will be offering you the best available treatment and care within clinical guidelines.

How do the doctors know if the immunotherapy is working?

It can be difficult to measure exactly how well it is working, although an assessment will be made at some point during your treatment (usually a CT scan after three or four courses of immunotherapy).

You may notice yourself that the treatment is working if your symptoms have improved, for example, you are less breathless or not coughing as much. With immunotherapy, some people do experience a significant health improvement and are able to return to work, do vigorous exercise such as running or get away on a long-overdue holiday.

With chemotherapy or targeted therapies, effective treatment would show up as a reduction, or no increase, in tumour size. Immunotherapy can be different. Your cancer may appear to grow at the beginning of your treatment. This is called *pseudo-progression*. It can make it look like your treatment isn't working but it is a known response to the treatment.

When immunotherapy treatment works as it should, it encourages more and more immune cells to attack the cancer. The immune cells collect inside and around the tumour making it appear larger on a scan. As treatment progresses, the immune cells can kill the cancer cells and the tumour can be seen to get smaller.

*“ Within two months my health had improved dramatically. The tumours had shrunk over 70%.
My lung reinflated as it had collapsed.*

*My pleural effusion gone. After six months,
I went back to work on reduced hours. I wasn't like
I was before I was diagnosed, but I was so much better
and had excellent quality of life.* ”

Tony

What if the immunotherapy doesn't work for me?

Immunotherapy can have remarkable benefits for some people with lung cancer and it can be easily assumed to be the answer to your cancer. As only one person in every five who is suitable for immunotherapy sees longer-term positive results, it is important to be realistic about how well it may work for you.

If you are one of those people whose lung cancer does not respond to immunotherapy, or you have more serious side effects from the treatment, your cancer doctor will stop your treatment and speak to you about what will happen next.

This may include other treatment options to try to reduce your cancer. If not, your cancer doctor will talk to you about treatments and care to manage your symptoms and maximise your quality of life. Treatment options may include chemotherapy or radiotherapy.

If I get the full course of immunotherapy treatment, what happens next?

If you have reached the end of the treatment plan for your immunotherapy drug, it probably means that your lung cancer has continued to respond to the treatment over that time.

Immunotherapy has the potential to keep your lung cancer at bay and you will receive regular checks from your medical team, perhaps every six to twelve weeks. If any further lung cancer is found, it will be thoroughly investigated, and new treatment options considered according to the findings.

After immunotherapy finishes

How will I feel after treatment ends?

If your lung cancer has responded well to the immunotherapy, you may feel positive and optimistic going forward.

On the other hand, you may be anxious that you are no longer going to the day unit for treatment. You may have been going for several months and suddenly your routine has changed. This can make you feel worried or low, and this is normal. However, over time, these feelings should ease.

How will I be followed up?

After your immunotherapy treatment course has finished, you may have a scan to find out how your cancer has responded to it. Your cancer doctor will then speak to you about the results. If your cancer has responded well to the treatment, you may not need further treatment straight away.

You will then have regular check-ups with your oncology team to check that your cancer hasn't become active again. This may include blood tests, scans or X-rays. If you have any problems, or notice new or changed symptoms in between your appointments, let your cancer doctor or lung cancer nurse specialist know as soon as possible.

In general, cancer patients will have these regular checks until they show no evidence of new disease (*relapse*) for five years, at which point they will be discharged from their cancer doctor's care. If they show the cancer has come back, the process of deciding on the best course of action will start, exploring treatment options or best supportive care. Your GP will be sent a report about your treatment.

It has been hugely important to me to have the support of my medical team. My oncologist, the nurses who treated me and my specialist nurse all help make sure I can live the best life I can for as long as I can.

Nicola

Treatment after immunotherapy

Whether your immunotherapy stopped early, or your cancer has come back, further immunotherapy with the same drug or a different one is currently not an option within clinical guidelines.

As with any previous treatment, your next treatment options will depend on the type of lung cancer you have. Some people may be offered chemotherapy or a combination of treatments to reduce and manage symptoms.

The options are complex and may vary, so speak to your cancer doctor or lung cancer nurse specialist to find out what treatments or clinical trials may be available to you.



For more information about chemotherapy, see our *Chemotherapy for lung cancer* booklet. See page 2 to find out how to get a copy.

“ I have been treated with the same chemotherapy that I had first line (which had failed), however, this time it was successful, and I have been on maintenance for seven months with very good results. ”

Pamela

Looking ahead and ongoing support

Not everyone receiving immunotherapy has adverse side effects, and some people can feel quite well or have manageable symptoms. While some people find coping with things one day at a time, you may be interested in asking healthcare professionals involved in your care how your illness may affect you in the coming weeks and months.

This may seem a scary prospect. However, you may feel it is important to be realistic about your lung cancer and what that means for you and your future. You may want as much information as possible now so you can be more prepared, make decisions and plan.

A new symptom may be unrelated, but it is still important to pay attention. Things can happen quickly or slowly, and you may, for example, just gradually notice a difference in the range of activities you feel comfortable doing.



While it may seem overdramatic, particularly if you feel quite well now, thinking ahead realistically about potential difficulties can help you and those supporting you to manage better over time.

Your doctors and other healthcare professionals will not be able to predict if, when or how your circumstances will change, but they will be able to speak to you about some of the things you could find out about. You may want to speak to physiotherapists, occupational therapists, dietitians, and other doctors and nurses in your cancer and palliative care teams.

Some of the problems and symptoms associated with lung cancer don't get resolved with treatment. For example, you may continue to have muscle weakness, problems walking, or difficulties with speaking or swallowing.

There are services available that can give you extra support to help you overcome or adapt to some of these problems:

- **Physiotherapy** – this can help you maintain or improve your strength, mobility, balance and coordination through exercise and other advice. Physiotherapy can also help you with breath control, as well as coughing and chest clearing techniques.
- **Occupational therapy** – if you are struggling with some every day activities, like getting up stairs, bathing or cooking, an occupational therapist will look at equipment or alterations that can be made to help. They can also help you deal with fatigue or poor sleep, as well as some aspects of going back to work, if this is an option for you.
- **Speech and language therapy (SALT)** – this is a specialist team that helps people who find speaking clearly or loudly enough difficult, or who are not able to eat and swallow properly.
- **Nutritionists and dietitians** – they assess, diagnose and treat dietary and nutritional problems, and help you make the right choices about what you eat.

If you are finding it hard to get around, do some things about the house or people are finding it hard to understand you, speak to your lung cancer nurse or consultant. Also speak to them if you are finding it hard to eat enough or are worried you may not be eating the right things. They will refer you to the services you need.

Palliative care

Palliative care (sometimes called *supportive and palliative care*) describes care and support that is given to someone when a cure is not possible. This approach to treatment may start as soon as you are diagnosed, and it is not the same as *end-of-life care*.

Many healthcare professionals, both in hospitals and in the community, including GPs and nurses, provide palliative care as part of their jobs. This care is about making you as comfortable as possible, by managing your pain and other distressing symptoms. It also involves psychological, social and spiritual support for you, your family or carers.

Using hospice services

Every year hospices provide care and support to around 200,000 people, including adults and children with life-limiting or terminal conditions, and their families and friends.

There are hospices in many areas of the UK. They offer a range of personalised care provided by professional staff and volunteers. As well as taking care of people's physical needs, they also look after their emotional, spiritual and social needs. They also support carers, family members and close friends, both during a person's illness and during bereavement.

Hospice care is free, and is provided for however long it is needed, which could be days, weeks or even months. Not everyone has a hospice nearby, but hospice care may also be offered in the community or at home.

Hospices provide a range of services, including:

- pain and symptom control
- psychological and social support
- rehabilitation
- complementary therapies, such as massage and aromatherapy
- counselling
- spiritual care
- practical and financial advice
- support in bereavement



You can find out more about hospices and check if there is one near you at:

- www.hospiceuk.org

Important phone numbers and addresses

Lung cancer nurse specialist

- Name:
- Phone number:

Chemotherapy/immunotherapy nurse

- Name:
- Phone number:

Treatment hospital

- Address:
- Phone number:

Dedicated treatment helpline and emergency phone numbers

-

Questions to ask your doctor or lung cancer

Before choosing immunotherapy as a treatment option, it is important to understand the expected benefits, side effects and risks. Ask your cancer doctor or lung cancer nurse specialist these questions on your next visit.

1. What type of immunotherapy will I be getting?
2. What is the aim of this immunotherapy?
3. Are there other types of treatment that could be suitable for me instead of immunotherapy?
4. What are the risks and side effects of immunotherapy I will be getting?
How do these side effects compare with the side effects of other treatments?
5. How long will I have to wait before starting treatment?
6. How will I know if the immunotherapy is working?
7. What can I do to prepare for treatment and reduce the chance of side effects?
8. Will I need to change my lifestyle in any way?
9. Is there anything I can't do during treatment?
10. Can I go on holiday? Can I go abroad? What about travel insurance?
11. Is it safe for me to have travel vaccinations?
12. Am I still allowed to drive?
13. What can I do to help myself?

About our lung cancer information

We follow established quality standards and production principles to make our information trustworthy and easy to read. It is evidence based, following national clinical guidelines and best practice for managing lung cancer.

We believe information that is clear, accurate, evidence based, up to date and easy to use allows people to become better informed and more involved in their health and care.

Our information is written either by our information team or by lung cancer experts. We have a panel of lung cancer experts made up of doctors, nurse specialists and other health professionals involved in the treatment and care of people affected by lung cancer. These people help us on a voluntary basis. You can find out about our Expert Panel at www.roycastle.org/expertpanel

This booklet has been published in partnership with Lung Cancer Nursing UK.



Our information is also reviewed by members of our Reader Panel (made up of people who have experience of lung cancer). This makes sure our lung cancer information meets their needs. You can find out about our Reader Panel at www.roycastle.org/readerpanel

You can find references to sources of information within this booklet at www.roycastle.org/evidence

If you have suggestions for new publications or additions or improvements to our existing range of booklets and factsheets, please let us know at info@roycastle.org

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ROY CASTLE
LUNG CANCER
FOUNDATION

Roy Castle Lung Cancer Foundation is the charity that gives help and hope to people affected by lung cancer. The charity has two aims – supporting people living with lung cancer and saving lives.

Supporting people living with lung cancer

Working closely with lung cancer nurses, we provide information, run lung cancer support groups and offer telephone and online support. Our patient grants offer some financial help to people affected by lung cancer.

Saving lives

We fund lung cancer research, campaign for better treatment and care for people who have lung cancer, and raise awareness of the importance of early diagnosis. Our lung cancer prevention work helps people to quit smoking and encourages young people not to start smoking.

Contact us

For more information, call our Lung Cancer Information and Support Services:

0333 323 7200 (**option 2**)

or visit our website: www.roycastle.org

Head Office

Cotton Exchange Building,
Old Hall Street,
Liverpool, L3 9LQ

Email: foundation@roycastle.org

Information and Support Services

98 Holm Street,
Glasgow, G2 6SY

Email: info@roycastle.org

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