Chemotherapy Treatment for Pancreatic Cancer

Chemotherapy drugs, how they are given and managing side effects.

Understanding pancreatic cancer booklet 4

In this booklet, you'll find out more about pancreatic cancer, and the types of chemotherapy treatment given to pancreatic cancer patients. It will also answer important questions about how this may affect you physically and emotionally, plus some practical considerations to think about when going through chemotherapy treatment.

Understanding Pancreatic Cancer – Patient Information Booklets

Receiving a diagnosis of pancreatic cancer can be an upsetting, stressful and confusing time. We have listened to patients, relatives and carers to understand what information is useful. Our patient information booklets are easy to understand and beneficial to have at hand to answer any questions or concerns you may have.

All of these publications are produced under the Information Standard certified scheme and are reviewed by medical professionals and patients/carers who have been affected by pancreatic cancer.

To order further patient information, please visit: **panact.org/patient-booklets**

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Introduction

What is the pancreas?

The pancreas is an organ about 6 inches long and shaped like a thin pear lying on its side. The wider end of the pancreas is called the head, the middle section is called the body, and the narrow end is called the tail. The pancreas is found deep inside your body, behind the stomach and in front of the spine.

The pancreas has two main jobs in the body, it makes:

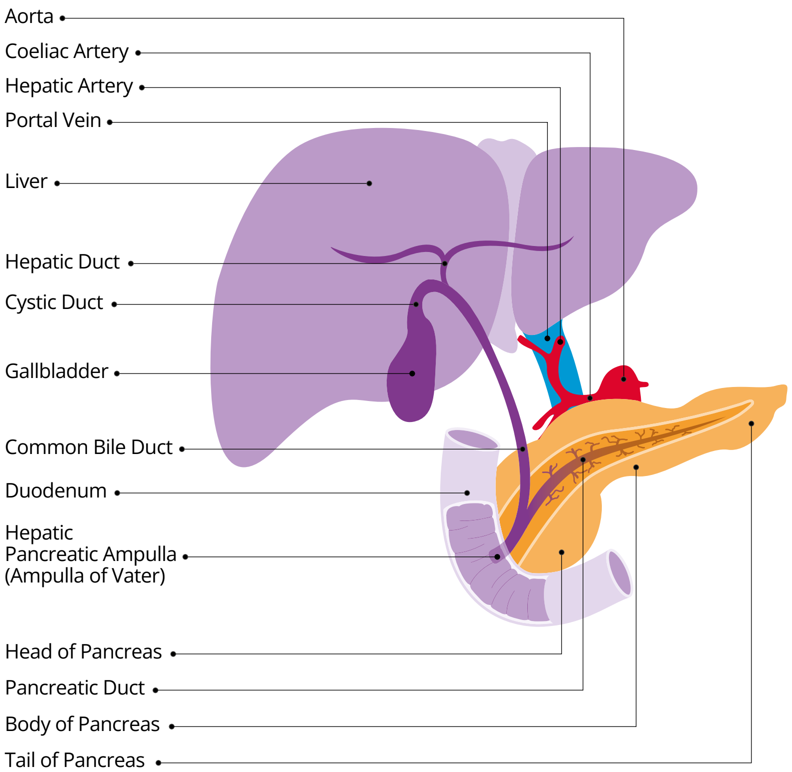
Enzymes
These help to digest (break down) foods.

Hormones
Such as insulin and glucagon, which control blood sugar levels.

The pancreas helps the body use and store the energy it gets from food.

A tube called the pancreatic duct connects the pancreas to the first part of the small intestine, known as the duodenum. Digestive enzymes pass through this tube to help break down food. Another tube, called the common bile duct, passes through the head of the pancreas. This tube carries bile (a substance that helps to digest fats) from the liver and gall bladder to the small intestine. The bile duct may get blocked when a pancreatic tumour invades it. This causes jaundice (yellowing of the eyes and skin and dark urine).

The location of the pancreas



The pancreas contains two types of glands:

Exocrine glands
Create the enzymes which help digest (break down) foods.

Endocrine glands
Create the hormones such as insulin and glucagon, which control blood sugars.

Introduction

What is pancreatic cancer?

Pancreatic cancer occurs when a malignant tumour forms in the pancreas.

Worldwide there are around 496,000 new cases each year; in Europe that figure is more than 104,000. In the UK, approximately 10,500 people are newly diagnosed each year.

Pancreatic cancer affects men and women equally with incidence increasing from the age of 45. The average age at diagnosis is 72.

There are two main types of pancreatic cancer:

Exocrine tumours

These make up the vast majority of all pancreatic cancers (around 95%) and come from the cells that line the ducts in the pancreas which carry digestive juices into the intestine.

These are called pancreatic ductal adenocarcinomas.

Other exocrine tumours of the pancreas are rarer, and include adenosquamous carcinomas and undifferentiated carcinomas.

Endocrine tumours

These are also known as neuroendocrine tumours, (NETS) and are much less common. The neuroendocrine tumours we discuss here are found in the pancreas and are called pancreatic neuroendocrine tumours (pNETS).

These are tumours that develop in our endocrine glands that release hormones (which regulate some processes in our bodies), these are then circulated around the body.

Other rare tumours that can affect the pancreas include pancreatic lymphoma, a cancer that arises from the lymphatic tissue in the pancreas; various cystic tumours and pancreatic sarcomas, which develop in the tissue that holds cells in the pancreas together.

Tumours that arise from tissues close to the pancreas, such as the bile duct (cholangiocarcinoma), Ampulla of Vater (ampullary adenocarcinoma), or duodenum (duodenal adenocarcinoma), may cause similar symptoms to pancreatic cancer but are different to pancreatic cancer and not covered by this booklet.

This booklet discusses the use of chemotherapy to treat pancreatic cancer. Chemotherapy may be given to try and improve quality of life, treat symptoms and try and prevent the cancer spreading or returning. Your medical team should discuss which treatments they believe are right for you, the pros and cons and impact on your quality of life. If you have any questions about your treatment or if chemotherapy is right for you, ask a member of your medical team for advice.

80% of **pancreatic cancers occur** in the **head of the pancreas,** less commonly in the body (15%) and tail (5%)

Chemotherapy and how it is given

What is chemotherapy?

Chemotherapy treatment is the use of cytotoxic (cell-killing) medicines to destroy cancer cells. It is an important treatment option for many types of cancer.

You may have chemotherapy on its own or alongside other treatments such as radiotherapy or surgery. Usually you will be given chemotherapy by injection into a vein (intravenous). You may also be able to take certain types of chemotherapy as tablets or capsules by mouth (orally). Drugs taken orally are absorbed into the blood from your digestive system. The medicine is distributed to the fast growing cells in your body, therefore is sometimes called systemic therapy.

The majority of chemotherapies for pancreatic cancer are given as an out-patient (when you don't have to stay in hospital overnight), however this depends on the type of chemotherapy prescribed. It is sometimes possible to have chemotherapy at home. Your oncologist will discuss with you how and where you will have your chemotherapy and any possible side effects.

Why is chemotherapy given?

The thought of chemotherapy can seem very scary, but chemotherapy is a medicine given to help. It can be provided for pancreatic cancer patients for several reasons, this depends on what stage the cancer is.

1. **Operable pancreatic cancer**
   (resectable, for those where surgery is a considered treatment)
   a. Before surgery, chemotherapy may be used either on its own, or alongside radiotherapy, to try to shrink the tumour in the pancreas. This is called neoadjuvant therapy. This is usually offered only as part of a clinical trial.
   b. After surgery, chemotherapy may be given; the aim is to reduce the risk of the cancer coming back. This is called adjuvant therapy.

2. **Locally advanced pancreatic cancer**
   (The tumour is local to the pancreas and has not spread anywhere else. It may involve the major blood vessels or be too close to them to make the tumour operable.)
   a. Chemotherapy may be given to shrink the tumour in case it can become operable (neoadjuvant therapy).
   b. If surgery is not an option, then to prolong and improve quality of life, then chemotherapy is used to treat symptoms and help stop the cancer from spreading further.

3. **Metastatic pancreatic cancer**
   (When the cancer has spread to other parts of the body.)

   Chemotherapy may be given to try to prolong and improve quality of life, treat symptoms of the disease and to help stop the cancer from spreading further.

   Sometimes chemotherapy can be given in combination with radiotherapy to increase the effectiveness of radiotherapy treatment. This combined approach is becoming more common and is known as chemo-radiotherapy or chemoradiation.

   You can also be given chemotherapy as part of a clinical trial (see page 44 for more information).

Chemotherapy and how it is given

What is a cycle of chemotherapy treatment?

Chemotherapy treatment is usually given in cycles. This means, it is given over a period of time but with breaks in between. The cycle will vary depending on what type of chemotherapy you are having. Below is information on what to expect for each type of chemotherapy drug, but this is not exclusive and may vary according to your circumstance.

For example, the chemotherapy drug gemcitabine is usually given in weekly doses for three weeks, then a week off. This is one cycle.

How is chemotherapy given?

Orally (by mouth)

Oral chemotherapy usually comes in tablet form (pills or capsules) but may be a liquid. Usually oral chemotherapy tablets are encased in a protective coating that is broken down in the stomach. The chemotherapy drug is then released and absorbed by the lining of the stomach and intestines.

Not all chemotherapy drugs can come in tablet form as some medicines can be destroyed by stomach acid and some can't be absorbed into the patient's body through the stomach lining or intestines. If the medicine is not absorbed, then it will simply pass into stools or urine and won't work. Some medications are too harsh to be taken orally as they damage the stomach lining.

An example of an oral chemotherapy drug sometimes used for pancreatic cancer is capecitabine, which is used in combination with gemcitabine. For more information on this chemotherapy combination ask your doctor.

Intravenous administration (IV) of chemotherapy

This is the most common method of delivering chemotherapy as most drugs are easily absorbed into the bloodstream.

Intravenous administration allows the drug to rapidly enter the body's circulation which carries it to the tumour through the bloodstream. Doses can be given which last from a few minutes to a few hours, depending on the cancer and the drug used. Continuous infusions can even be given over a few days or weeks at a time. Sometimes portable infusion pumps are used which allows medication to be given in a slow continuous way.

There are various methods used to deliver chemotherapy drugs intravenously.

Cannula

A small, thin plastic tube or cannula may be inserted into a vein in the forearm or the back of the hand. The cannula may be uncomfortable, or even painful, but this soon eases. Once inserted, the cannula is securely taped to fix it in place and the drugs are given through a drip. This is a temporary device which is removed after each individual treatment.

Portable infusion pump

These allow your medication to be delivered continuously at a slow rate. Portable infusion pumps are pressure pumps, which means that they don't need a battery. This type of pump is quite small. You can carry it in a small bag (which you will be given in hospital) or through your belt. There are also small battery operated pumps known as ambulatory pumps. There are different types of these and your nurse will show you how to operate the pump you need to use.

You may need to have your continuous pressure or battery operated pump changed regularly. This can either be done in hospital or by a home chemotherapy or district nurse.

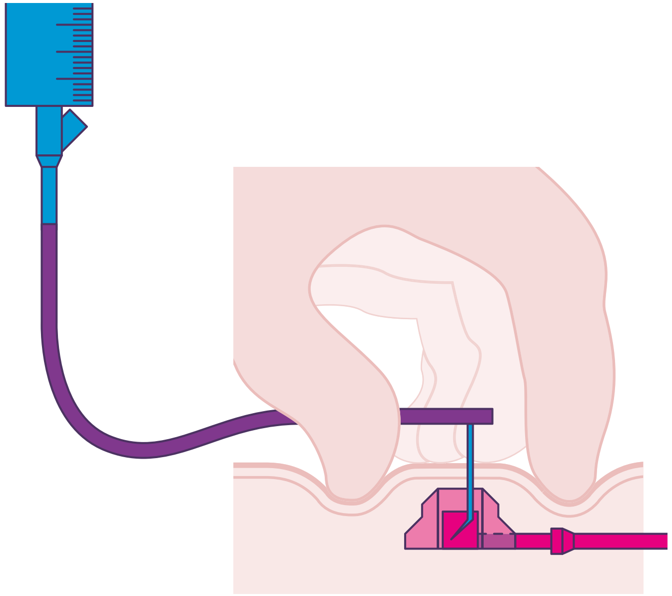
Chemotherapy and how it is given

Port-a-cath

A port-a-cath, also known as an implantable port or a subcutaneous port, is often used for patients who need frequent or continuous administration of chemotherapy. Sometimes chemotherapy drugs can, over time, damage smaller veins of the body and are painful. To make the treatment more comfortable and convenient, a port-a-cath system can be used.

A port-a-cath is made up of two parts: a port and a catheter. The catheter is a thin, soft, plastic hollow tube that is put into a vein in your chest or arm and has an opening (port) just under the skin. It allows medicines to be given into the vein, or blood to be taken from the vein. The port is about 2.5-4 cm (1-1.5 inches) in diameter and has one chamber which is covered by a plastic membrane. It is through this membrane that a special needle known as a Huber needle will be inserted to deliver the medication or to take blood.

Port-a-cath



A port-a-cath is usually inserted under local anaesthetic but occasionally a general anaesthetic will be used. The procedure, which takes less than an hour, is performed in an operating theatre or an area called the vascular radiology unit, and x-ray machines and ultrasound machines will be used to obtain the correct position of the port-a-cath.

The catheter or tube is usually inserted under the skin of your chest, or in your arm. The tip of the catheter lies in a large vein just above your heart. The other end of the catheter connects with the port, which sits under the skin on your upper chest or arm. You will not normally be able to see the port as it is underneath your skin, but you will be able to feel it like a small bump.

You may feel a little discomfort at the site of insertion after the anaesthetic wears off, and there may be some swelling and tenderness around the port for a few days. You may shower 24 hours after the port-a-cath has been inserted and take a bath after two weeks. Once the wound has healed, no dressing will be required.

Typically you will be allowed to go home a few hours following the procedure once you have recovered from the sedation. It is recommended that you do not perform any strenuous exercises or do any heavy lifting for two weeks following the procedure.

A port-a-cath can be left in place for many months and even years (although this is rarely the case). Rarely can the catheter get blocked with clots and tissue growth and sometimes can become infected.

Tell your doctor or nurse if:

- **the area around the port becomes red, swollen or painful**
- **you develop a high temperature (fever)**
- **you have chest pain**
- **you feel shortness of breath or dizziness**

If you do have an infection, you'll be given antibiotics. If these don't clear it, or if the infection is serious, the port may have to be removed.

Chemotherapy and how it is given

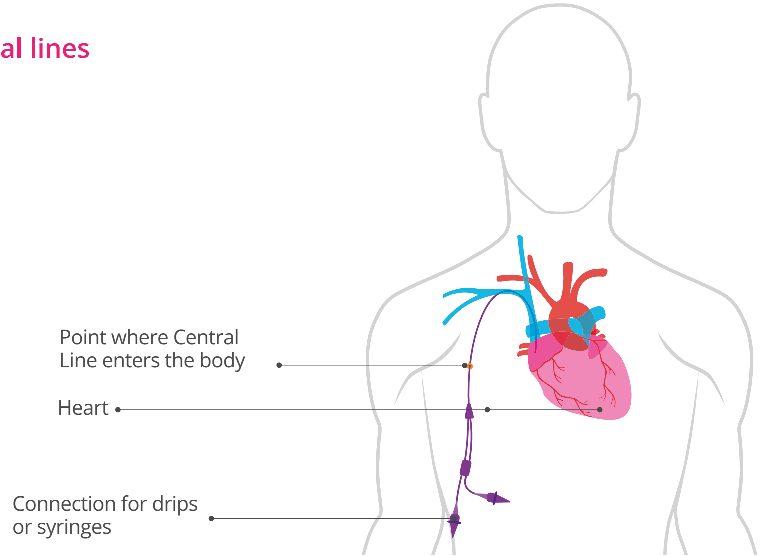
Central Lines (Tunnelled Catheters)

Central lines, known by trade names, Hickman® or Groshong® Lines, are placed through the skin in the middle of the chest. They are pushed through the subcutaneous tissue (the layer of tissue between the skin and the muscle) and inserted into the superior vena cava (the vein that carries blood to the heart from the upper body). These catheters can have several lumens (entrances) to allow blood samples to be taken or drugs given at the same time. Each lumen has a special cap at the end of the line outside the body. A drip line can be attached to these lumens.

Central lines are usually inserted under a local anaesthetic in an out-patients department. In most cases it only takes a few minutes to put in. Once in place, the central line is stitched and taped firmly to your chest to prevent it from being pulled out of your vein. The stitches will be removed about 10-14 days afterwards depending on the hospital practice.

Central lines can stay in place for months or even years (although this is rarely the case). Central lines prevent the need to have a cannula put into your veins each time you receive treatment. This may be very helpful if it is difficult to get needles into your veins, or if the walls of your veins have been hardened by previous chemotherapy treatment. Central lines can also be used with portable infusion pumps which allow medication to be given at a slow continuous rate (see page 8).

Central lines



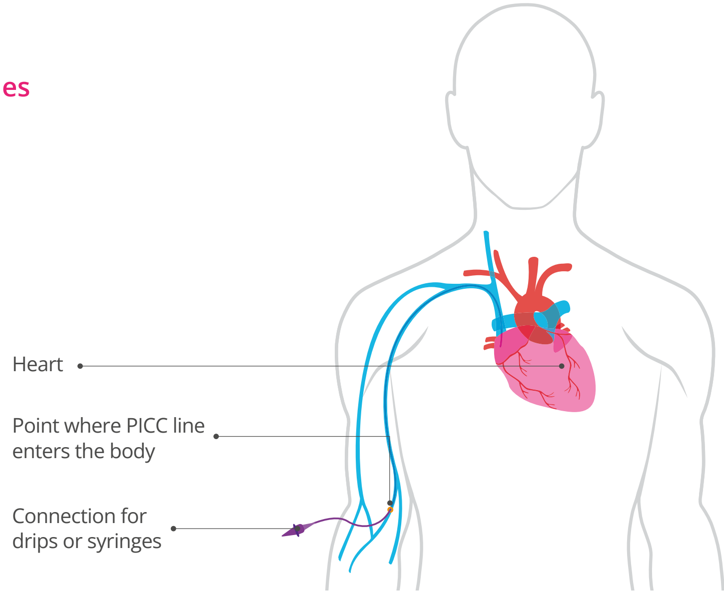
PICC Line

A PICC line (Peripherally Inserted Central Catheter) involves the placement of a thin flexible tube into a vein in your arm. The tube is threaded through the vein until one end of the tube sits close to your heart. Once in place, the PICC line may be stitched in and taped firmly to your arm.

A special x-ray called fluoroscopy confirms that the PICC line is in the right place. The stitches will remain in as they prevent the line from being pulled out of your vein. It can also be held in place with a transparent dressing.

This procedure is usually done under local anaesthetic by a specially trained nurse or doctor. PICC lines are temporary and can remain in place from a few weeks to a few months. As with a central line, you will not need a cannula put in each time you have your chemotherapy. Blood can also be taken through the line for testing.

PICC lines



Chemotherapy and how it is given

Problems with central lines

On occasion, some problems can occur with central lines.

The main problems can be:
- Blockage
- Infection
- The tube falling out

Blockage

Blockages are caused by blood clotting where the line enters your vein. Depending on the type of line you have, it may need to be flushed with saline containing heparin (a drug to prevent clotting) once a week to prevent blockages.

Infection

If you have a temperature over 38°C (105°F), notice swelling, redness, darkening and soreness of the skin around the central line you may have an infection in the line. You will need to contact your doctor or nurse straight away and, if you have an infection, you will need antibiotics to clear it up. This is particularly important while you are having chemotherapy because changes in your immune system mean you can be at greater risk of an infection becoming serious.

Tube falling out

It is generally quite hard for the tube to fall out as your skin will grow around it. If it does fall out, do not panic but do contact the hospital straight away. Your medical team will give you details of who to contact in these circumstances.

If your tube has fallen out, put a clean dressing over the area to keep it covered before you go into the hospital. Do not throw the line away as your doctor or nurse will need to check it to make sure it is complete and that no parts have been left inside your skin.

On very rare occasions, the line can snap or puncture. Contact the hospital immediately if this happens and clamp the tube by tying a knot above the hole. Do not throw away the rest of the line, but take it with you to the hospital.

Caring for central and PICC lines — tips and hints

- Keep the site clean and dry
- When getting dressed, be careful that the line does not get caught
- Wear loose fitting tops or shirts for easy access
- Place a plastic dressing or cling film over the site when showering or bathing
- Swimming should be avoided as this may cause infection
- Do not pull or tug on the tubing
- If you have a PICC line, avoid lifting heavy objects with the arm your line is in
- If you are worried that your site is showing signs of infection or clotting, contact your medical team straight away
- If your line falls out, place a clean dressing over the site before going to hospital and bring the line with you - do not throw it away

Practicalities and chemotherapy

Will chemotherapy affect my everyday life?

Chemotherapy affects different people in different ways. You may be able to carry on as normal. However, if you have to go into hospital for your treatment, you will need to make changes to your usual routine.

If there is a special occasion that you would like to attend, or you want to go on holiday, it may be possible to arrange the timing of your treatment to suit your needs. Your oncologist can tell you whether this is possible.

Many people feel tired a lot of the time during and after chemotherapy. If you are recovering from surgery or having radiotherapy as well as chemotherapy you may feel especially tired. If this happens to you, cutting down on the things you don't really need to do may help.

There is some evidence that exercise of low to moderate intensity may help to substantially reduce this tiredness. It is best not to overdo it. Do as much as you think you can manage and make sure you get enough rest and sleep.

While having your chemotherapy, you may find that you are able to carry on doing everything as normal but if you work you may need some time off.

Planning your chemotherapy

The decision to start a course of chemotherapy will be yours. The doctor will give you guidance to help you make your decision. The doctor will consider several things when planning your treatment:

- The type of cancer that you have
- Where in the body it is situated
- If it has spread
- Your general health

How often you have your treatment and how long it takes depends on the type of cancer you have, the drugs you are taking, how well the disease responds to treatment and any side effects that you are experiencing.

You may need several cycles of chemotherapy. Your oncologist will discuss this with you when he/she takes consent for treatment. The process of consent is important. The oncologist's job is to ensure you understand what your choices are and that you are happy to proceed with the chemotherapy treatment offered. It may be a good idea to bring someone along with you to that appointment.

You will need blood tests before every chemotherapy treatment. This is to check you are fit to have treatment. It may be possible for you to have blood taken at your GP's surgery 2-3 days beforehand. This will save you waiting around at the hospital before your chemotherapy can start.

If you are very fearful or anxious of needles and are having difficulty with chemotherapy because of this, please mention it to someone in your specialist team who will work out a way of overcoming this problem.

Interactions with other medicines

It is important to tell your doctors about any other prescription or over-the-counter medicines you are taking or planning to take, as these may affect how the chemotherapy works in your body. These include herbal remedies and antioxidant and nutritional supplements (such as vitamins and minerals) as well as pharmaceutical treatments.

Drugs commonly used

Chemotherapy drugs explained

Chemotherapy drugs aim to stop cell division in the tumour, to stop it growing or spreading to other parts of the body. Chemotherapy is usually most effective at killing cancer cells, but it can also kill healthy cells, causing some side effects, see page 26 for more information on common side effects.

Names of chemotherapy drugs

Chemotherapy drugs usually have two names, a genetic name which is the chemical name of the drug, for example paracetamol, also a brand name given by the company/ manufacturer of the drug for example Panadol®. Below the general names are stated first, in brackets are the brand names.

Chemotherapy drugs commonly used for Pancreatic Cancer

The chemotherapy drugs we mention in this booklet are used to treat exocrine pancreatic cancer—the most common form of which is pancreatic ductal adenocarcinoma (PDAC). Approximately 95% of all pancreatic cancers are PDAC.

The choice of chemotherapy you will be offered will depend on your situation (please see page 8) and your general health. Each person is different, so the type of chemotherapy will be selected on what is thought to be best for you. Do speak to your doctor about the different options.

The chemotherapy treatments listed below are the drugs most commonly used for pancreatic cancer.

Gemcitabine (Gemzar®)

What is it?

Gemcitabine is commonly used to treat pancreatic cancer. Gemcitabine is a drug that stops normal cell metabolism occurring. Cells that take in Gemcitabine are unable to divide normally. This is in a group of chemotherapy drugs called antimetabolites. Usually the side effects of Gemcitabine are relatively mild.

How is it given?

This is usually given in the vein, and you will be an outpatient (when you go into hospital without staying overnight). It is a colourless fluid, which is usually given by intravenous infusion (through a drip) with each infusion usually lasting around 30 minutes. Usually in cycles, often weekly for 3 weeks, then 1 week off.

You will often be given anti-sickness drugs (anti-emetics) at the same time.

When is it given?

Gemcitabine is one of the main chemotherapy drugs used for pancreatic cancer. It does depend on your circumstance, but Gemcitabine is often used for borderline and operable cancer, for locally advanced, and for metastatic cancer.

Gemcitabine is used alone or sometimes in combination with other chemotherapy drugs such as fluorouracil, capecitabine or nab-paclitaxel (see below). It can also be considered as second-line treatment for people whose cancer has progressed after first-line FOLFIRINOX (see below).

Fluorouracil 5-FU®

What is it?

Fluorouracil is a type of chemotherapy in the antimetabolite group, this is a drug that stops normal cell division occurring. 5-Fluorouracil (5-FU) is a liquid, and sometimes a vitamin called folinic acid is given at the same time as this helps the chemotherapy drug work better.

You will often be given anti-sickness drugs (anti-emetics) at the same time.

How is it given?

This is usually given in the vein (IV) through a drip. It is used alone and is given as a long infusion. The exact amount and frequency depends on your situation.

When is it given?

This is often used as an adjuvant therapy (after surgery) or as a sensitiser (making tumour cells more responsive) for chemo-radiotherapy or as a second line therapy for advanced pancreatic cancer for those who don’t cope well with Gemcitabine.

Drugs commonly used

Capecitabine (Xeloda®/ GemCap®)

What is it?

Capecitabine is the oral form of 5-Fluororacil (5-FU). It is taken in tablet form by mouth and is converted inside cancer cells to 5-fluorouracil (5-FU), the active form of the medicine. Capecitabine, is part of the antimetabolite group, it stops normal cell division occurring.

GemCap® is a combination therapy of Gemacitbine (Gemzar®) and Capecitabine. Capecitabine is usually given alongside Gemcitabine, but not exclusively.

How is it given?

Capecitabine is an oral form of chemotherapy, (taken by a tablet), so you do not need to go to hospital to take this. Capecitabine is often given as a combination of 500mg and 150mg tablets. You need to make sure that you are taking the right dose at the right time.

Capecitabine works best when it's broken down in the stomach with food, so it is best to take your tablets, with water, within 30 minutes of finishing a meal. The doses should be spaced apart, so it is sensible to take one dose in the morning with breakfast and another just after your evening meal. If you have trouble swallowing, the capecitabine tablets can be dissolved in warm water. Stir the mixture until the tablets are completely dissolved, then drink immediately, make sure you wash your glasses thoroughly.

GemCap is usually given in weekly intravenous infusion (IV) of Gemcitabine plus 1 tablet of Capecitabine twice per day for 3 weeks then a break with no treatment for a week. Then the next cycle will begin.

When is it given?

Capecitabine is most commonly given in combination with gemcitabine (GemCap®) after surgery (adjuvant therapy).

FOLFIRINOX

What is it?

This is a combination of four different agents (folinic acid [leucovorin], fluorouracil, irinotecan and oxaliplatin). Combinations are often used as they can target the tumour in different ways. Folinic acid is not a chemotherapy drug, however it has been shown to help the others work more effectively.

How is it given?

This is usually given in the vein, and you will be an outpatient (when you go into hospital without staying overnight). This treatment is usually repeated every 2 weeks for a total of six to twelve cycles dependant on your situation.

Day 1: Oxaliplatin (a colourless fluid) infusion (by drip) over 2 hours, followed by Irinotecan (a clear, slightly yellow fluid) and folinic acid (a clear, pale yellow fluid) infusion over 2 hours.

Next, Fluorouracil (a colourless fluid) as a fast infusion, over 15 minutes, followed by Fluorouracil as a slow infusion over 46 hours (at home) via a small portable pump through a central venous catheter (PICC line).

Day 3: A district nurse will make a home visit to take off the pump and flush the line.

Day 15: Repeat of day 1 and start of next cycle of treatment.

When is it given?

It is often used to treat advanced pancreatic cancer when surgery is not possible and occasionally before surgery to remove a tumour. It can cause more side effects than having individual chemotherapy drugs, therefore, it is usually only given to very fit patients or after surgery.

Nab-paclitaxel (Abraxane®)

What is it?

Nab-paclitaxel is usually given in conjunction with Gemcitabine. Nab-paclitaxel has EU/UK approval for use in combination with gemcitabine for advanced pancreatic cancer.

How is it given?

Abraxane® is given in combination with gemcitabine through the vein and you will be treated as an outpatient. It is usually given in conjunction with gemcitabine on days 1, 8 and 15 of each 28-day cycle.

When is it given?

This is often given for patients with advanced pancreatic cancer.

Oxaliplatin (Eloxatin®)

This is one of the drugs in the combination, FOLFIRINOX. It is considered for patients with advanced cancer as a second line treatment for people that have not already had this chemotherapy drug (see below for more information).

You can go to our website for more information on each of these drugs, including specific side effects for each drug panact.org/chemotherapydrugs

Second-line chemotherapy

Sometimes chemotherapy drugs can stop working. If this happens, your oncologist may prescribe a different chemotherapy for you instead. This is known as second line chemotherapy. The factors your oncologist will take into account before prescribing second line chemotherapy will include:

- How you responded to treatment before
- Possible side effects
- Whether you have an allergy to any potential chemotherapy drugs
- The likely benefits of the drug
- How well you are
- Your quality of life

What's used in second-line chemotherapy?

Suggested second-line treatments for pancreatic cancer are;

1. For individuals that have not already had oxaliplatin chemotherapy treatment, this is often considered as a second line treatment.
2. For individuals who have had FOLFIRINOX treatment and your cancer has still progressed, Gemcitabine-based therapy could be recommended.

Your oncologist should discuss the risks and benefits of each treatment option with you before making any decision on second-line or subsequent chemotherapy. They may also discuss available clinical trials. You should be given time to discuss your treatment options with your healthcare team, members of your family and others, such as your GP, if you wish.

Chemotherapy safety at home

Your medical team may advise you to follow these recommendations for chemotherapy safety when at home. The advice will differ depending on what drug(s) you have been prescribed. If in doubt, ask your oncologist or cancer nurse specialist.

- Don't crush or cut chemotherapy tablets. If you can't swallow a tablet whole, talk to your doctor.
- Store chemotherapy tablets, capsules or injections as directed by your doctor or pharmacist. Keep them out of reach of children. Seal empty tablet containers in a plastic bag and return them to your pharmacy or hospital oncology department.
- After using the toilet, flush it twice with the lid down, for up to a week following a treatment session.
- Wash items soiled with body fluids in a separate load. Choose the most intense washing cycle that the fabric will allow. After washing and drying, these items can be used safely.
- Keep a supply of disposable rubber gloves and cleaning cloths on hand. Wear these rubber gloves when handling clothing or bed sheets soiled with vomit or any other bodily fluids, when used, seal them in a plastic bag before putting them in the bin.
- If body fluids or chemotherapy medication spill onto household surfaces (such as a carpet or mattress), wear rubber gloves, soak up the spill with disposable paper towels, clean around the area with a disposable cloth and soapy water, and rinse the area with water.
- If medication spills on your skin, wash it with soap and running water.
  Contact the hospital if any redness or irritation caused by the spillage doesn't clear up within the hour.
- Protect your partner from your body fluids by using a condom or a female condom if you have any type of sex within a few days after a treatment session. Your doctor or nurse can give you more information about how long you need to use this protection.

Side effects

What are side effects?

Chemotherapy is given because it kills cancer cells. However, chemotherapy can also kill normal cells such as those in the bone marrow, digestive tract, skin, hair and reproductive organs. When normal cells are damaged, this causes side effects.

Many chemotherapy drugs will cause the number of blood cells produced by your bone marrow to drop. This usually begins around seven days after you start each treatment and can return to normal levels about three to four weeks after treatment. Your doctors will be regularly checking your blood to monitor your blood cell counts while you are having chemotherapy treatment.

The drop in blood cells can lead to the following side effects:

- A drop in white blood cells (neutropenia) can lead to an increased risk of infection. With fewer white blood cells, particularly your infection fighting neutrophil cells, your body finds it harder to fight infections. Symptoms of infections can include headaches, feeling shivery, having a cough or sore throat, achy muscles and a high temperature (above 38°C).
- A drop in red blood cells (anaemia) can leave you very tired and breathless. Sometimes the levels drop so low that a blood transfusion may be necessary.
- A drop in platelets (thrombocytopenia) can cause bruising and nosebleeds, because platelets help the blood to clot. You may also find that your gums bleed after you brush your teeth. Low platelet counts can also cause a rash consisting of tiny red dots, called petechiae, or bruises on your arms and legs.

If you feel you have any of the above symptoms please discuss with your doctor and they can suggest what will be suitable to help with these side effects.

General side effects

As noted, some chemotherapy drugs can cause damage to other types of normal cells in your body. People can often carry on with many of their day-to-day activities while having chemotherapy, but some drugs due to the potential damage to normal cells can sometimes cause side effects. The side effects of chemotherapy will vary from person to person and will depend on the type of drug(s) you are taking. Your medical team will discuss potential side effects with you before your treatment starts.

Below are the general side effects of chemotherapy, in the following section we list some everyday things, hints and tips to help you cope with these.

- Being or feeling sick (vomiting and nausea)
- Diarrhoea
- Constipation
- Mouth ulcers
- Poor appetite
- Hair loss
- Redness and peeling on the palms of the hands and soles of the feet (palmar-plantar syndrome). This is more common with capecitabine or 5-FU chemotherapy
- Nerve changes (e.g. pins & needles)
- Infertility (inability to have children)

Side effects are mostly temporary and steps can often be taken to prevent or reduce them. Speak to your medical team if you are concerned about any side effects that you may be having.

Blood Clots

Cancer can make your blood more likely to form a clot (thrombosis) and having chemotherapy also increases this risk. Blood clots can be very serious so it is important to tell your doctor straight away if you have pain, redness and swelling in a leg, or breathlessness and chest pain.

Most clots can be successfully treated with drugs that thin the blood. Speak to your doctor or nurse for more information.

Coping with side effects

Managing your side effects and general well-being

Here are some hints and tips to help you manage your general well-being and cope with the side effects of chemotherapy.

Keep a side effects log

It can be useful to record information about your chemotherapy treatment so you remember details about any side effects you're experiencing. It is important to share this information with your medical team in order for them to help you with suggestions for dealing with side effects or to adjust your treatment, if appropriate.

Keeping a diary in paper form or logging information on a smartphone are ways of doing this. A side effects log can be found on page 53.

Coping with fatigue

Feeling tired and lacking energy (fatigue) is the most common, and often debilitating, side effect of chemotherapy. It can make you feel drowsy, confused or irritable and you might find it difficult to do daily activities. Fatigue can appear suddenly and rest may not relieve it. You might still feel tired for weeks or months after your treatment has finished.

Tips for managing fatigue

- Save your energy. Help your body to recover by resting more. Try to plan activities for the times of day when you have the most energy.
- Try to get more sleep at night and take naps during the day if you can. If you have trouble sleeping, speak to your medical team.
- Light exercise, such as walking can be helpful. If you have a normal exercise routine and you feel up to it, talk to your doctor about whether it is safe for you to continue. It is not advisable to start a new exercise routine until you have completed treatment.
- Let people help you. Family, friends and neighbours often want to assist but may feel unsure about what to do. They could help with shopping, childcare, driving or housework.
- If you are employed, consider asking your employer if they will allow you to work flexibly around your treatment, reduce your hours or take some time off.
- Doing relaxation or meditation exercises may be beneficial.
- Check with your doctor whether your fatigue is related to low red blood cells (anaemia) which can be treated.

Coping with side effects

Coping with feeling and being sick

Chemotherapy may make you feel sick (nauseous) or be sick (vomit). Not everyone feels sick during or after chemotherapy, but if nausea does affect you, it usually starts a few hours after treatment. Nausea may last for many hours and be accompanied by vomiting or retching. Your oncologist will tell you if your chemotherapy treatment is likely to cause nausea and vomiting.

Anti-sickness medication (known as anti-emetics) can help.
Anti-emetics may be available as:

- Injections – usually given by the nurse before chemotherapy
- Tablets – can be taken regularly at home
- Wafers – dissolved under or on top of the tongue
- Suppositories – placed in the rectum where they dissolve
- Liquids – added to the chemotherapy
- Patches – worn on the upper arm

You may be prescribed medication before treatment to reduce the side effects. Some people find it takes time before they find a medication that works for them. Let your nurse or doctor know if you still have nausea after a few days of taking the medication or if you have been sick for more than 24 hours.

Tips for coping with sickness & nausea

- Eat little and often especially before treatment (e.g. soup and dry biscuits or toast), and drink as much fluid as possible.
- Instead of drinking a lot at once, try sipping small amounts of liquid often. Sucking on ice cubes can also help to increase your fluid intake.
- If you wake up feeling sick, eat a dry biscuit (ginger biscuits may help with nausea) or a slice of toast. This is better than skipping breakfast or forcing yourself to eat. If you are diabetic, consult your medical team.
- Fizzy drinks such as ginger ale or soda water can often help relieve an upset stomach.
- It is important to keep up your fluid intake to prevent you from becoming dehydrated if you have been vomiting a lot. You should contact your medical team if you are unable to keep fluids down.
- Avoid strong odours and cooking smells, which can trigger nausea and vomiting.
- Sometimes the taste of certain types of food can change. Your sense of taste should return to normal a few weeks after you have completed your treatment.
- Speak to your dietitian for more detailed advice on eating and drinking while undergoing chemotherapy treatment.

Coping with side effects

Coping with hair loss

Some chemotherapy drugs used to treat pancreatic cancer will cause complete hair loss while others can cause your hair to thin, especially around the hairline.

When hair loss does occur, it usually starts 2–3 weeks after the first treatment and grows back after you have finished your treatment. In addition to hair loss, it can be common for the scalp to feel itchy, hot and tingly in the period when the hair is falling out.

It is common also to lose hair from other regions of the body such as your eyebrows, eyelashes, arms, legs, chest and pubic area.

Tips for coping with hair loss

- Use a mild shampoo like baby shampoo.
- Use a brush with soft bristles to gently brush your hair.
- Make an appointment with a hairdresser who can make your hair look as good as possible even if it is thin or patchy.
- Avoid perms and chemical dyes, and limit the use of hair dryers, hair straighteners or heated rollers.
- If you prefer to leave your head bare, protect it against sunburn and the cold.
- If your eyelashes fall out, protect your eyes from the sun by wearing glasses or sunglasses while outside.
- Tell your nurse if the skin on your scalp becomes very sensitive, itchy or painful.
- Your nurse should be able to provide you with information on ways to cover your head including where to get wigs, turbans etc.

Coping with skin problems

It can be common for your skin to react to chemotherapy treatment. Some people find that their skin becomes dry, itchy, uncomfortable to touch and begins to peel. Some people find that their skin darkens. It usually becomes more sensitive to the sun, so it is important to wear a high factor sunscreen and a hat when going outside, especially in the summer.

Tips for dealing with skin problems

- Shower using a moisturising soap or a cream soap replacement.
- After showering, gently pat your skin dry with a towel, trying not to rub your skin too hard.
- Use a moisturising lotion or cream immediately after showering to stop your skin getting too dry.
- It may be helpful to wear loose clothing made from cotton instead of synthetic or rough fibres.
- Wash your clothing in detergent for people with sensitive skin.
- If you shave, it is a good idea to stop until your skin has healed.
- Keep hydrated by drinking plenty of water.
- Tell your medical team if your skin becomes very red or sore.

Coping with side effects

Coping with mouth sores

Some chemotherapy drugs can cause mouth sores such as ulcers or infections. If you notice any change in your mouth or throat, such as ulcers or thickened saliva, or if you find it difficult to swallow, contact your medical team.

If you have dental problems and need to see a dentist, speak to your doctor first. You should also tell your dentist that you are having chemotherapy.

Tips for dealing with mouth sores

- Use a soft toothbrush to clean your teeth.
- Avoid mouthwashes that contain alcohol - a salt mouthwash may help ulcers to heal.
- Eat moist foods such as soup. Avoid foods that are very hot, spicy or coarse.
- Sucking on ice while you're having intravenous (through a drip) chemotherapy may help to reduce mouth ulcers.
- Avoid smoking and alcohol as these can irritate your mouth.

Coping with constipation and diarrhoea

Some chemotherapy drugs, pain relief medicines and anti-sickness drugs can cause constipation or diarrhoea. Tell your doctor or nurse if your bowel habits change significantly.

Tips for dealing with constipation

- Tell your medical team if you have constipation for more than a couple of days. They may change your medication or give you treatment to relieve it.
- Juices such as prune juice can sometimes help ease constipation.
- Eating more high-fibre foods, such as wholegrain bread and pasta, bran, fruit and vegetables, nuts and legumes (e.g. baked beans or lentils) may help.
- Drink plenty of fluids.
- Light exercise, such as walking, may help to get your bowels moving again.

Tips for dealing with diarrhoea

- Drink plenty of fluids to replace those lost.
- Avoid spicy or rich food and food that is fatty or fried. Cutting out wholegrain foods and raw fruits and vegetables and replacing with bland food such as boiled rice may help.
- Limit the amount of fruit juices, strong tea and coffee and alcohol you drink, as these can stimulate the bowel.
- Speak to your pharmacist about any over-the-counter remedies that may be helpful in treating diarrhoea.
- If the diarrhoea becomes severe, it can cause dehydration and you may need to be admitted to hospital to receive additional fluids via a drip.

Coping with side effects

Coping with and preventing infections

Chemotherapy treatment can cause a drop in the number of white blood cells which can make it harder for your body to fight infection. This makes colds and flu difficult to recover from, and means that cuts and scratches may take longer to heal and are more likely to get infected.

It is wise to seek medical help if you feel unwell while having chemotherapy treatment even if it is just a cold. Talk to your medical team about having the flu vaccine.

It is advisable to ensure you are cautious about hygiene by washing your hands when you have been out and/or carry alcohol gels to help prevent infection.

If family or friends are suffering from colds or flu or tummy upsets, it is best to delay seeing them until they are better.

Signs that you may have an infection include shivering or shaking, headaches and flu like symptoms. Take your temperature if you get any of these symptoms. It is a good idea to keep a thermometer at home.

Contact your doctor urgently if any of the following occur:

- Sweats or shivering (chills)
- Your temperature rises to 38°C (100.4°F) or more
- Persistent or severe vomiting
- Severe abdominal pain, constipation or diarrhoea
- Unusual bleeding
- Pain, tenderness, redness or swelling around the site of the cannula (where a drip is inserted into the skin)
- Any serious sudden side effects that are not normal for you, or a rapid deterioration in your health.

Medication to increase neutrophils (G-CSF therapy)

Neutrophils are a type of white blood cell that help to protect you against infection. Chemotherapy can reduce the number of neutrophils in your blood which can leave you at a greater risk of picking up infections. Your blood will be tested for the neutrophil count before every chemotherapy session. If your neutrophil levels become too low, your doctor may prescribe an injection of granulocyte-colony stimulating factor (G-CSF) after chemotherapy to increase the number of neutrophils.

If you are given G-CSF, your doctor or nurse will speak to you about possible side effects. Some people may experience bone pain, tenderness at the injection site or show signs of an allergic reaction.

Tips for preventing/dealing with infections

- Keep a thermometer at home that is for your use only. Use this to check your temperature if you feel unwell.
- Be vigilant with personal hygiene, ensuring that you wash your hands before preparing and eating food and after using the toilet.
- Be careful when handling raw meat: use separate boards and utensils for raw and cooked foods and store them separately in airtight containers.
- Avoid eating food or drink that is past its use-by or best before date.
- Wash fruit and vegetables well, and peel where possible.
- It may be advisable to avoid soft cheeses; raw fish, uncooked meat and eggs and unpasteurised dairy products.
- Avoid people who are unwell, especially if they have flu, or another contagious disease such as measles, mumps, chicken pox or even if they have a cold.

These tips are general advice only and not a substitute for the medical advice you get from your doctor or nurse.

Coping with side effects

What happens when my chemotherapy stops?

After you have had your chemotherapy, you are likely to have a CT scan and/or blood tests. This is to check what effects the chemotherapy has had on your cancer. Your oncologist will discuss with you the results, check any side effects you may have been having and discuss what the next steps are.

It can take some time for side effects to go after chemotherapy, and a while to adjust back to how life was before. This is a normal experience.

Day to day life and chemotherapy

Emotions

Everyone's experience of chemotherapy is an individual one, both physically and emotionally. Some people will suffer from many side effects, and others will have hardly any. It is natural for the diagnosis of cancer and side effects of treatment to influence your mood and how you are feeling. Most people will go through ups and downs throughout their chemotherapy treatment.

There is no right way for you to feel. These feelings might last a long time or may quickly pass. The important thing is to find a way for you that helps you cope.

Often talking to someone can help, whether this be someone close to you, your doctor or local support groups. Local support groups, or others at your chemotherapy sessions can be helpful as you are talking with people who understand your situation and are going through something similar. You are not alone in this; many people go through chemotherapy.

Even after chemotherapy treatment has finished, it is not unusual to feel strange and different to how you were before your diagnosis.

If you are having continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you might be experiencing depression.

Depression is not a sign of failure or an inability to cope. Depression can be common with cancer diagnoses and can often be treated successfully. There are both medical and non-medical approaches to managing depression. Your doctor or psychiatrist will be able to help. Although it may seem hard, help is there for you.

If you are having some of these thoughts or feelings, you can call the Samaritans' 24-hour confidential helpline: 116 123

For more information on coping with cancer and chemotherapy we recommend the Macmillan Cancer Support website, where there is a lot of helpful information. macmillan.org.uk/information-and-support/coping

Day to day life and chemotherapy

Fertility and sex life

It is advised not to have children while going through chemotherapy, and for a certain period after treatment as the drugs can affect the developing baby. The amount of time to wait after having chemotherapy treatment to try and have children again should be discussed with your doctor.

Fertility

For men this can mean that there is a reduction in the amount of sperm produced and can lead to infertility.

For women this can mean that your ovaries may stop releasing eggs. Chemotherapy can cause temporary or permanent infertility, irregular periods or periods stopping for a while. If you are pre-menopausal (usually before the age of 45), be aware that chemotherapy can sometimes cause early menopause (permanent infertility). This is when you stop releasing eggs and having periods and therefore cannot naturally have children.

Chemotherapy is likely to affect fertility in women of all ages, but the younger you are the more likely you are to have periods again and be able to have children.

If there is a risk your chemotherapy could cause permanent infertility and you are still wanting to have children, it may be possible to preserve your eggs or sperm before treatment starts. Please discuss this with your doctor or a fertility specialist.

Check the NHS website for symptoms of menopause and discuss this with your doctor.
nhs.uk/conditions/menopause/symptoms/

Sex life

Chemotherapy can effect your sex life, this is normal. This may be due to physical symptoms of tiredness, feeling weak, nauseous and your desire to have sex (libido) may have changed. You may also experience emotional affects such as feeling stressed, anxious or sad. This is normal to feel but may influence how you feel about sex. Additionally, the effect of the cancer diagnosis, or any changes to your body due to surgery, or side effects of chemotherapy (such as hair loss) may make you self-conscious, feel vulnerable or influence your confidence.

Chemotherapy should not have a long term affect on your sex life. What can help is talking to your sexual partner about this and communicating how you feel. Talk to your doctor about contraception methods while having chemotherapy.

Work

Being treated with chemotherapy may affect your ability to work. This can be due to the side effects of having pancreatic cancer and treatments making working more difficult, but also the time you need to take to go to clinical appointments can also have an impact. Discuss with your doctor or chemotherapy nurse the likely effects of your treatment and where you will have to travel to. This will help you to prepare for how much time you may need off work.

If you feel your work will be affected, talk to your manager or HR (human resources) Officer as early as possible. If you feel nervous or uncomfortable doing so, ask for it to be private and not a rushed conversation. You can also take someone with you. You should be aware that in the UK you are covered by legislation that protects your rights at work. If you live in England, Scotland or Wales, the Equality Act 2010, and for Northern Ireland, the Disability Discrimination Act 1995 (DDA) (as amended) protects you, even if you are self-employed or a carer. It may be helpful to discuss with your doctor whether your treatments will affect your ability to work. For more information see: **macmillan.org.uk/information-and-support/organising**
or call them on 0808 808 00 00.

Diet

Chemotherapy can influence what you want to eat and how much you can eat. Often common side effects of chemotherapy include making you feel sick and nauseous. Chemotherapy can change your senses of taste and smell which can affect your appetite. Occasionally, some people suffer from mouth sores.

Eating smaller portions little and often may be helpful. See our Diet and Nutrition booklet for pancreatic cancer patients for more information on your diet, or our recipe book for helpful foods to consider eating.

Second opinions

Second opinions

All decisions regarding treatments are made by a multidisciplinary team (MDT, who are specialists in surgery, pathology, oncology and radiology). They use the national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion about your diagnosis or treatment.

You may have doubts about your diagnosis, may not understand the information you are given, or are not happy with the treatment that has been recommended, or you may just want to talk to another doctor or specialist about your diagnosis or treatment.

All patients in the UK have a right to a second opinion on the NHS and this may form a valuable part of your decision-making process. Some people feel uncomfortable asking their doctor for a second opinion, but specialists are used to patients doing this. You can ask your GP to refer you to another consultant or specialist, either on the NHS or privately. Or you can ask your current consultant or specialist to refer you for a second opinion.

As the specialists from a region are likely to have been involved with the initial decision, regarding your treatment, obtaining a second opinion will normally require travel to a different regional specialist centre. It may also be a good idea for a family member or friend to come with you to support you and help process the complex information. It is worth thinking about what you would like to get out of the second opinion before the appointment and writing down questions you would like to ask.

For more information, call Pancreatic Cancer Action on **0303 040 1770** or visit panact.org.

Treatment decisions

What treatment you have, is your decision. The medical experts are there to advise you with their knowledge and what they think may be the best treatment option for you. Remember, you are an individual who knows your body, values, preference and your social circumstance. These are also important factors in treatment decisions.

This is a difficult time. This is likely to be a time of great stress and anxiety, especially just after diagnosis. You are expected to understand and take in crucial information about complex care, by a wide range of specialists. When you are stressed and anxious it can decrease your attention and ability to retain and understand the information given to you. Having a family member or friend with you at consultation appointments can be helpful.

Seeking treatment abroad

Patients wanting to seek treatment abroad should be aware that in some healthcare systems the decision to treat can be sometimes influenced by financial return as much as whether the procedure will improve the outcomes for the patient.

In the UK, treatment decisions are evidence-based. Therefore when a treatment is offered, it is on the basis that the benefits outweigh the risks. If a treatment is not offered it's because your medical team believe that the risks outweigh the benefits.

Clinical trials

What are clinical trials?

Clinical trials are where drugs are tested in volunteers. They are necessary so we know how safe and effective a drug is before it is approved for routine use in patients. There are three stages (phases) a drug (or other treatments) pass through before it becomes available as an accepted treatment. Before a drug can be assessed in a trial, there will have been many years of development in research laboratories, the results of which have to suggest that there is a potential benefit to using the drug in patients.

Phase I trials:

This type of trial is the first time that a drug has been given to humans. It is mainly a study of how well the drug is tolerated and what side effects occur. The drug will already have been shown to be well tolerated in animal studies, and the study often starts by giving volunteers the drug at a very low dose. If this is shown to be well tolerated, the dose is increased until the optimal balance between benefits and side effects is reached. At this stage there is little or no evidence that the new drug is better, the same or not as effective as the standard treatments.

Phase II trials:

This type of trial looks at how effective a drug is, but doesn't usually compare if it is more or less effective than standard treatments. These trials often provide more information on safety (side effects) or dosing (how much drug should be given). The aim is to provide information to ensure that the next (phase III) trial is designed appropriately and includes enough patients to show whether the new drug is an improvement on the current standard of care.

Phase III trials:

These are the most important trials but also the most difficult to run. They often require a very large number of patients (as differences between treatments may be small but significant) and involve many specialist units and even international cooperation. In these trials, patients are allocated randomly to receive either the current best-proven treatment, or the new drug or combination of drugs. At this stage there is usually no evidence that the new drug is better, the same or not as effective as the established treatment. The benefit may be through better disease control or a better side effect profile. At the end of the trial the results are analysed and a conclusion reached, which may show no benefit or could result in a change in what is considered best-proven treatment.

If you have questions about trials, or inclusion in trials, speak to your specialist nurse or oncologist, who will be able to let you know what trials are currently being undertaken in your specialist centre.

See the Pancreatic Cancer Action website for more information on clinical trials: panact.org.

How to take part in a clinical trial?

Treatment opinions can differ when new (and unproven) treatments are being tested as part of a clinical trial. Most regional pancreatic centres will be involved in research trials, but the clinical trials offered may be different from one centre to another. You should remember that a trial is being carried out because the benefit of the treatment is unknown (it may be better, the same, or sometimes not as good as the standard treatment). It may be worth asking your medical team if there is a pancreatic cancer clinical trial operating in your specialist unit that you may be eligible for.

If you go to our website, there is information on the latest clinical trials available. Also talking to your doctor or nurse about more information will be helpful. panact.org/clinicaltrials.

Who is my medical team?

Medical Team

The core medical team:

- **Medical oncologist:** A specialist doctor who prescribes and coordinates the course of chemotherapy.
- **Clinical oncologist:** A specialist doctor who prescribes and coordinates the course of radiotherapy, which is sometimes used with chemotherapy.
- **Registrar:** A qualified doctor undergoing additional training to be a specialist consultant.
- **Cancer Nurse Specialist (CNS):** Coordinates your care and liaises on your behalf with different specialist care providers.
- **Radiographer (Therapy):** Therapy radiographers operate the machines that give you your radiotherapy treatment. They are trained in radiotherapy and in patient care.
- **Chemotherapy Nurse:** Gives the course of chemotherapy and supports and assists you through all stages of your treatment.
- **Pharmacist:** Dispenses medications and gives advice about drugs, dosage and side effects.
- **Dietitian:** Recommends an eating plan for you to follow while you are in treatment and recovery.
- **Palliative Care Team:**
  Help you to manage your symptoms, including pain management and also helps with other needs you and your family may have.

Further information

What to ask your doctor

You may find the following list helpful when thinking about the questions you want to ask your doctor about your illness and treatment. If you don't understand any of the answers you are given, it is okay to ask for it to be explained again. Sometimes it is useful to bring your partner, another family member or a friend with you when you meet with your doctor to help remember what has been said.

☐ What type of pancreatic cancer do I have?
☐ What treatments do you advise and why?
☐ What are the risks and possible side effects of each treatment?
☐ Will I have to stay in hospital, or will I be treated as an outpatient?
☐ How long will the treatment take?
☐ Will I have pain from the cancer or any of the treatments? What will be done about this?
☐ Will the treatment affect me physically or sexually?
☐ Will I need to change my diet after treatment?
☐ Are there other treatment choices for me? If not, why not?
☐ What will happen if I don't have any treatment?
☐ Are there any clinical trials I should know about?
☐ How often will I have check-ups and what will they involve?

Other questions such as "is it hereditary?" or "is it caused by lifestyle?" may well be answered by information on our website. Visit panact.org

Further information

Pancreatic Cancer Action

We are a national charity dedicated to saving lives through early diagnosis and improving the quality of life for those affected by pancreatic cancer. Please call or go to our website for more free information on pancreatic cancer.

Tel: 0303 040 1700
panact.org

Clinical trials information

For further information about clinical trial types, pros and cons and how to find and take part in a trial.

panact.org/clinicaltrials

EUROPAC (European Registry of Hereditary Pancreatitis and Familial Pancreatic Cancer)

This is a collaborative study based at the University of Liverpool with pancreatic specialists from around Europe. They are investigating hereditary pancreatic cancer diseases.

Tel: 0151 706 4168
Email: europac@liverpool.ac.uk
panact.org/EUROPAC

Macmillan Cancer Support

Resources and information designed to provide physical, financial and emotional support to cancer patients and their families

Tel: 0808 808 0000
macmillan.org.uk

Maggie's Centres

Maggie's centres provide free practical, emotional and social support to people with cancer and their family and friends. They are often built next to NHS cancer hospitals.

maggiescentres.org

Glossary

adenocarcinoma
This is cancer of the exocrine cells that line the pancreatic ducts. The majority of pancreatic cancers are this type.

adenosquamos carcinoma
This is a very aggressive form of pancreatic cancer.

adjuvant therapy
A treatment given with or shortly after another treatment to enhance its effectiveness with the aim of a cure.

ampullary adenocarcinoma
Cancer that develops in the Ampulla of Vater (where pancreatic ducts and bile ducts merge).

Ampulla of Vater
The widened portion of the duct through which the bile and pancreatic juices enter the intestine.

anaemia
Deficiency in the number or quality of red blood cells in the body.

anti-emetics
Drugs used to reduce nausea (feeling sick) or vomiting.

artery
A blood vessel which delivers oxygen rich blood from the heart to the body.

bile
A fluid made in the liver and stored in the gallbladder that helps with the digestion of fats.

bile duct
The passage leading from the liver and gallbladder to the duodenum. Bile travels through the bile duct.

bone marrow
The spongy material inside bones. Bone marrow contains stem cells that produce red blood cells, white blood cells and platelets.

cannula
A plastic tube inserted into a narrow opening (usually a vein) so that fluids can be introduced or removed.

cells
The basic 'building block' of all living things. A human is made of billions of cells, which are adapted for different functions.

central line
A type of central venous access device used to give direct access to a vein in the chest or neck.

Glossary

chemotherapy
The use of cytotoxic (cell killing) drugs to treat cancer by killing cancer cells or slowing their growth.

chemo-radiotherapy
A combination of chemotherapy and radiotherapy.

cystic tumours
Tumours that cause fluid filled sacs in the pancreas, most are benign.

cytotoxic
A substance (e.g. chemotherapy) that is toxic to cells and kills or slows their growth.

diagnosis
The identification and naming of a person's disease.

duodenum
The first section of the small bowel (small intestine).

fertility
The ability to conceive a child.

glucagon
Is a hormone that is naturally made in the pancreas and works to raise blood sugar.

granulocyte-colony stimulating factor (G-CSF)
A protein that helps increase the production of certain white blood cells called neutrophils by the bone marrow. Neutrophils help fight infection.

Hickman® / Groshong® line
A type of central venous access device inserted into a vein in the chest.

Huber needle
A specially designed hollow needle used with implanted ports.

infusion
An injection of a substance into a vein or other tissue.

insulin
A chemical messenger (hormone) secreted by the pancreas to regulate the amount of sugar (glucose) in the blood. If the body does not produce enough insulin, diabetes will develop.

intravenous (IV)
Inserted into a vein.

metabolism
The result of chemical reactions that take place within a cell which provide energy for vital processes needed to maintain life.

malignant
Cancerous. Malignant cells can spread (metastasis) and can eventually cause death if they are not treated.

metastasis
A cancer that has spread from another part of the body. Also known as secondary cancer.

neoadjuvant therapy
A treatment given before the primary treatment to enhance the primary treatment's effectiveness.

neuroendocrine tumours
Neuroendocrine tumours (NETs) start in the cells of the neuroendocrine system. The neuroendocrine system is a network of endocrine glands and cells throughout the body.

neutropenia
A condition in which the number of neutrophils (a type of white blood cell) in the bloodstream is decreased, affecting the body's ability to fight off infections.

neutrophil
A type of white blood cell that defends the body against bacteria.

oncologist
A Doctor who specialises in chemotherapy and/or radiotherapy.

pancreas
An organ in the digestive system. The pancreas produces insulin and enzymes that help to digest food.

pancreatic lymphoma
Pancreatic lymphoma, or primary pancreatic lymphoma (PPL) is a cancer of the lymphatic system of the body that originates as a pancreatic mass. This is very rare.

pancreatic sarcomas
Tumours that form in the connective tissue that holds together the pancreatic cells. This is very rare.

peripherally inserted central catheter (PICC)
A type of central venous access device that is inserted into a vein in the arm.

petechiae
Small red spots on the skin caused by the breakage of small blood vessels beneath the skin. Often as a result of a drop in platelets due to chemotherapy treatment.

Glossary

platelets
An irregular, disc shaped element in blood that assists in blood clotting. During normal blood clotting, the platelets clump together, also called thrombocytes.

port-a-cath (port)
A type of device that allows access to central veins. A port-a-cath is inserted under the skin in the chest or arm with a connecting tube inside the body that enters the vein.

portable infusion pump
Small portable pump which delivers continuous chemotherapy at a slow rate.

radiotherapy
The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow and multiply, also called radiation therapy.

red blood cells
One of three types of blood cell. Red blood cells carry oxygen around the body, also called erythrocytes.

second line therapy
Treatment that is given after the cancer has not responded to a first course of therapy or a patient ceases first line of therapy.

side effect
Unintended effect of a drug or treatment.

subcutaneous
The area beneath the layers of the skin.

thrombocytopenia
An abnormal decrease in the number of blood platelets.

tissue
A collection of cells that make up a part of the body.

tumour
A new or abnormal growth of tissue on or in the body. A tumour may be benign or malignant.

vaccine
A substance given to stimulate the body's production of antibodies and provide immunity against a disease.

vein
A blood vessel that takes blood towards the heart.

white blood cells
One of three types of cell found in the blood. White blood cells help to fight infection. They are made up of neutrophils, lymphocytes and monocytes (also called leucocytes).

My side effects log

Date	Time	Side effects	Notes/action taken

My side effects log

Date	Time	Side effects	Notes/action taken

Date	Time	Side effects	Notes/action taken

My side effects log

Date	Time	Side effects	Notes/action taken

Date	Time	Side effects	Notes/action taken

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For sources and references used in the compilation of this booklet, please contact us at the address overleaf.

Pancreatic Cancer Action

This booklet has been funded through the generosity of supporters of Pancreatic Cancer Action, a UK charity founded by a pancreatic cancer survivor, Ali Stunt, who was diagnosed with pancreatic ductal adenocarcinoma in 2007.

With a focus on early diagnosis, it is Pancreatic Cancer Action's mission to improve survival rates by raising awareness of pancreatic cancer and its symptoms among the public, medical education, improved information and by funding research specifically to improve early diagnosis of the disease.

If you would like to support us or find out more, please contact us at **enquiries@panact.org or visit panact.org**

Pancreatic Cancer Helpline 0303 040 1770

If you would like to help us by either holding an awareness event or by fundraising, please **email enquiries@panact.org** or call **0303 040 1770**. For more information or to donate directly please visit **panact.org**

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Saving lives through early diagnosis

We are certified by the Information Standard so you can trust that our public health information is accurate, up-to-date, evidence-based and unbiased.

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