

# FOLFOX for pancreatic cancer

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

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 FOLFOX?

FOLFOX is made up of a combination of chemotherapy drugs:

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

FOLFIRINOX 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 FOLFOX used?

FOLFOX may be used if you have locally advanced or advanced pancreatic cancer.

- It may be used for people who have already had chemotherapy.
- Or it may be used instead of FOLFIRINOX for people who are having problems with side effects of irinotecan.

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 FOLFOX 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.

FOLFOX is given in a two weekly 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 FOLFOX 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.

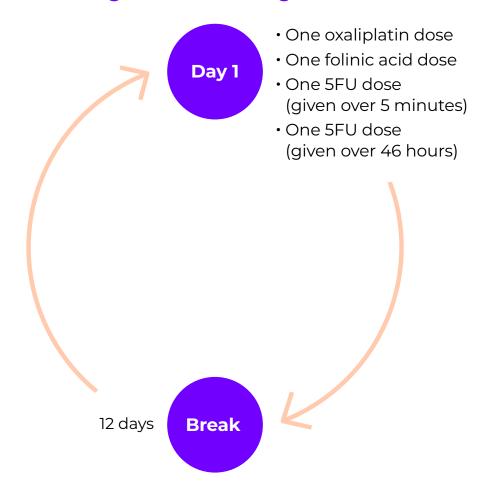
Read more about central lines and see a diagram on our website at: pancreaticcancer.org.uk/havingchemotherapy

Each cycle is given in the following way.

- On the first day of each cycle, you will have an infusion of oxaliplatin and folinic acid.
- 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 will give the FOLFOX drugs slightly differently. Speak to your chemotherapy team about how you will have FOLFOX.

#### Diagram showing how FOLFOX is given



#### Reaction to the chemotherapy

Some people have a reaction while FOLFOX 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.

A reaction needs treating straight away. If you have any of these symptoms or anything else unusual, tell your chemotherapy nurse.

## What are the side effects of FOLFOX?

FOLFOX 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 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.

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, 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

FOLFOX 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 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

#### **Bruising and bleeding**

FOLFOX 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.

#### Anaemia (low red blood cells)

FOLFOX 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.

#### 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

#### Feeling or being sick (nausea or vomiting)

This is a common side effect of FOLFOX 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

#### **Fatigue (extreme tiredness)**

Fatigue is a common side effect of FOLFOX. 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

#### Tingling and numbness in your fingertips and toes

FOLFOX 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 about any tingling or numbness, so 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 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.

#### **Hair loss**

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

#### **Taste changes**

FOLFOX 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 taste changes on our website at: pancreaticcancer.org.uk/diettips

#### Sore mouth and mouth ulcers

FOLFOX 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

FOLFOX 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 creams or painkillers to help with this. If you have badly peeling skin, it is very painful, or you have 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

FOLFOX 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

FOLFOX 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 FOLFOX, 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

## **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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