

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.

Contents

What is FOLFIRINOX?	2
How is FOLFIRINOX used?	3
How is FOLFIRINOX given?	3
What are the side effects of FOLFIRINOX?	6
Further information and support.....	12



You can also speak to our specialist nurses on our confidential Support Line. Call free on **0808 801 0707** or email **nurse@pancreaticcancer.org.uk**



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

Read more about chemotherapy in our fact sheet:
Chemotherapy for pancreatic cancer

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

What is FOLFIRINOX?

FOLFIRINOX is made up of a combination of chemotherapy drugs:

- FOL – folinic acid (leucovorin), which is a vitamin that helps fluorouracil work better
- F – fluorouracil (5FU)
- IRIN – irinotecan
- OX – oxaliplatin.

FOLFOX

Sometimes folinic acid, 5FU and oxaliplatin are used without irinotecan. This is known as **FOLFOX**.



Read more about FOLFOX on our website at:
pancreaticcancer.org.uk/oxaliplatin

FOLFIRI

Sometimes folinic acid, 5FU and irinotecan may be used without oxaliplatin. This is known as **FOLFIRI**.

FOLFIRI may be used for people who are having problems with side effects of oxaliplatin, such as tingling and numbness in their hands and feet (peripheral neuropathy). It may also be used as a second-line treatment for people who have already had a gemcitabine based chemotherapy.

FOLFIRI is given in the same way as FOLFIRINOX, but without the oxaliplatin.

Your chemotherapy team can talk to you about these options.

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 to try to stop the cancer coming back.
- If you have cancer that has grown close to major blood vessels near the pancreas (borderline resectable cancer), you may have FOLFIRINOX 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.
- If you have locally advanced or advanced pancreatic cancer and surgery is not possible, you may have FOLFIRINOX to try to control the growth of the cancer.

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



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 that you will go into hospital for treatment, but you will not need to stay overnight.

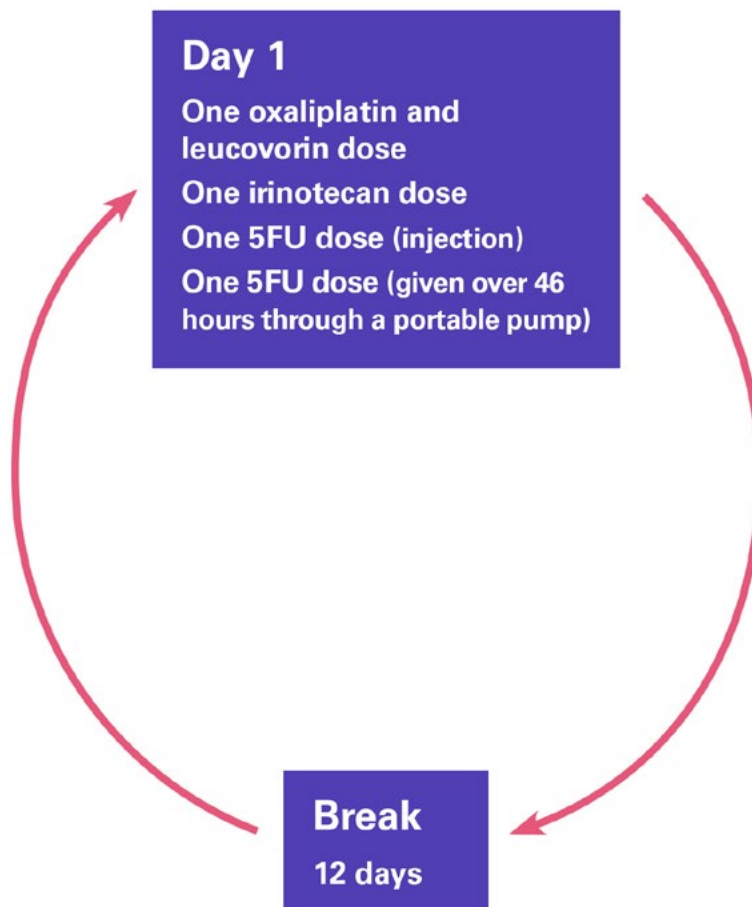
FOLFIRINOX is given in a two week cycle. This means you will have the chemotherapy over two days, and then a break of 12 days before you have the next cycle. The break allows your body to recover. The number of cycles you have will depend on how the treatment is working and how chemotherapy affects you.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

The FOLFIRINOX drugs are given as an injection or infusion into a vein. You may hear an infusion called a 'drip'. You will have the infusion through a cannula, or a central line. A cannula is a thin tube which is put into a vein in the back of your hand or lower arm. A central line, such as a PICC line or a portacath, is a long tube that is put into a vein in your arm or chest. Part of the tube remains outside the body and is attached to a drip to give you your chemotherapy. The line will be flushed out between each different drug.

FOLFIRINOX cycle

On the first day of each cycle, you will have an infusion of oxaliplatin, folinic acid and irinotecan. You will then have an injection of fluourouracil into a vein. This will all take about six hours, but check this with your chemotherapy team, as it may vary at different hospitals. After this you will have an infusion of fluourouracil 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.

Diagram showing how FOLFIRINOX is given



Each chemotherapy team may give FOLFIRINOX slightly differently. For example, you may have oxaliplatin and folinic acid one after the other, or you may have them at the same time. Speak to your chemotherapy team about how you will be given FOLFIRINOX.



Read more about how chemotherapy is given, including cannulas and central lines, at:
pancreaticcancer.org.uk/havingchemotherapy

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.

Some people may also have runny poo (diarrhoea) or tummy pain, caused by a reaction to the infusion.

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

What are the side effects of FOLFIRINOX?

FOLFIRINOX can cause side effects, but 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 help with side effects to take home and use when you need to. Ask the team any questions you have. Knowing what to expect can help you to cope with any side effects.

If you have lots of side effects, your doctor may change the dose of some of the FOLFIRINOX drugs to make it easier to cope with. This is sometimes known as mFOLFIRINOX (modified FOLFIRINOX). Your chemotherapy team can talk to you about this.

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, runny poo (diarrhoea) and feeling or being sick. You will have a blood test to check for DPD-deficiency before you start chemotherapy.

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



Read more about the side effects of chemotherapy in our fact sheet: **Chemotherapy for pancreatic cancer**
Or at: pancreaticcancer.org.uk/chemoeffects

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 temperature – your chemotherapy team will tell you what a high temperature is
- 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 on our website at: **pancreaticcancer.org.uk/blood**

Runny poo (diarrhoea)

If you have diarrhoea, try to drink as much water as you can. If you are finding it hard to drink enough fluids, contact your chemotherapy team. If you have diarrhoea more than four times a day, tell your chemotherapy team. They can give you medicines to control it. Your chemotherapy may be delayed until the diarrhoea 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/bowelhabits

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 after a few days. There are things that you can do to help with fatigue. See how the chemotherapy affects you and work out how much activity you can manage.

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 can take medicines to stop you feeling or being sick. You will normally be given anti-sickness medicines to manage sickness. If these medicines don't help, speak to your chemotherapy team about changing 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, but for some people it may never go away. This can be worse in the cold, so wrap up well if you are going outside.

Talk to your chemotherapy team if you have any tingling or numbness in your fingers or toes.



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 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, but this is normally only if you are out in the cold or having a cold drink. It should stop a few days after your treatment finishes. Try to avoid cold drinks and wrap up warmly 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 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 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 problems you have with your mouth. They can make sure you don't have a mouth infection and give you a mouthwash which should 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 peel. Your doctor or nurse may give you a vitamin or creams to help with this. If you have badly peeling skin, it is very painful, or you have broken skin that looks infected, call the 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 that you check your temperature before taking any paracetamol or ibuprofen. If you have a high temperature, call the emergency number straight away.

Skin changes

FOLFIRINOX 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, 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 can cause chest pain. It can also make you feel short of breath, dizzy, or cause an irregular heartbeat. It is important to tell your chemotherapy team straight away if you have any of these symptoms. 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 one of your arms or legs, or you feel short of breath, call the 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.

Further information and support

Pancreatic Cancer UK services

We are here for everyone affected by pancreatic cancer.

Our specialist nurses are here to talk now

If your world has been turned upside down by a pancreatic cancer diagnosis, we are here to talk now. We can answer your questions, recommend practical steps and provide the emotional support you and those close to you need, when you need it most.

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

Expert information

Our free information covers everything about pancreatic cancer to help you understand your diagnosis, ask questions, make decisions and live as well as you can.

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

Download or order our free publications at:
pancreaticcancer.org.uk/publications or call **0808 801 0707**

Our online forum

The forum is a supportive online space where everyone affected by pancreatic cancer can be there for each other at any time.

Go to: **forum.pancreaticcancer.org.uk**

Living with Pancreatic Cancer Online Support Sessions

Our online support sessions are hosted by our specialist pancreatic cancer nurses and will give you the chance to connect with others who have also been diagnosed.

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

Real life stories

Read other people's experiences of pancreatic cancer to find out how they coped with their diagnosis and treatment and their tips on looking after themselves.

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

Useful organisations

Cancer Hair Care

www.cancerhaircare.co.uk

Telephone: 01438 311322

Support with hair loss and hair care during cancer treatment.

Cancer Research UK

www.cancerresearchuk.org

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

Information for anyone affected by cancer.

Healthtalk

www.healthtalk.org

Personal experiences presented in written, audio and video formats, including people talking about pancreatic cancer.

Macmillan Cancer Support

www.macmillan.org.uk

Support Line: 0808 808 00 00 (Every day, 8am-8pm)

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

Maggie's Centres

www.maggies.org

Telephone: 0300 123 1801

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

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.

Pancreatic Cancer UK

Westminster Tower
3 Albert Embankment
London SE1 7SP

020 3535 7090
enquiries@pancreaticcancer.org.uk
pancreaticcancer.org.uk

© Pancreatic Cancer UK April 2022
Review date April 2024

Registered charity number 1112708 (England and Wales), and SC046392 (Scotland)