

FOLFIRINOX for pancreatic cancer

This fact sheet is for people with pancreatic cancer who are having FOLFIRINOX chemotherapy.

FOLFIRINOX is one of the main chemotherapy treatments for pancreatic cancer. It is made up of several different chemotherapy drugs.

Each hospital may do things slightly differently, and treatment will vary depending on your cancer. Speak to your doctor or nurse about your treatment.

You can speak to our specialist nurses on our confidential Support Line about any questions you have about chemotherapy. Call free on **0808 801 0707** or email **nurse@pancreaticcancer.org.uk**

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Read more about chemotherapy in our fact sheet:

[Chemotherapy for pancreatic cancer](#)

Or on our website at: pancreaticcancer.org.uk/chemotherapy

Read about the other chemotherapy drugs used for pancreatic cancer at: pancreaticcancer.org.uk/chemotherapydrugs

What is FOLFIRINOX?

FOLFIRINOX is made up of a combination of chemotherapy drugs:

- FOL – folinic acid (leucovorin)
- F – fluorouracil (5FU)
- IRIN – irinotecan
- OX – oxaliplatin.

FOLFOX and FOLFIRI are also combinations of drugs that may be used. Your chemotherapy team can talk to you about these options.

Read more on our website at:

pancreaticcancer.org.uk/chemotherapydrugs

How is FOLFIRINOX used?

FOLFIRINOX is used in different ways.

- If you have cancer that can be removed with surgery (such as the Whipple's procedure), you may be offered FOLFIRINOX after surgery. The aim is to try to stop the cancer coming back.
- You may have FOLFIRINOX if you have cancer that has grown close to major blood vessels near the pancreas (borderline resectable cancer). The aim is to try to shrink the cancer to make surgery possible. This depends on which blood vessels are affected, and how far the cancer has grown.
- You may have FOLFIRINOX if you have locally advanced or advanced pancreatic cancer and surgery is not possible. The aim is to try to control the growth of the cancer.

FOLFIRINOX is only given to people who are well enough to deal with (tolerate) a few different chemotherapy drugs. This is because it can cause side effects that can be hard to cope with. Read about side effects on page 6.

Sometimes you may start with a lower dose of some of the FOLFIRINOX drugs to make it easier to cope with. This is known as mFOLFIRINOX (modified FOLFIRINOX). Your chemotherapy team can talk to you about this. Sometimes, if you cope well with it, the dose may gradually be increased

Read more about how chemotherapy is used in our fact sheet:
[Chemotherapy for pancreatic cancer](#)

Or on our website at: **pancreaticcancer.org.uk/chemotherapy**

How is FOLFIRINOX given?

You will have your chemotherapy at the hospital as an outpatient. This means you will go into hospital for treatment, but you will not need to stay overnight.

FOLFIRINOX is given in a two week cycle. This means you will have the chemotherapy over two days, and then a break of 12 days before you have the next cycle. The break allows your body to recover. The number of cycles you have will depend on how the treatment is working and how chemotherapy affects you. Your chemotherapy team will talk to you about your treatment cycles.

The FOLFIRINOX drugs are given as an infusion into a vein. You may hear an infusion called a 'drip'. You will have the infusion through a central line such as a PICC line or a portacath. This is a long tube that is put into a vein in your chest or arm. The line is attached to a drip to give you your chemotherapy.

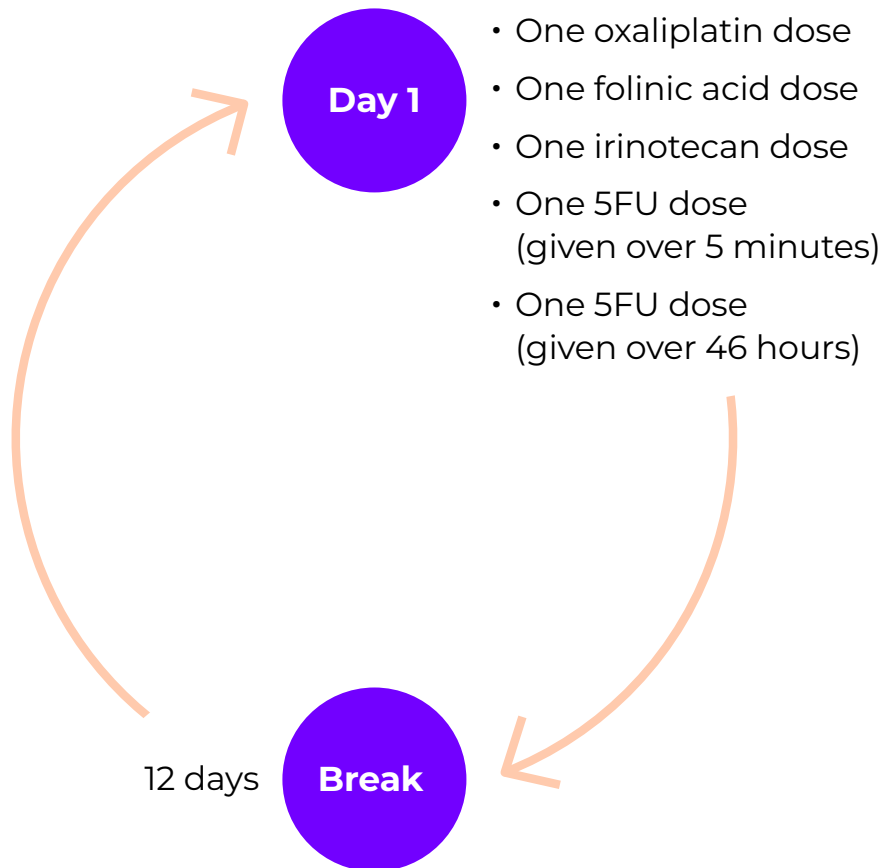
Read more about central lines and see a diagram on our website at: pancreaticcancer.org.uk/havingchemotherapy

Each cycle is given in the following way.

- On the first day of each cycle, you will have an infusion of oxaliplatin, folinic acid and irinotecan.
- You will then have a small infusion of 5FU over 5 minutes.
- This will all take about 4 hours but check this with your chemotherapy team.
- After this you will have an infusion of 5FU over 46 hours. This is given through a small pump attached to your central line. You can have this at home by attaching the pump to a belt and carrying it around with you.
- You will then have a break from chemotherapy for the next 12 days.

Each chemotherapy team may give FOLFIRINOX slightly differently. Speak to your chemotherapy team about how you will be given FOLFIRINOX.

Diagram showing how FOLFIRINOX is given



Reaction to the chemotherapy

Some people may have a reaction while FOLFIRINOX is being given. Signs of a reaction are:

- an itchy rash
- a high temperature
- feeling dizzy or faint
- feeling short of breath and difficulty breathing normally
- tummy pain.

These reactions need treating straight away, so if you have any of these symptoms or anything else unusual, tell the nurse who is giving the chemotherapy.

What are the side effects of FOLFIRINOX?

FOLFIRINOX can cause side effects. These can affect everyone differently, and you may not get all the side effects mentioned here. Your chemotherapy team should give you information about any possible side effects and how to manage them. They may give you medicines to take home to help with side effects. Ask the team any questions you have. Knowing what to expect can help you to cope with any side effects.

Your chemotherapy team should give you a 24 hour emergency number to call if you are unwell or have any signs of infection. Or if you need information about any side effects. Your oncology specialist nurse or chemotherapy nurse will explain when to use this number. If you haven't been given a number, ask them about this.

Read more about the side effects of chemotherapy in our fact sheet:

[Chemotherapy for pancreatic cancer](#)

Or on our website at: pancreaticcancer.org.uk/chemoeffects

DPD-deficiency

Fluorouracil (5FU) is broken down in the body by an enzyme called dihydropyrimidine dehydrogenase (DPD). Some people have lower amounts of the DPD enzyme, which is known as DPD-deficiency. People with DPD-deficiency can have side effects that are much worse than usual. These include infections, severe runny poo (diarrhoea) and feeling or being sick.

You will have a blood test to check for DPD-deficiency before you start chemotherapy. If you do have DPD deficiency, you will have 5FU at a lower dose to begin with. If you have not been told about testing for DPD-deficiency, speak to your specialist nurse or chemotherapy team.

Common side effects

Infection

FOLFIRINOX can increase your risk of getting an infection. **An infection is an emergency if you are having chemotherapy, and needs treating straight away.**

Signs of an infection include:

- a high or low temperature – your chemotherapy team will tell you what to watch out for
- feeling shivery and cold
- headaches
- sore muscles
- a cough or sore throat
- pain or burning when you pee
- feeling generally unwell or tired.

Call the 24 hour emergency number your chemotherapy team will have given you if you have signs of an infection. You should phone if you have any of these symptoms or feel suddenly unwell, even if your temperature is normal or low.

Read more about infections and how they can be treated in our fact sheet: [Chemotherapy for pancreatic cancer](#)

Or at: pancreaticcancer.org.uk/blood

Runny poo (diarrhoea)

If you have diarrhoea, try to drink as much water as you can manage. Call the 24 hour emergency number if you have diarrhoea more than four times a day or are finding it hard to drink enough fluids. You may be given medicines to control the diarrhoea. Your chemotherapy may be delayed until it is better, or the dose of your chemotherapy drugs may be lowered.

Read our tips for coping with diarrhoea on our website at: pancreaticcancer.org.uk/tipspoo

Constipation

Constipation is when you find it harder to poo. Drink as much water as you can manage and try to eat high fibre foods, such as fruit and vegetables. Gentle exercise such as walking can also help. Speak to your doctor about medicines that can help.

Fatigue (extreme tiredness)

Fatigue is a common side effect of FOLFIRINOX. It is not the same as feeling tired. Fatigue can make you feel weak and have problems concentrating.

Some people find that the fatigue starts a few hours to a few days after having chemotherapy and starts to get better a few days later. There are things that you can do to help with fatigue.

Oxaliplatin may also cause dizziness. Feeling tired and dizzy can affect your ability to drive. You might want to get someone else to drive you until you know if you are affected.

Read our tips for coping with fatigue on our website at:
pancreaticcancer.org.uk/fatigue

Feeling or being sick (nausea or vomiting)

This is a common side effect of FOLFIRINOX but you will be given anti-sickness medicines to stop you feeling or being sick. If these don't help, call the emergency number. You may be able to change to a different medicine.

Read more about feeling and being sick, and our tips for coping with it, on our website at: pancreaticcancer.org.uk/sickness

Tingling and numbness in your fingertips and toes

FOLFIRINOX can affect the nerves in your hands and feet, which can cause tingling and numbness. This is called peripheral neuropathy. It normally gets better after your treatment finishes. This can be worse in the cold, so wrap up well if you are going outside.

It's important to tell your chemotherapy team if you have any tingling or numbness in your fingers or toes. They can manage it to make sure it does not become a long term problem.

Read more about peripheral neuropathy at:
pancreaticcancer.org.uk/chemoeffects

Problems swallowing and breathing (laryngeal spasm)

Oxaliplatin can affect your throat, which can make it hard to swallow or breathe. If this happens when you are being given oxaliplatin, tell your chemotherapy nurse straight away. They may stop the infusion of oxaliplatin while they give you medicine to help with this.

You may also get this side effect in the first few hours after having oxaliplatin. This is normally only if you are out in the cold or have a cold drink. It can be scary but is easily treated by having a warm drink. If you are worried, call the 24 hour emergency number. This side effect should stop a few days after your treatment finishes. Try to avoid cold drinks and wrap up warm if you go out in the cold.

Anaemia (low red blood cells)

FOLFIRINOX can lower the number of red blood cells in your blood. This is called anaemia, and can make you feel tired, dizzy or short of breath. If any of these symptoms happen suddenly, call the 24 hour emergency number. If your red blood cell level is very low, you may need to be given blood through a drip. This is called a blood transfusion.

Bruising and bleeding

FOLFIRINOX can lower the number of platelets in your blood. This is called thrombocytopenia. You may bruise more easily than normal, and you may be more likely to have nosebleeds or bleeding gums. If you have a nosebleed that does not stop after five minutes, call the 24 hour emergency number.

Hair loss

FOLFIRINOX may cause your hair to thin, or you may lose some hair. But it should grow back once your treatment stops.

Taste changes

FOLFIRINOX may cause a funny taste in your mouth. Some people say this tastes like metal or cardboard. You may find that food loses its flavour, or you stop enjoying some foods or drinks. This normally gets better once you finish your chemotherapy.

Read our tips for coping with taste changes on our website at:
pancreaticcancer.org.uk/diettips

Appetite loss

During your treatment you may not feel like eating, and you may start to lose weight. Try eating small meals often. If your appetite does not get better after a few days, tell your doctor or dietitian.

Read our tips for coping with loss of appetite on our website at:
pancreaticcancer.org.uk/diettips

Sore mouth and mouth ulcers

FOLFIRINOX can make your mouth sore, or cause mouth ulcers which can be painful. Tell your chemotherapy team about any mouth problems you have. They can make sure you don't have a mouth infection and give you a mouthwash to help. You should also tell them if you have white spots in your mouth. This is a sign of oral thrush, which is normally easy to treat.

Sore hands and feet

FOLFIRINOX can make the palms of your hands and the soles of your feet red and sore. The skin may also start to crack or peel. Your doctor or nurse may give you creams or painkillers to help with this. If you have badly peeling or painful skin, or broken skin that looks infected, call the 24 hour emergency number. The soreness normally gets better when your chemotherapy finishes.

Joint and bone pain

Oxaliplatin can cause problems with your joints, such as swelling or pain. Let your doctor or nurse know if you have this side effect. They can give you painkillers to help. Make sure you check your temperature before taking any paracetamol or ibuprofen. If you have a high temperature, call the 24 hour emergency number straight away.

Skin changes

5FU can make your skin darken or become more sensitive to the sun. Use a high factor sun cream if you are going outside. Tell your chemotherapy team about any skin changes. These changes normally get better when your treatment finishes.

Eye problems

FOLFIRINOX can cause sore, dry, itchy or watery eyes. Tell your doctor or nurse if this happens, as they may need to give you some eye drops. Some people get blurred vision when having FOLFIRINOX, but this is less common.

Less common side effects

Heart problems

Fluorouracil (5FU) can cause chest pain. It can also make you feel short of breath, dizzy, or cause an irregular heartbeat. If you have any of these symptoms, call the 24 hour emergency number. If you have chest pain, go straight to A&E and tell them you are having chemotherapy.

Risk of a blood clot in a vein

Chemotherapy can increase the risk of a blood clot in a vein. If you have any pain or swelling in an arm or leg, or you feel short of breath, call the 24 hour emergency number straight away. Or phone an ambulance and tell them you are having chemotherapy. A blood clot is serious if it's not treated.

Read more about blood clots in a vein, and the symptoms, on our website at: pancreaticcancer.org.uk/bloodclots

If you have any questions about FOLFIRINOX or side effects, speak to your chemotherapy team. You can also speak to our specialist nurses on our free Support Line.

More information and support

We are here for you

If you or someone you care about has pancreatic cancer, we are here to help.

Find out more at: **pancreaticcancer.org.uk/support**

Our specialist nurse Support Line

Our specialist nurses are experts in pancreatic cancer. They can talk for as long as you need, as often as you like. Whether you have a long list of questions or don't know where to start, they will provide practical, honest information to help you make the right choice for you.

Call free on **0808 801 0707** or email **nurse@pancreaticcancer.org.uk**

Information about pancreatic cancer

Our website, videos and publications can answer your questions. The information can help you understand what you have heard from your medical team, and make decisions about your treatment and care.

Go to: **pancreaticcancer.org.uk/information**

Download or order our free publications at:

pancreaticcancer.org.uk/publications or call **0808 801 0707**

Real life stories

Whether you want to read other people's stories or tell your own, sharing experiences of pancreatic cancer could help.

Go to: **pancreaticcancer.org.uk/stories**

Webinars

Our regular webinars cover topics including diet, wellbeing and treatment. They are hosted by our friendly nurses and other experts, are informal, and you can ask questions. You can look back at previous sessions, or sign up to one.

Go to: **pancreaticcancer.org.uk/webinars**

Useful organisations

Cancer Focus Northern Ireland

cancerfocusni.org

Nurse line: 0800 783 3339 (Mon, Weds, Fri, 9am-1pm)

Care and support for people affected by cancer and their families in Northern Ireland.

Cancer Research UK

cancerresearchuk.org

Helpline: 0808 800 4040 (Mon-Fri 9am-5pm)

Information for anyone affected by cancer.

Macmillan Cancer Support

macmillan.org.uk

Support Line: 0808 808 0000 (7 days a week, 8am-8pm)

Provide practical, medical and financial support for anyone affected by cancer.

Maggie's

maggies.org

Tel: 0300 123 1801

Centres around the UK and online offer free, comprehensive support for anyone affected by cancer.

Tenovus Cancer Care

tenovuscancercare.org.uk

Tel: 0808 808 1010

Advice and support for people affected by cancer in Wales.

This fact sheet has been produced by the Support and Information Team at Pancreatic Cancer UK.

We make every effort to make sure that our services provide up-to-date, accurate information about pancreatic cancer. We hope this will add to the medical advice you have had, and help you make decisions about your treatment and care. This information should not replace advice from the medical team – please speak to your doctor, nurse or other members of your medical team about any questions.

Email us at publications@pancreaticcancer.org.uk for references to the sources of information used to write this fact sheet.

Give us your feedback

We hope you have found this information helpful. We are always keen to improve our information, so let us know if you have any comments or suggestions. Email us at publications@pancreaticcancer.org.uk or write to our Information Manager at the address below.

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