A practical guide to tests and treatments

UNDERSTANDING CANCER RESEARCH TRIALS (CLINICAL TRIALS)
About this booklet

This booklet gives information about cancer research trials (clinical trials). These are carried out to try to find new and better ways to prevent, diagnose, treat and control cancer and its symptoms. They may also look at how quality of life or sense of well-being can be improved for people with cancer.

Trials that are carried out on patients are known as clinical trials.

We can’t advise you about the best treatment for you. This information can only come from your doctor, who knows your full medical history.

In this booklet, we’ve included quotes from people who have taken part in clinical trials, which you might find helpful. Some are from the website healthtalk.org Others are from people who have chosen to share their story with us.

To find out more

If you’d like to discuss this information, call the Macmillan Support Line free on 0808 808 00 00, Monday–Friday, 9am–8pm. If you’re hard of hearing, you can use textphone 0808 808 0121, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit macmillan.org.uk
There’s a list of questions you may want to ask before you decide whether to take part in a trial on pages 42–43. We also explain how to find out if there is a trial suitable for you (see pages 47–49). Turn to pages 57–59 for some useful addresses and helpful websites.

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.
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WHAT ARE CLINICAL TRIALS?

Clinical trials
Clinical trials

Clinical trials are medical research trials involving people. Volunteers for trials can include healthy people or patients. People take part in trials in all areas of medicine, not just in cancer and not just to test treatments. For example, a clinical trial may be used to compare different ways of diagnosing an illness. Or it might look into whether it’s possible to prevent a particular cancer.

Doctors and patients need evidence from clinical trials to know which treatments are the safest and most effective.

This information is written for people with cancer, who may have the option of joining a clinical trial as part of their cancer treatment. In this information, we refer to these people as patients.

Treatment trials

Treatment trials are the most common type of trial. In cancer care, they may be done to:

• test new treatments such as new chemotherapy drugs and targeted therapies

• look at new combinations of existing treatments, or change the way they are given, in order to make them more effective or to reduce side effects

• compare the effectiveness of drugs used for symptom control

• discover which treatments have fewer side effects
• find out more about how cancer treatments work
• see which treatments have the least impact on peoples’ everyday lives
• see which treatments are the most cost-effective.

Treatment trials are the only reliable way of finding out whether a different operation, type of chemotherapy, targeted therapy or radiotherapy is better than what is already available.

If doctors already knew that a new treatment was better than the standard treatment, there would be no need for a clinical trial. Patients would be offered the treatment routinely as part of their care.

The treatment being tested may aim to:
• improve survival (how long people live after treatment)
• relieve the symptoms of cancer
• reduce the side effects of treatment
• improve quality of life or sense of well-being for people with cancer (see page 9).

Many drugs that are now commonly used in cancer care have been previously tested in clinical trials. Without ongoing research, it wouldn’t be possible to add to our knowledge about effective treatments.
Other types of trial

Prevention trials look at whether a specific treatment may help to prevent a specific type of cancer. For example, trials have looked at whether people with a higher risk of cancer, because of their family history, would benefit from taking medicine to reduce their risk.

Screening trials look at new ways of testing a person for a specific cancer. These trials are often aimed at finding cancer early when the chance of a cure may be highest. They may be carried out in the general population. Or in people who are at a higher risk of cancer because of their family history.

Diagnostic trials look at new ways of accurately finding a cancer – perhaps using new scans or tests. These trials usually include people who may have symptoms of cancer.

Quality of life trials look at ways of improving a person’s sense of well-being. Many quality of life trials are combined with treatment trials. This is because doctors want to know what effect a particular treatment has on a person’s everyday life. They often include questionnaires, which people complete at different stages during the trial. These may look at the psychological and financial impact of the treatment on both patients and their carers. For example, a trial might look at whether someone has to take time off work to care for you while you have treatment.
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How trials are carried out

Treatment-related clinical trials are usually carried out in a series of steps or phases.

Potential new cancer drugs or treatments are first tested in the laboratory (pre-clinical trials) before they’re given to people in trials. If it seems they may help to treat a particular cancer, they are tested in what are called phase 1 trials. If these are successful, the drug is used in phase 2 trials and then phase 3 trials. Phase 4 trials test drugs that are already licensed.

Feasibility studies and pilot studies may be carried out before a planned clinical trial.

A feasibility study is designed to see how possible a clinical trial is. For example, it will look at how easy it will be to recruit people to the trial, how many people the trial might need and how long the trial could take to complete.

Pilot studies are a smaller ‘test’ version of the main clinical trial. They are done before the main study to check whether the ideas behind the trial and the suggested methods (the ‘trial design’) work in practice.

Researchers who run trials involving patients have to offer a treatment they believe is at least as good as, or possibly better than, the best treatment that is currently available. The trials have to be carried out following strict rules and guidelines (see pages 28–39).
Phase 1 trials

Phase 1 trials test a possible new cancer treatment or drug that has only been tested on cancer cells in the laboratory. This is the first stage in which the drug or potential treatment is used in patients.

Phase 1 trials may involve chemotherapy or targeted therapies.

A phase 1 trial aims to find out:
- whether the medicine has an effect on the body
- how much of the medicine can be given safely without causing serious side effects
- what side effects the medicine causes.

How does the trial work?
The first patients are given a small dose of the drug that is expected to be safe. If none of the patients have any side effects, the next group will be given a higher dose. The dose is gradually increased with each group. This is called dose-escalation.

The researchers look carefully at the effects of the drug until they find the dose at which side effects are acceptable. This is known as the maximum tolerated dose.

For targeted therapies, it may be necessary to test a biopsy specimen first. This is to see whether the patient is likely to benefit from the new treatment. A biopsy is a sample of cells that may have been removed when you were diagnosed. The cells can be looked at and tested under a microscope to find out whether the patient is likely to benefit from the new treatment.
In a phase 1 trial, it’s likely that most people won’t benefit from the new treatment. But it’s possible that some people will. Finding out the best dose and the side effects of the drug is a very important stage before testing how effective the drug is.

Sometimes, phase 1 studies include different ways of giving the new drug or medicine. For example, patients may be given the same drug by injection or as tablets.

**Who can take part?**
Phase 1 trials involve very few patients. These trials are only open to people whose cancer has come back or spread. They have already had treatment and there is currently no other standard treatment available.

It’s difficult to know whether a new medicine will cause harmful side effects, so people in this type of trial need to be selected and checked very carefully. For example, people need to be feeling reasonably well to take part in these sorts of trials. This is because the trials are specifically looking at side effects. It would not be safe or fair to have people who were already feeling unwell taking medicines which might possibly make them feel worse – particularly with no proof yet that the medicine is effective.

**Where do the trials take place?**
Phase 1 trials are usually carried out in clinical research units. These are often based at specialist hospitals, rather than in local hospitals. Sometimes, this may involve some travelling to and from the hospital.
How long does the trial last?
Phase 1 trials can take from several months to a year to finish. At the end of the trial, the research team will know the major side effects of the treatment and whether it has any effect on the cancer. If the treatment is shown to be safe and looks like it does have an effect on the cancer, it will then be tested in phase 2 trials. Not all treatments tested in phase 1 trials make it to phase 2.

Phase 2 trials
A phase 2 trial aims to find out:

• whether the drug works well enough to be tested in a larger, phase 3 trial
• which types of cancer it might be best used to treat
• more about the side effects and how best to manage them
• more about the best dose to use.

Phase 2 trials have more patients, usually about 20–40 people, and may last a couple of years. These patients will be closely followed up to see whether their cancer is responding. If the cancer shrinks, it’s known as a response to the treatment (see pages 44–45).

The trial will also look further at any side effects caused by the treatment. Although the new treatment would have been tested in a phase 1 trial, it’s still possible that it will cause side effects that haven’t been seen before. This is because it is being tested in a larger group of patients.
Phase 3 trials

A phase 3 trial aims to compare what looks like promising new treatments with standard treatments. It also gives more information about the side effects that the new treatment may cause.

Sometimes, a phase 3 trial may test whether a new treatment will be as good as the standard treatment but cause fewer side effects. For example, a new way of giving radiotherapy may be tested and compared to the standard radiotherapy treatment.

‘I was invited to take part in clinical trials of a new chemotherapy. However, under the trial protocol, I ended up having the original chemo treatment. My progress would be measured against the new variety.’

Ron

Sometimes a new treatment will be tested when no standard treatment currently exists. In these trials, the new treatment may be compared with the current routine ‘standard of care’ that would be given. This routine care might involve regular appointments to see how well the person is and to treat any symptoms. This is sometimes called observation or best supportive care. Sometimes phase 3 trials may involve a placebo (see page 20).
Phase 3 trials are large and may include hundreds, or sometimes thousands, of patients from many different hospitals, often from several countries. They may take many years to complete.

A phase 3 trial aims to find out:

- how long patients stay free of cancer – this is known as **disease-free survival**
- the number of people who are alive, with or without signs of cancer – this is known as **overall survival**
- whether the cancer grows more slowly
- how the treatment affects patients’ quality of life.

Phase 3 trials usually involve a randomisation process (see pages 22–23).

Manufacturers of drugs that have been shown to be safe and effective in phase 3 trials can then apply for the drug to be granted a licence. This is known as a marketing authorisation. Licensed drugs are then available to be used in healthcare.

Most licences are granted by the European Medicines Agency (EMA) as the licence covers all countries in the European Union. The Medicines and Healthcare products Regulatory Agency (MHRA, see page 28) can grant a licence for a drug to be used just in the UK. Drugs that are licensed may be further researched in phase 4 trials.
Phase 4 trials

Phase 4 trials are carried out after a drug has been shown to be effective and has been granted a licence. They aim to find out:

- how well the drug works when it’s used more widely
- the long-term risks and benefits of the drug
- more about possible rare side effects and the safety of the drug.
Trial design

If you’re asked to take part in a phase 2 or phase 3 trial, you may hear terms such as controlled trials, placebo, randomisation, blind trials and double-blind trials.

Controlled trials

In most trials, one group of patients will have the trial treatment and one group will have the standard treatment. The people having the trial treatment are called the **trial group** and the people having the standard treatment are the **control group**. The control group is compared against the trial group. The results of both groups are compared to:

- see whether there’s any benefit from the new treatment
- see whether the side effects are better, worse or different
- measure how much of the improvement in the patients is due to the new treatment. And how much would have happened by chance or is due to standard treatment.

Sometimes, the standard treatment is to ‘watch and wait’. This means that the person does not have any treatment unless the cancer starts to develop or cause symptoms.
Placebo

In some situations, where there is no standard treatment to compare with the trial treatment, patients may be given a placebo. A placebo is a treatment that looks the same as the treatment being studied. It contains no medicine and is also known as an inactive treatment.

Placebos may be used when a therapy, such as a targeted therapy, is being added to the standard treatment to see whether this gives better results. One group of people will be given the standard treatment plus the trial therapy, and one group of people will be given the standard treatment plus a placebo. People who take part in a trial that uses a placebo won’t know whether they’re getting the actual treatment or the placebo. In some trials (known as double-blind) the doctors won’t know either. We explain this more on page 24.

Comparing people’s responses to the placebo and to the treatment being tested tells the researchers whether a treatment is having any real benefit.

‘We were told it’s 50% of the people that are picked go on the trial, 50% don’t. It wasn’t a placebo, nothing like that. You’re either on it, or you’re on the trial but you’re not having the drug. They wanted to compare the two.’

Wendy
Randomisation

Most phase 3 and some phase 2 trials are randomised. In a randomised trial, a computer programme is used to put patients into treatment groups. This means that if you agree to take part, neither you nor your doctors will be able to choose which treatment you’re given.

Trials are often randomised because if the researchers or doctors were to decide who should get which treatment, they might be influenced by what they know about their patients. This means they might put people who they think are more or less likely to respond to a new treatment into a particular group. This is known as introducing bias and it could affect the accuracy of the research results.

Bias can be prevented if people are put into treatment groups by a computer. The computer can match the groups so that they are similar. For example, they can be matched so that each group has a similar mix of patients of different ages, gender or state of health. If one group does better than another group, it’s therefore more likely to be because of the treatment. This process is shown on the opposite page.
Patient information is entered into a computer.

The computer randomly assigns patients to two or more groups. This helps to prevent bias.

Control group receives standard treatment.

Trial group receives new treatment.
Blind trials and double-blind trials

If you take part in a trial of a new drug, you may not be told which treatment group you are in. This is called a **blind trial**. The medicine used will look the same, whether it’s the new treatment, standard treatment or a placebo.

Some randomised trials are called **double-blind trials**. This means that neither you nor the doctor treating you will know which treatment you’re getting. Your doctor opens a specially coded treatment pack and only the trial organisers know which drug it contains. In an emergency, your doctor can find out from the trial co-ordinators which treatment you’re having. Or the pharmacy department at the hospital will be able to break the code.

Blind trials or double-blind trials aim to reduce any bias. For example, knowing you’re having a new treatment might make you feel more positive or negative. This could influence what you report to the researchers. Similarly, if your medical team knew that you were having a new treatment for which they had high hopes, this might affect how they judged your response to it.
Entry criteria

All clinical trials have strict guidelines about who can take part. These are known as entry criteria or eligibility criteria. Anyone who wants to take part in a clinical trial must meet these criteria.

For example, some trials may include people with a specific type of cancer or a particular stage of cancer. Staging takes into account the cancer’s size, its position in the body and whether it has begun to spread.

All trials also have exclusion criteria. These explain who cannot take part. Exclusion criteria help to ensure the safety of people taking part and make sure the results are as accurate as possible. Examples of exclusion criteria sometimes include:

• having another health condition
• taking particular medicines
• having had particular treatments in the past.

Your cancer specialist can tell you whether you’re suitable for a specific trial.
ARE YOU THINKING OF TAKING PART IN A CLINICAL TRIAL?

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Safety in clinical trials

Understandably, anyone who enters a clinical trial will want to know that it’s safe for them to do so. There are a number of ways people are protected before and during a trial.

**Medicines and Healthcare products Regulatory Agency (MHRA)**

The UK’s MHRA makes sure trials meet international standards of good practice, which are there to protect the people taking part. All serious side effects must be reported.

**Research ethics committees**

All research in the UK involving people, whether done in the NHS or the private sector, has to be approved by an ethics committee. These are independent groups that put the rights, safety, dignity and well-being of research participants at the centre of their decision-making. They make sure that patients are fully informed, and check that any information given is clear and accurate. They also ensure that patients are compensated if anything goes wrong.

The research ethics committee looks at each research proposal and gives an opinion about the trial and whether the research is ethical.
The committees cover a local area and must be made up of a mix of health professionals and non-medical people. They often include patients, lawyers and members of the public. Having non-medical people is important as they can look at the trial from an ‘outsider’s’ point of view.

The research ethics committee is independent of research sponsors, funders and investigators. It checks that:

• the researchers are qualified to do the trial
• the trial is well planned
• the likely benefits are greater than the possible risks
• patients are recruited to the trial correctly.

Patients and members of the public are becoming more involved with research teams. They bring the patient’s perspective of illness and treatment, which can help the researcher’s understanding. For example, they comment on the possibility of people wanting to participate in a trial and what aspects of the trial might put people off taking part.

Patients and members of the public can also suggest new areas for research and help to write information about clinical trials for the public.
Monitoring trials and stopping rules

Before a trial begins, a data monitoring committee is usually set up to monitor patient safety and the effectiveness of the treatment during the trial.

The data monitoring committee along with the research ethics committee can stop a trial if they are concerned that a new drug or treatment is causing harm to a person. For example, they can stop a trial if there are severe side effects. This is unlikely to happen in phase 3 or 4 trials because new drugs or treatments are well tested during phases 1 and 2.

‘If they see that it’s having serious effects and negative effects, they’ll pull you out of it. So you always have the option of stepping back from it.’

Tom

Trials can also be stopped early if the results of the new treatment appear to be much better than the standard treatment. The new treatment can then be used instead of the standard treatment so that everyone in the trial can benefit from it. Sometimes patients will then move from being in the control group, to the new treatment group.
Insurance

The drugs used in clinical trials are made to the highest standards of purity and quality. Drug companies are insured so that if a patient is harmed by an unforeseen event due to the drug, compensation can be paid. It’s very rare for patients to be seriously harmed by trial drugs, although some may cause unpleasant side effects.

Trials funded by the Department of Health, the UK Medical Research Council or medical charities may not have this kind of insurance, but a payment would be made if something did go wrong.

All trials will have a legal sponsor. One of the sponsor’s roles is to make sure that there are arrangements, such as insurance, to protect those taking part against damage or loss. However, individual NHS trusts are responsible for insuring themselves against harm caused by local trials. Research ethics committees will refuse approval for trials where there is no insurance or provision for compensation.
Benefits and risks of trials

Clinical trials are designed to make the risks as low as possible and the benefits as great as possible for all the people who take part, whichever treatment they get.

Benefits of taking part in a trial

Taking part in a trial means that you may be given a new treatment that works better than the standard treatment. The new treatment might not otherwise be available yet because it does not have its license. You’ll also be helping doctors find out which treatments may benefit future patients.

When you take part in a trial, you’ll be followed up very carefully during and after the study. Your doctors will probably want you to have regular tests, such as blood tests, and you may be asked some extra questions about how you’re feeling. This means that any changes in your health – whether or not they are related to the treatment you’re having – can be noticed and dealt with as soon as possible. Some patients find this reassuring. Others would prefer not to have more hospital visits and therefore would rather not take part in trials.

Potential risks

With any clinical trial, there is always a small risk that the treatment could harm you or that you could experience side effects that are unpleasant or unexpected. During the trial, researchers make every effort to minimise these risks.
Practical issues

Taking part in a trial may mean going to your hospital or GP more often than you would normally, so bear this in mind before you agree to take part. Attending the hospital can be tiring and the extra travel may cost a lot of money.

Ask your doctor how many extra visits will be needed and think about how convenient this will be for you. You can also ask whether the research trial will pay for your additional travel costs, and how you can claim.

Making a decision

If you are finding it difficult to decide whether or not to join a clinical trial, it may be helpful to talk things through with your doctor or nurse. You might also find it helpful to speak with your family and friends as they may be able to help talk things through with you.

Sometimes something as simple as writing a list of pros and cons can be helpful.

It is important to know there is no right or wrong decision. Any decision you make will be the right one for you at the time.

If you need more support, you can call the Macmillan Support Line on 0808 808 00 00 to talk to our cancer support specialists. Our booklet Making treatment decisions also has helpful advice about how to make a decision about your treatment.
Taking part in a clinical trial

Information and giving consent

Before you go into a trial, a doctor, nurse or other researcher will ask for your permission. They can’t enter you into the trial if you don’t give your written consent, after you have had plenty of time to think about it.

To help you decide whether you want to take part, the researchers should tell you:

• what the trial is trying to find out

• what the trial will involve and what you’ll have to do.

There are guidelines for researchers that explain what information people need to help them decide whether to take part in a clinical trial. But there’s a lot of discussion about how much people really want to know, and this varies from person to person.

‘Find out all the information you can, ask as many questions as you can, and do make the decision that’s right for you.’

Wendy
It’s important that you have enough information to make an informed decision. You should feel able to ask any questions that will help you to make a decision. Before you decide, you should also feel that you have been given enough time to think about the trial and what it will mean to you.

Someone from your medical team will be able to answer any questions you may have. They will go through the possible benefits and risks of joining the trial. They should also discuss any other treatments that may be appropriate in your situation.

You may want to talk about it with your family or friends, and think about any practical aspects, such as extra appointments and tests.

You will be given a patient information leaflet about the trial. You can take this away and read it in your own time before you are formally invited to take part.

**If you decide to take part**
If you decide that you want to take part, you may be asked to give your consent verbally to the person carrying out the trial, who will write it in your notes. You’ll then be asked to sign a consent form that says that you agree to take part. Your doctor will also sign the consent form. You’ll be given a copy to keep.

**If you decide not to take part**
If you decide not to take part in the trial, you can tell your doctor or nurse. Your decision will be respected and you don’t have to give a reason. There will be no change in the way that the hospital staff treat you, and you’ll be offered the standard treatment for your type of cancer.
Who is responsible for your care?

During the trial, your cancer specialist and GP are still the people in charge of your care. They will make the day-to-day decisions with you about your treatment.

Withdrawing from a trial

Remember that even if you agree to take part in a trial, you can leave it at any time without giving a reason. If you’re having a new treatment as part of a trial and then leave the trial, you may not be able to continue having the new treatment. In this situation, you’ll have the appropriate standard treatment for your type of cancer.

If you’re thinking of leaving a trial, it’s a good idea to discuss it with your specialist or your research nurse.

‘I think you have to remember that you can pull out of the trial at any stage, however far in you are or how little time you’ve been in it. And you have to trust that it’s not going to compromise your care, although I do understand the concerns that people will have about that.’

Ben
Confidentiality

If you agree to take part in a clinical trial, your GP will only be told if you give your consent. It can sometimes help for your GP to know you’re in a trial as they’re responsible for your day-to-day health at home. If you have any queries or problems during the trial, you should talk to the specialist doctor responsible for it, or your research nurse.

Your medical records concerning the trial are confidential. Sometimes, a representative of a relevant drug company or staff from the trials office who are co-ordinating the trial may look at your records to check that all the necessary information is collected accurately. No one who looks at your notes can give information to anyone outside the healthcare team looking after you. In the same way, when the results are published you will not be named.

Research using blood and tumour samples

You may have had blood and tumour samples taken when you were diagnosed. You may be asked for your permission to use some of your samples for research into cancer. If you take part in a trial, you may also give other samples. These may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you can’t be identified.

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of cancer and its treatment, which will hopefully improve the outlook for future patients.
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Questions to ask

Here are some questions you might like to ask before deciding whether to take part in a trial. Your doctor or nurse will probably answer most of these when they tell you about the trial. Most of these will be covered in the written information you are given about the trial.

General questions

• What is the trial called?

• What is the aim of the trial and how will it help people?

• Why have I been invited to take part?

• What are the treatment choices in the trial?

• What are the benefits of the trial for me?

• What are the possible risks?

• How long is the trial expected to last?

• Can I withdraw from the trial at any time? The answer should always be yes.

• What happens if I leave the trial early?

• How long will it be before the results of the trial are known? Remember that it may be some time before the results are available – see pages 44–46. It’s not unusual for trials to take many years before the results are available. While doctors may see quite soon whether people respond to a new treatment, it will take much longer to see how long the response will last.

• Will I be informed of the results?
Practical questions

You may also want to ask some practical questions to make sure you’re happy with any demands that the trial will make on you:

• How much of my time will be needed?

• Will I need to take time off work?

• Will I need extra help from family and friends?

• Will my fares to and from the trial centre be paid?

• If so, how can I claim the costs back?

• What extra tests or appointments will I have?

• Will I have to collect the drug from the hospital?

• Will the drug be sent to me by post or will I get it through my GP?

• Will I have to fill in questionnaires or keep a diary? Sometimes questionnaires are simple tick-box lists, or you may be asked to record your answers online.
Trial results

Why trial results take a long time to be published

It can sometimes take many years to get the results of a trial. This may be because many thousands of people need to take part to show a small but important difference between treatments.

If a trial is looking at how long people live after their cancer treatment, they need to be monitored for many years – often five years, but sometimes 10 years or more. Researchers continue to collect this information during this time. The information is collected from the hospital, national records or a patient’s GP. Patients’ names are removed so individual people will not be identified in the study results.

Understanding trial results

Researchers need to collect information (called outcomes or endpoints) to help them decide which treatment is most effective and safest.

In a phase 2 trial, the first outcome that researchers look for is how effective the treatment has been in treating the cancer. In solid tumours (not blood cancers like lymphomas, leukaemias and myelomas), if the cancer has stopped growing, shrunk or disappeared, it’s known as a response.
You may hear your doctors use different phrases to describe your response to treatment, such as a complete or partial response, or stable disease.

- **A complete response** is defined as the disappearance of all of the detectable cancer for at least four weeks. Clearly this is a very good result, but a complete response doesn’t always mean a cure. It takes several years with no sign of the cancer returning (recurrence) before it can be thought of as cured.

- **A partial response** is a decrease in cancer size by at least 30% for at least four weeks, without any signs of growth elsewhere in the body.

- **Stable disease** is when the cancer has shrunk in size, but by less than 30%, and there are no signs of growth elsewhere in the body.

These definitions also help doctors to describe the effects of the drugs on the tumours in a standard way.

Some trials look at long-term outcomes of treatment. In a phase 3 trial, researchers are often looking at how long people live after the treatment (survival). Doctors and researchers monitor whether more people are cured, or live longer, with the new treatment.
Finding out results

The results of most clinical trials will be published in medical journals. However, a final report of a trial may not be published until many years after people were treated. If you don’t read medical journals, you may not get to know the results. But sometimes they are published in newspapers or discussed on TV or the radio, especially if the results are presented at doctors’ conferences.

Researchers are expected to think about how people taking part in their trial will be told the results. If this isn’t explained to you when you join the trial, ask the research team. Generally the best way to find out results is to ask your specialist. However, more patients are now being contacted directly when results of trials are available.
Finding out about current trials

To be able to take part in a trial, your cancer specialist or GP has to refer you to the doctor in charge of the trial.

It can sometimes be difficult to find a trial to take part in. Your cancer specialist or specialist nurse should be able to tell you about trials in your area, and they may know of other trials that might be suitable for you. Not all hospitals have the facilities or expertise to take part in some trials, so you may have to travel to a different hospital.

If you’ve been invited to take part in a clinical trial, you may be introduced to a research nurse. They can tell you all about the trial and answer your questions.

If you’d like to find out about other trials that may be suitable, our cancer support specialists on 0808 808 00 00 can give you information about current trials available nationwide.

You can search for trials in the UK on websites such as:

- Cancer Research UK – cancerresearchuk.org/cancer-help/trials
- UKCRN (UK Clinical Research Network) study portfolio – public.ukcrn.org.uk/search
- UK Clinical Trials Gateway – ukctg.nihr.ac.uk
It can sometimes be possible to take part in a trial abroad. This may mean that you have to pay for the treatment as well as your travel costs, which can be very expensive. Try to get as much information as possible about the trials from trustworthy sources and websites. It’s a good idea to be cautious of trials run by small clinics rather than research hospitals. Also, be careful to avoid trials offering ‘miracle cures’, often at great expense, as these are unlikely to help you.

You can discuss any trials with your cancer specialist, who can give you further advice. Trials conducted abroad may not be regulated in the same strict way that trials in the UK are.

You can search for trials abroad on websites such as the US website National Cancer Institute (visit cancer.gov/about-cancer/treatment/clinical-trials/search). This website also lists UK trials.
Influencing future research

New clinical trials are being set up all the time. Some are started by the government-funded Medical Research Council (MRC) or the National Cancer Research Institute (NCRI). Others are started by charities such as Cancer Research UK. Clinical trials are also set up by international organisations or drug companies.

Many of these organisations have patient groups that help to decide on areas that need further research. Cancer specialists are very aware of the gaps in their understanding of the diagnosis and treatment of cancer, but patients, their families and friends may see other aspects of their care that need further research. If you have any thoughts about research that might be useful, talk to your doctor or nurse.

The organisation INVOLVE has information and advice about how you can get involved with research. You can find out more at invo.org.uk
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About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more leaflets or booklets like this one. Visit be.macmillan.org.uk or call us on 0808 808 00 00.

We have booklets on different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer and information for carers, family and friends.

All of our information is also available online at macmillan.org.uk/cancerinformation. There you’ll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- Easy Read booklets
- ebooks
- large print
- translations.

Find out more at macmillan.org.uk/otherformats. If you’d like us to produce information in a different format for you, email us at cancerinformationsteam@macmillan.org.uk or call us on 0808 808 00 00.
Help us improve our information

We know that the people who use our information are the real experts. That’s why we always involve them in our work. If you’ve been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you’d like to hear more about becoming a reviewer, email reviewing@macmillan.org.uk. You can get involved from home whenever you like, and we don’t ask for any special skills – just an interest in our cancer information.
Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we’re here to support you. No one should face cancer alone.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line
Our free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists can:
• help with any medical questions you have about your cancer or treatment
• help you access benefits and give you financial advice
• be there to listen if you need someone to talk to
• tell you about services that can help you in your area.

Call us on 0808 808 00 00 or email us via our website, macmillan.org.uk/talktous

Information centres
Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you’d like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at macmillan.org.uk/informationcentres or call us on 0808 808 00 00.
Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That’s why we help to bring people together in their communities and online.

Support groups
Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting macmillan.org.uk/selfhelpandsupport

Online community
Thousands of people use our online community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people’s posts at macmillan.org.uk/community

The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

‘Everyone is so supportive on the online community, they know exactly what you’re going through. It can be fun too. It’s not all just chats about cancer.’

Mal
Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you’ve been affected in this way, we can help.

Financial advice
Our financial guidance team can give you advice on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits
Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants
Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on 0808 808 00 00 to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit macmillan.org.uk/financialsupport to find out more about how we can help you with your finances.

Help with work and cancer

Whether you’re an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit macmillan.org.uk/work

Macmillan’s My Organiser app
This free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search ‘My Organiser’ on the Apple App Store or Google Play on your phone.
Other useful organisations

There are lots of other organisations that can give you information or support.

Finding a clinical trial

Cancer Research UK
Angel Building,
407 St John Street,
London EC1V 4AD
Tel 0808 800 40 40
(Mon–Fri, 9am–5pm)
www.cancerresearchuk.org/
cancer-help/trials
The world’s leading independent organisation dedicated to cancer research. Supports research into all aspects of cancer. Its website contains information on how trials are conducted, and you can search a database of trials currently recruiting cancer patients in the UK.

National Cancer Institute (NCI)
www.cancer.gov/clinicaltrials
Part of the National Institutes of Health (NIH), which is one of 11 agencies that compose the Department of Health and Human Services (HHS) in the United States. The ‘Find a clinical trial’ database has details of open cancer trials, providing details of trials in the UK and many other countries.

General cancer support organisations

Cancer Black Care
79 Acton Lane,
London NW10 8UT
Tel 020 8961 4151
Email info@cancerblackcare.org.uk
www.cancerblackcare.org.uk
Offers information and support for people with cancer from ethnic communities, their friends, carers and families.
Cancer Focus
Northern Ireland
40–44 Eglantine Avenue,
Belfast BT9 6DX
Tel 0800 783 3339
(Mon–Fri, 9am–1pm)
Email hello@cancerfocusni.org
www.cancerfocusni.org
Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

Cancer Support Scotland
The Calman Centre,
75 Shelley Road,
Glasgow G12 0ZE
Tel 0800 652 4531
Email info@cancersupportscotland.org
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Irish Cancer Society
43–45 Northumberland Road,
Dublin 4, Ireland
Tel 1800 200 700
(Mon–Thu, 9am–6pm, Fri, 9am–5pm)
Email helpline@irishcancer.ie
www.cancer.ie
National cancer charity offering information, support and care to people affected by cancer. Has a helpline staffed by specialist cancer nurses. You can also chat to a nurse online and use the site’s message board.

Maggie’s Centres
1st Floor,
One Waterloo Street,
Glasgow G2 6AY
Tel 0300 123 1801
Email enquiries@maggiescentres.org
www.maggiescentres.org
Maggie’s Centres provide information about cancer, benefits advice, and emotional or psychological support.
**Teenage Cancer Trust**
3rd floor,  
93 Newman Street,  
London W1T 3EZ  
Tel 020 7612 0370  
Email hello@teenagecancertrust.org  
www.teenagecancertrust.org
A charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer, their friends and families.

**Tenovus**  
Head Office,  
Gleider House,  
Ty Glas Road,  
Cardiff CF14 5BD  
Tel 0808 808 1010  
(Mon–Sun, 8am–8pm)  
Email info@tenovuscancercare.org.uk  
www.tenovus.org.uk
Aims to help everyone get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, an ‘Ask the nurse’ service on the website and benefits advice.

**Counselling and emotional support**

**British Association for Counselling and Psychotherapy (BACP)**  
BACP House,  
15 St John’s Business Park,  
Lutterworth,  
Leicestershire LE17 4HB  
Tel 01455 883 300  
Email bacp@bacp.co.uk  
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at itsgoodtotalk.org.uk
Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support’s Cancer Information Development team. It has been approved by our medical editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Christine Clarke, Macmillan Specialist Oncology Pharmacist; Kelly Leonard, Research Nurse; and Rhonda McMenemin, Consultant Clinical Oncologist. Thanks also to the people affected by cancer who reviewed this booklet, and those who shared their stories.

Sources

We’ve listed a sample of the sources used in this publication below. If you’d like further information about the sources we use, please contact us at bookletfeedback@macmillan.org.uk

Can you do something to help?

We hope this booklet has been useful to you. It’s just one of our many publications that are available free to anyone affected by cancer. They’re produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we’re there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

**Share your cancer experience**
Support people living with cancer by telling your story, online, in the media or face to face.

**Campaign for change**
We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

**Help someone in your community**
A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

**Raise money**
Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

**Give money**
Big or small, every penny helps. To make a one-off donation see over.

Call us to find out more

0300 1000 200
macmillan.org.uk/getinvolved
Please fill in your personal details

Mr/Mrs/Miss/Other
Name
Surname
Address

Postcode
Phone
Email

Please accept my gift of £
(Please delete as appropriate)
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Don’t let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

☐ I am a UK taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you’d rather donate online go to macmillan.org.uk/donate

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ
More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don’t have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you’re entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit macmillan.org.uk