Pancreatic Cancer UK

BDA The Association of UK Dietitians Yorkshire Branch

NHS The Leeds Teaching Hospitals NHS Trust

# Dietetic Management & Pancreatic Cancer

## Wednesday 9 October 2019

## Thackray Medical Museum Leeds

Pancreatic Cancer UK

| Time | Session | Speaker |
|---|---|---|
| **8.30 – 9.15** | **Arrivals & registrations** | |
| 9.15 – 9.30 | Welcome & introduction to the day | **Anna Burton**<br>HPB Dietitian<br>Leeds Teaching Hospitals NHS Trust |
| 9.30 – 10.15 | Introduction to pancreatic cancer | **Lynne McCallum**<br>Pancreatic Specialist Nurse (North)<br>Pancreatic Cancer UK |
| 10.15 – 11.00 | Nutritional assessment & treatment in pancreatic cancer | **Anna Burton** |
| **11.00 – 11.15** | **Break** | |
| 11.15 – 12.00 | Managing diabetes alongside pancreatic cancer | **Louise Hopewell**<br>Diabetic Nurse Specialist<br>The Christie NHS Foundation Trust |
| 11.45 – 12.30 | Pancreatic surgery, enteral tube feeding & enzymes | **Kelly Wilson**<br>Pancreatic Dietitian<br>Leeds Teaching Hospitals NHS Trust |
| **12.30 – 13.15** | **Close of meeting, lunch & networking** | |

Pancreatic Cancer UK

# Pancreatic Cancer

Lynne McCallum

Pancreatic Cancer UK

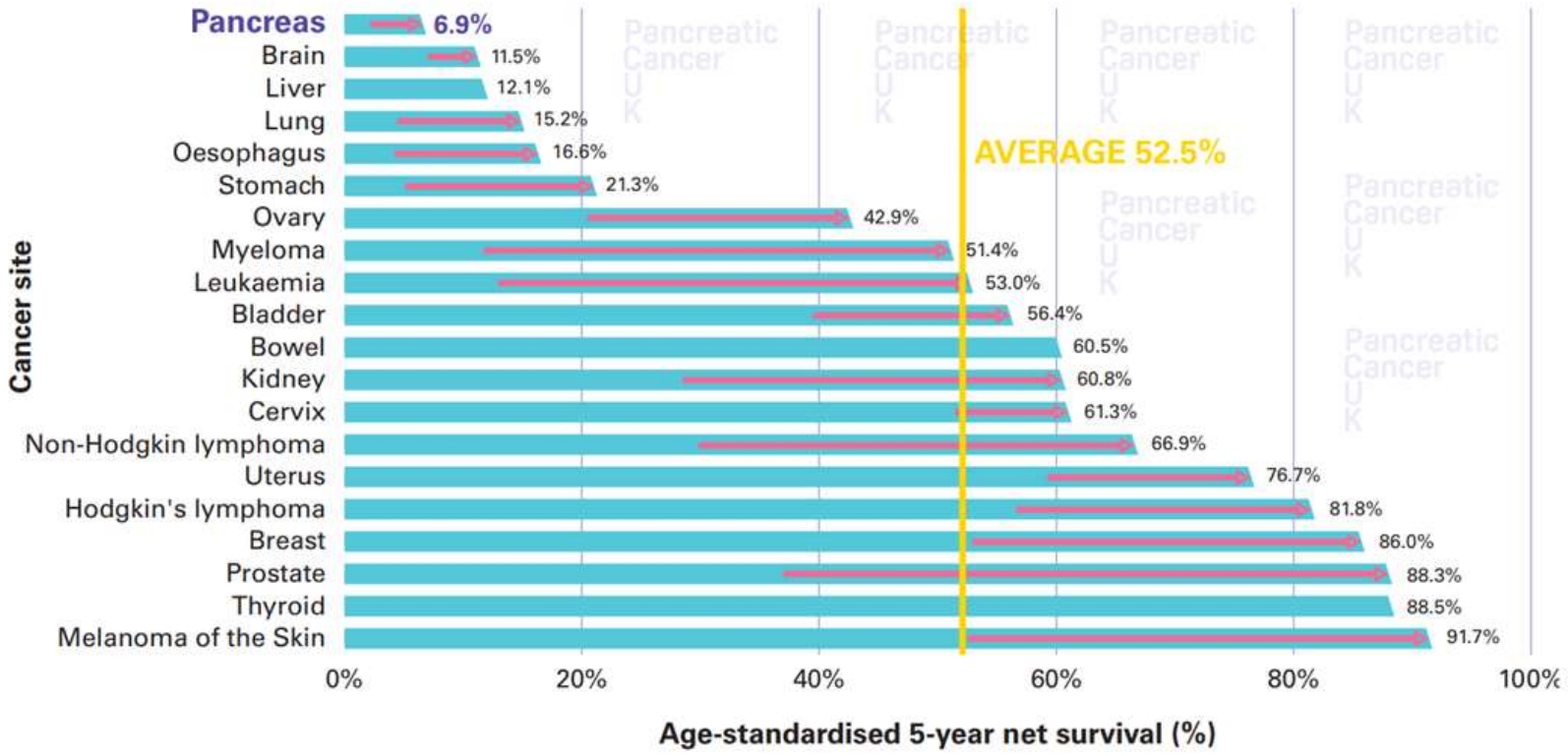
# Aims of Today

Pancreatic Cancer UK

# Pancreatic cancer is tough

Pancreatic Cancer UK

# Five-year survival in the last 45 years

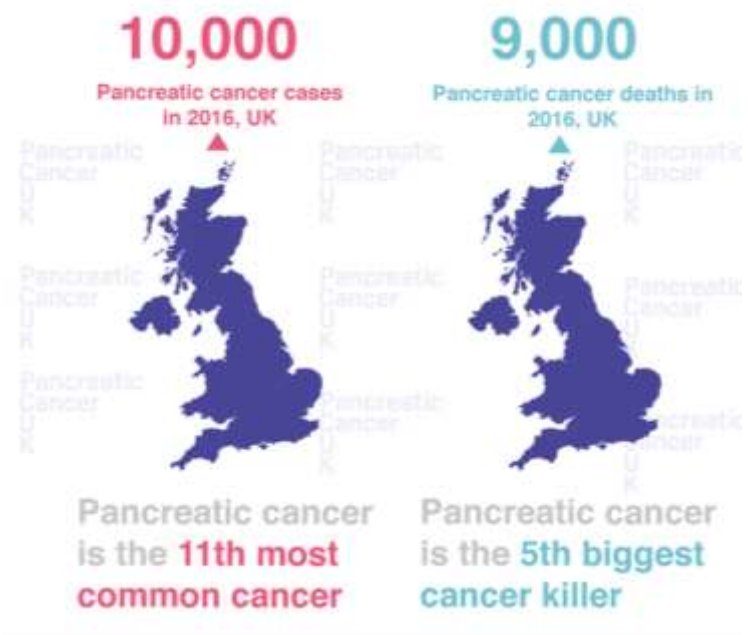


Pancreatic Cancer UK

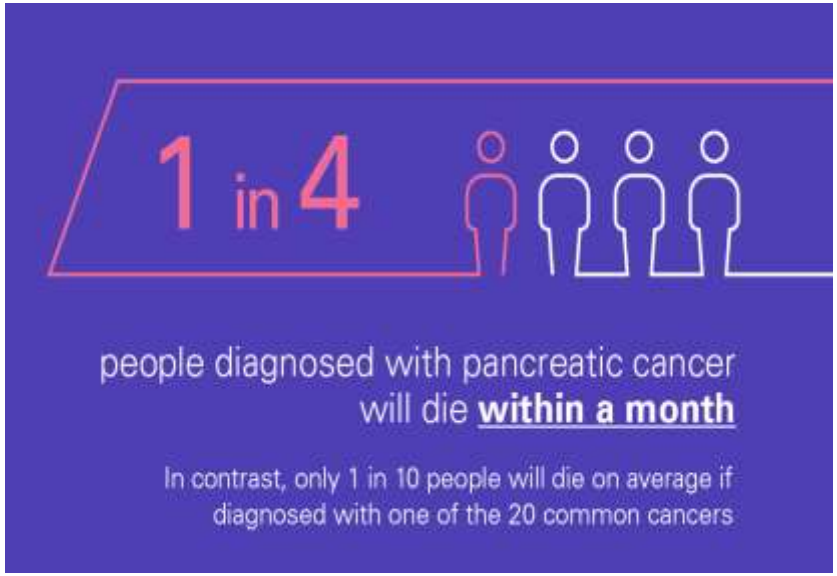
# Pancreatic cancer UK statistics:

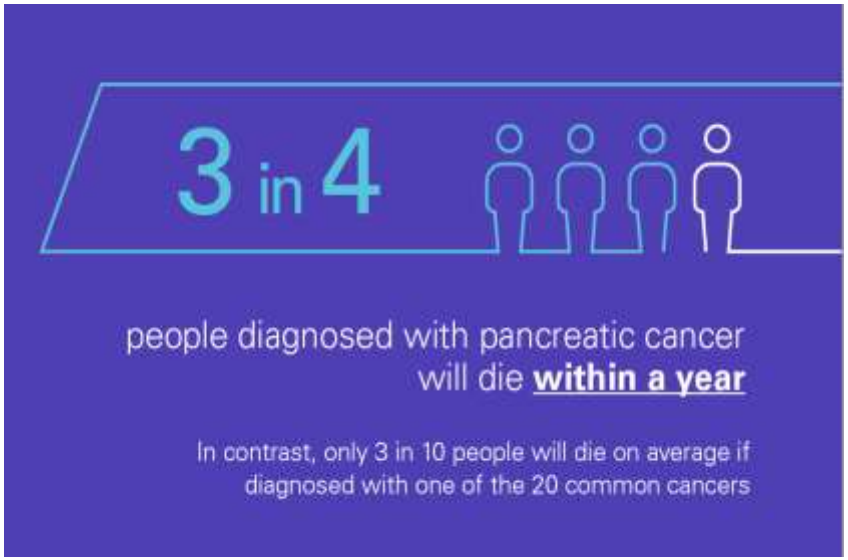
**Pancreatic cancer is a disease for which mortality closely parallels incidence**

- **10,000** people diagnosed every year
- **9,000** people die every year



Pancreatic Cancer UK



Pancreatic Cancer UK

- **Vague and non specific symptoms**
- **Symptoms often don't present until a late stage**
- **No simple diagnostic test**

## These are some of the symptoms that can indicate a problem with your pancreas, such as pancreatic cancer.


If you have jaundice you should go to your GP without delay. If you have any of the other symptoms and they are unexplained or persistent (lasting 4 weeks or more), visit your GP. Remember, these symptoms can be signs of other conditions and may not be pancreatic cancer.

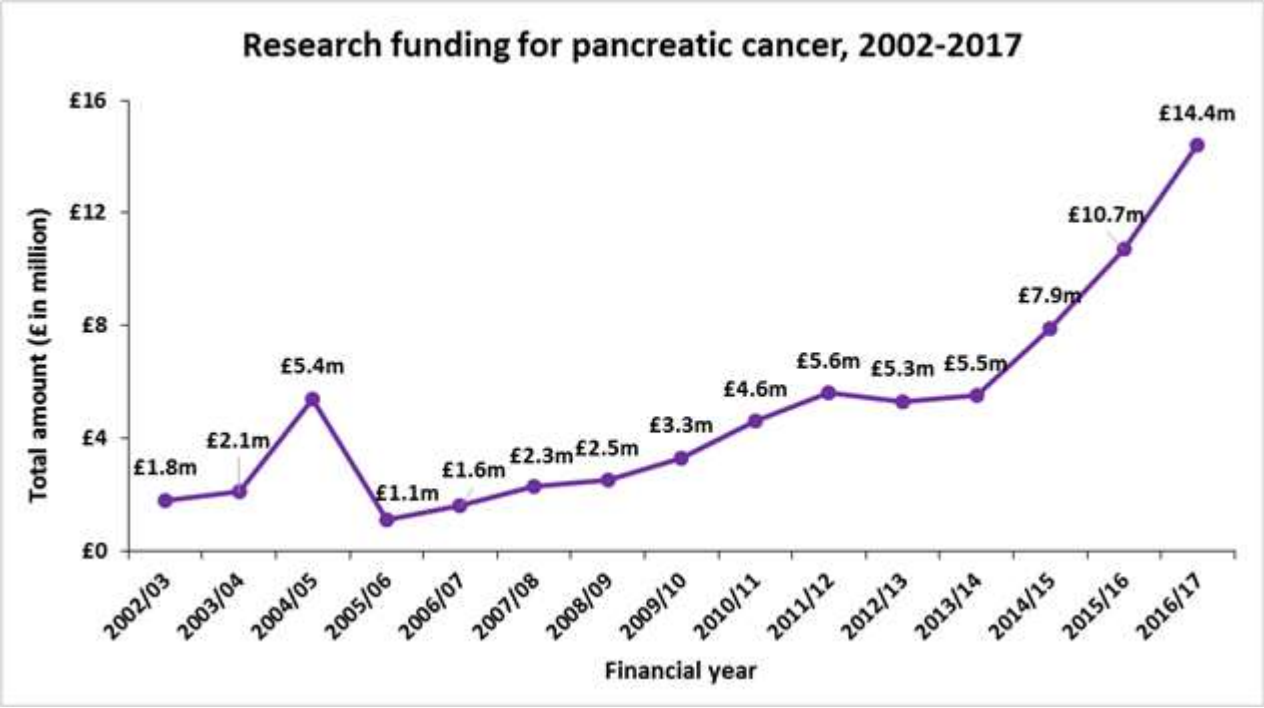
Contact the Pancreatic Cancer UK Support Line

**0808 801 0707** freephone weekdays 10am-4pm **support@pancreaticcancer.org.uk**

Pancreatic Cancer UK

# Tough to research

**Pancreatic cancer research historically underfunded. Over the last decade it's received only 1% of the cancer research budget.**



Pancreatic Cancer UK

# Pancreatic Cancer is Undertreated

- ✓ **7 in 10** people with pancreatic cancer do not receive any active treatment, including surgery, chemotherapy or radiotherapy
- ✓ **Only 1 in 10** people with pancreatic cancer receive potentially curative surgery
- ✓ **Only 2 in 10** people will receive chemotherapy

Pancreatic Cancer UK

# The Need for Speed

## Diagnosing Pancreatic Cancer Earlier, Giving Patients a Chance of Living Better for Longer

*"Whatever you can do, or dream you can, begin it. Boldness has genius, power, and magic in it."*
Goethe

November 2017

The report was researched and funded by Pancreatic Cancer UK who provide the Secretariat for the All-Party Parliamentary Group on Pancreatic Cancer.



appg on Pancreatic Cancer

- Increased research
- Increase public awareness
- GP support
- Better diagnostic pathways
- Faster treatment
- Developing strategy & Cancer Alliances

Pancreatic Cancer UK

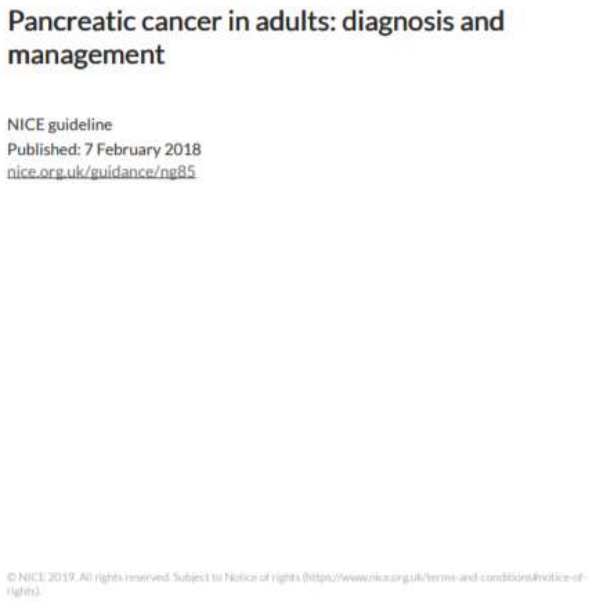
NICE National Institute for Health and Care Excellence

NICE guideline

- ✓ Published in February 2018
- ✓ First ever guidelines on pancreatic cancer
- ✓ Set best care standards to reduce variations and transform care for people with the disease
- ✓ This guideline includes recommendations on:

- diagnosis
- monitoring for people with an inherited high risk of pancreatic cancer
- staging
- psychological support
- pain and nutrition management
- management for resectable, borderline resectable and unresectable cancer

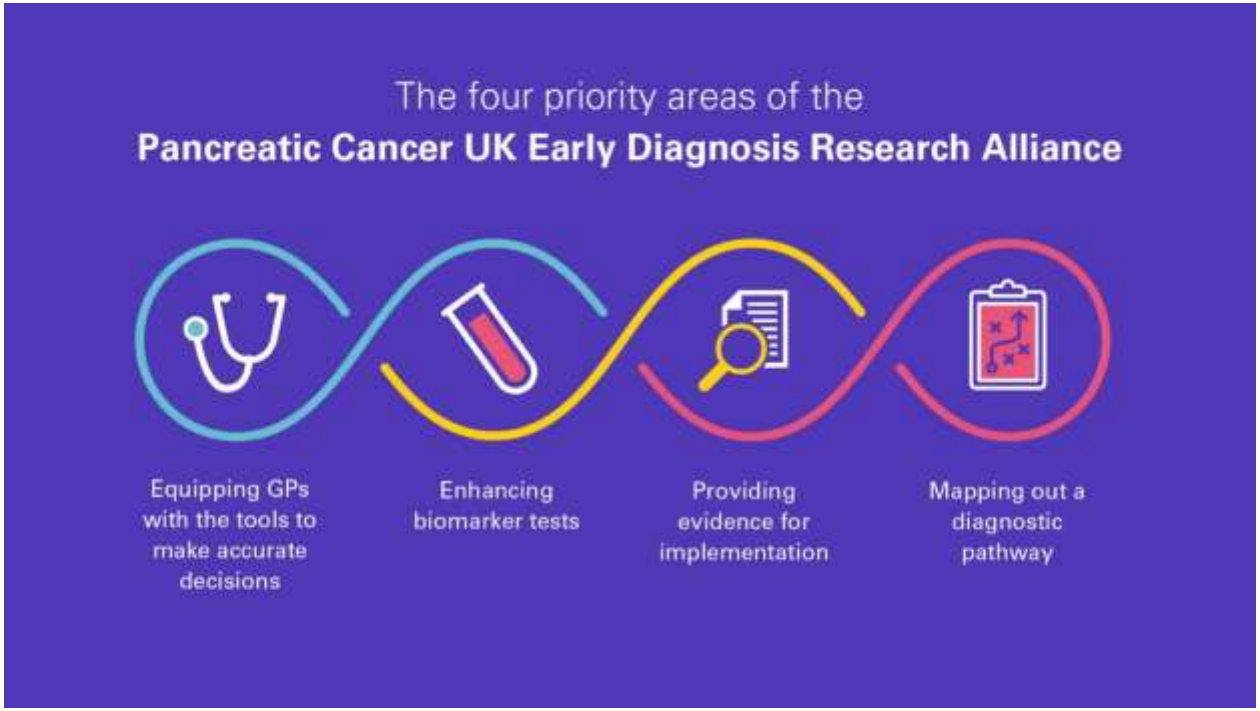
- ✓ Full guideline at https://www.nice.org.uk/guidance/ng85


Pancreatic cancer in adults: diagnosis and management

NICE guideline
Published: 7 February 2018
nice.org.uk/guidance/ng85

Pancreatic Cancer UK

# Unite-Diagnose-SaveLives



Pancreatic Cancer UK

DEMAND

FASTER

TREATMENT

In November 2018 we launched the ***Demand Faster Treatment*** **campaign** which has been supported by **100,600 people**.

Pancreatic Cancer UK

DEMAND FASTER TREATMENT

**The campaign called for:**

- **Faster treatment**
- **Roll out fast–track surgery**
- **Dedicated pancreatic cancer clinics for people who are not eligible for surgery**
- **One–stop clinics for people with pancreatic cancer that accelerate treatment decisions for them post diagnosis**
- **Pancreatic cancer pathway patient navigators – to better coordinate people's access to care and treatment**

Pancreatic Cancer UK

# Presentation & Diagnosis

Pancreatic Cancer UK

- Pancreatic cancer is predicted to become the **4th** biggest cancer killer by 2026
- The **5-year net survival** of pancreatic cancer is **6.9%**, the lowest of the 20 common cancers in England (2015)
- The only potential cure of pancreatic cancer is surgery; yet only **8%** of patients are currently **resected**
- 55% of patients are diagnosed with metastatic disease

Pancreatic Cancer UK

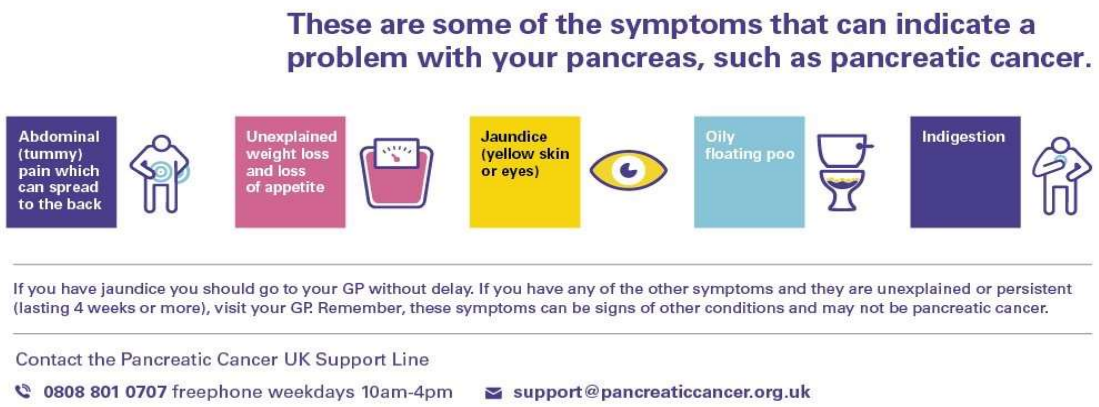
## What are the known risk factors?

There is **good** evidence that, age, smoking, being overweight, family history of cancer, pancreatitis and diabetes **may** increase your risk of pancreatic cancer.

**Some** evidence has suggested that there are other things **may** also increase risk, such as alcohol, red and processed meat and hx of cancer – more research is needed.

Pancreatic Cancer UK

- 48% of patients are diagnosed via A&E (v's 22% in other cancers)
- Abdominal pain +/- back pain
- Dyspepsia/reflux/bloating
- Fatigue
- Change in bowel habits
- Unintentional weight loss
- New onset diabetes
- Jaundice
- Clots



Pancreatic Cancer UK

# Pancreatic Cancer is an Emergency

thebmj

*BMJ* 2014;349:g5261 doi: 10.1136/bmj.g5261 (Published 4 September 2014)



VIEWS & REVIEWS

PERSONAL VIEW

## Pancreatic cancer should be treated as a medical emergency

"The greatest oncological challenge" results partly from delays to diagnosis and treatment, writes **J-Matthias Löhr**

J-Matthias Löhr *professor of gastroenterology and hepatology and senior consultant, Karolinska Institutet and Karolinska University Hospital, Gastrocentrum, Stockholm, Sweden*

Outcomes for pancreatic cancer are poor, and the following case shows why. A 63 year old man presented to his general practitioner with abdominal pain and weight loss and eventually had diabetes diagnosed. He subsequently developed obstructive jaundice and was admitted to the emergency department of his local hospital on a Friday afternoon. Endoscopic retrograde management (ERCP, multidisciplinary team discussion, surgery, chemotherapy).

In reality, only a third of patients experience the third scenario, and most patients are seen initially at primary or secondary hospitals, particularly in countries with large rural areas. Once diagnosed, pancreatic cancer qualifies for fast track surgery in

Pancreatic Cancer UK

# Diagnosing Pancreatic Cancer

**Blood tests |** CA 19-9 and CEA  specific pancreatic tumour markers, however if raised does not necessarily mean 'cancer'.

**Abdominal Ultrasound |** inexpensive, non invasive.  If highlights an abnormality,  then CT requested.

**CT (computed tomography)** |often given IV injection of contrast to highlight blood supply to certain organs.  Good diagnostic tool.

**MRI/MRCP (magnetic resonance imaging/cholangiopancreatography) |** useful addition to imaging, can be more specific for liver metastases and highlighting abnormalities with in the bile ducts

Pancreatic Cancer UK

# Diagnosing Pancreatic Cancer

**ERCP – (endoscopic retrograde cholangiopancreatography) |** endoscope is passed through mouth, down the oesophagus into stomach and into the duodenum. A smaller tube is then inserted through the centre of endoscope and dye is injected to highlight any obstruction to its flow through the biliary system.

**PET – (Positron Emission Tomography) |** very specialised nuclear medicine scan that utilizes radioactive substances. Use more often with those cases with locally advanced disease

**EUS – (Endoscopic Ultrasound) |** Endoscope & ultrasound combined. Very accurate, good for visualizing Lymph nodes and taking biopsies in particular.

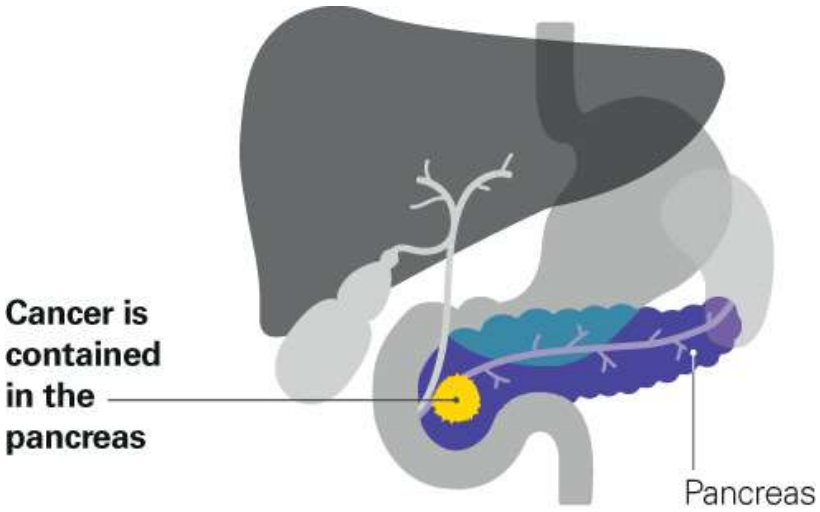
**Tissue Diagnosis is imperative for treatment to be planned.**

Pancreatic Cancer UK

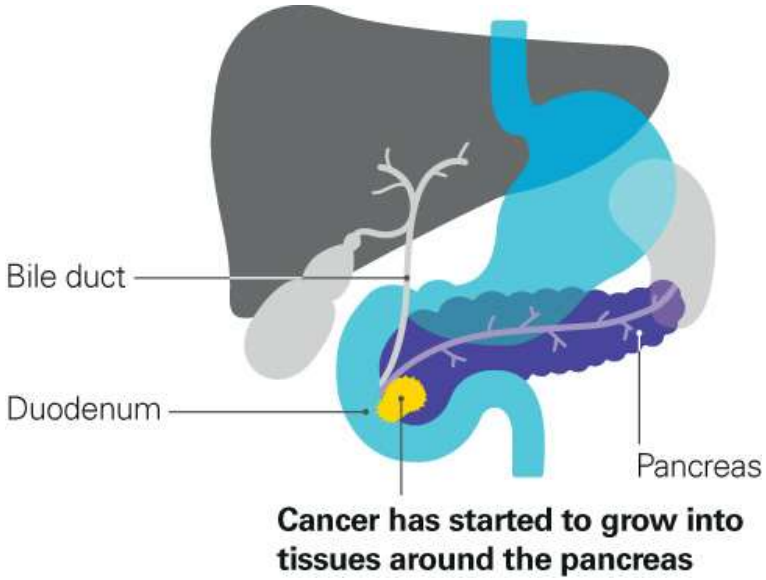
# Staging

Pancreatic Cancer UK

# Stage 1

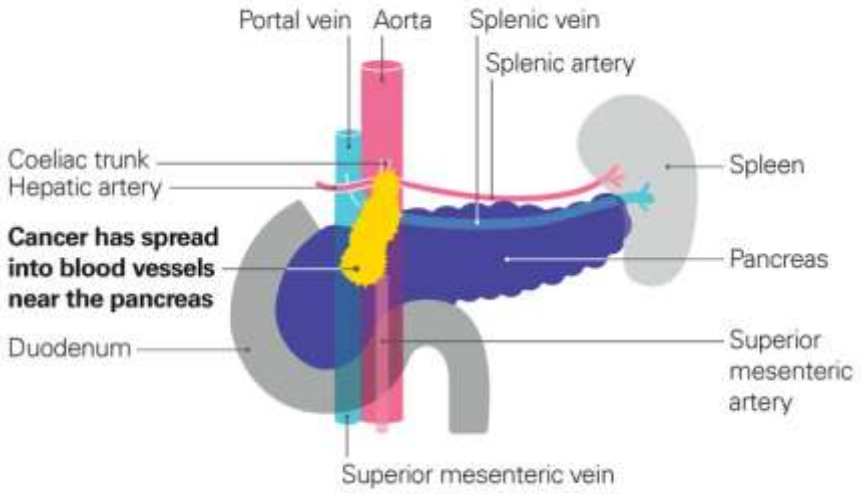



# Stage 2

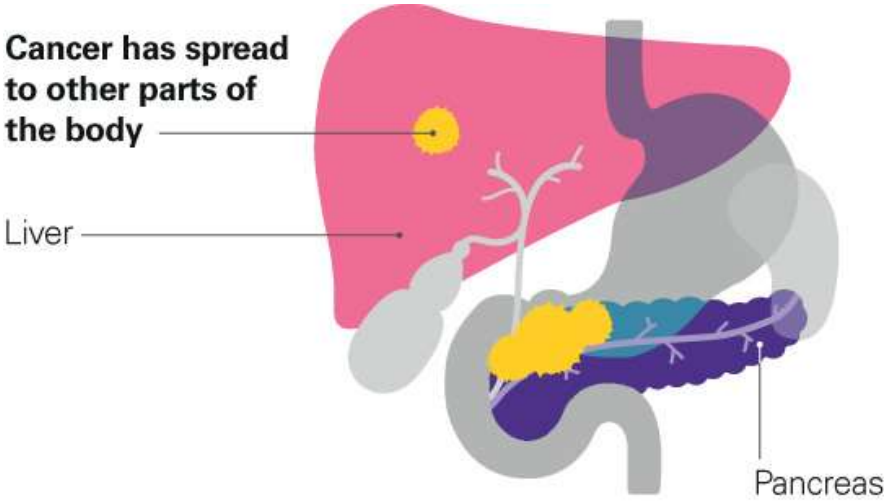


Pancreatic Cancer UK

# Stage 3



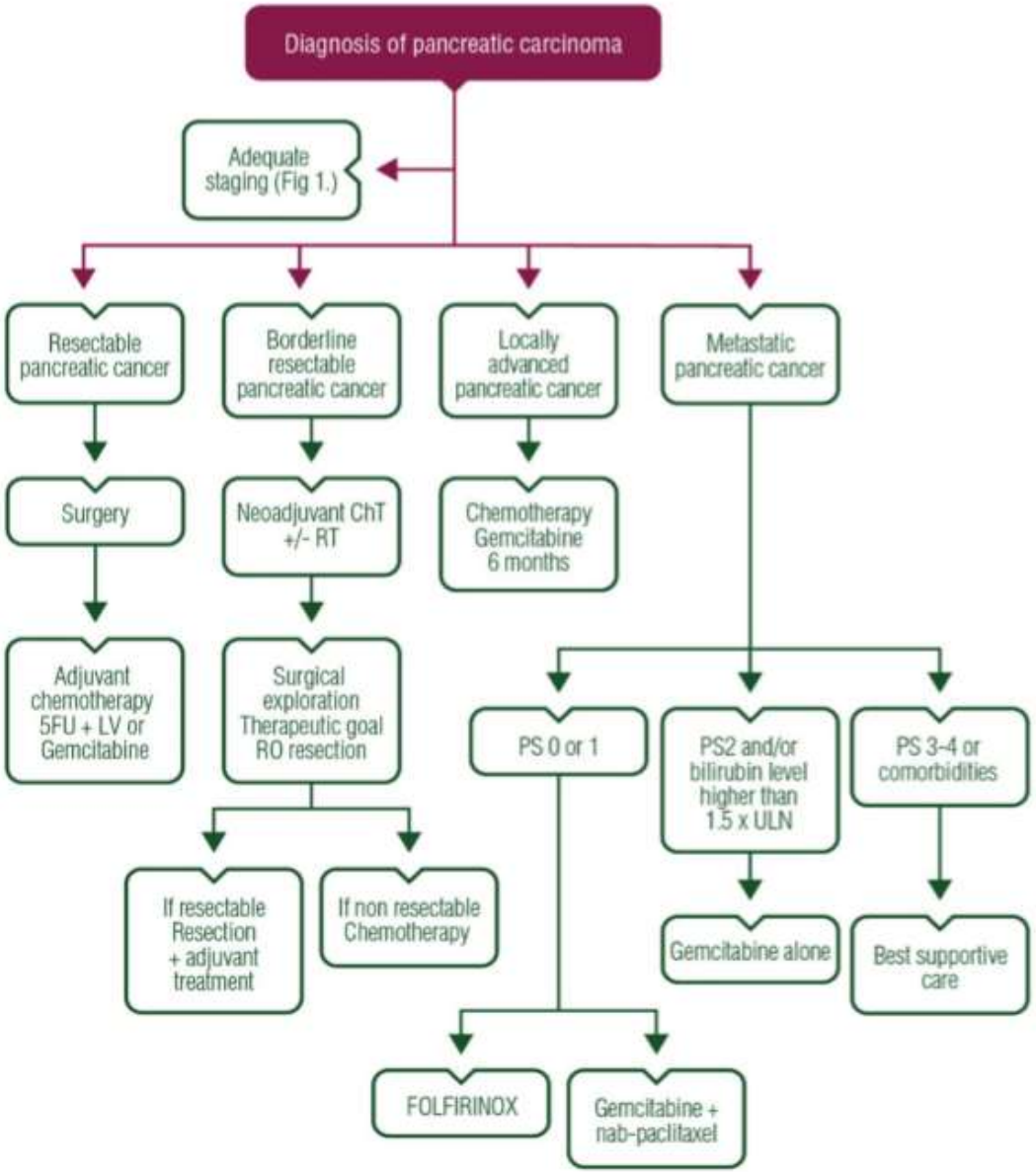

# Stage 4



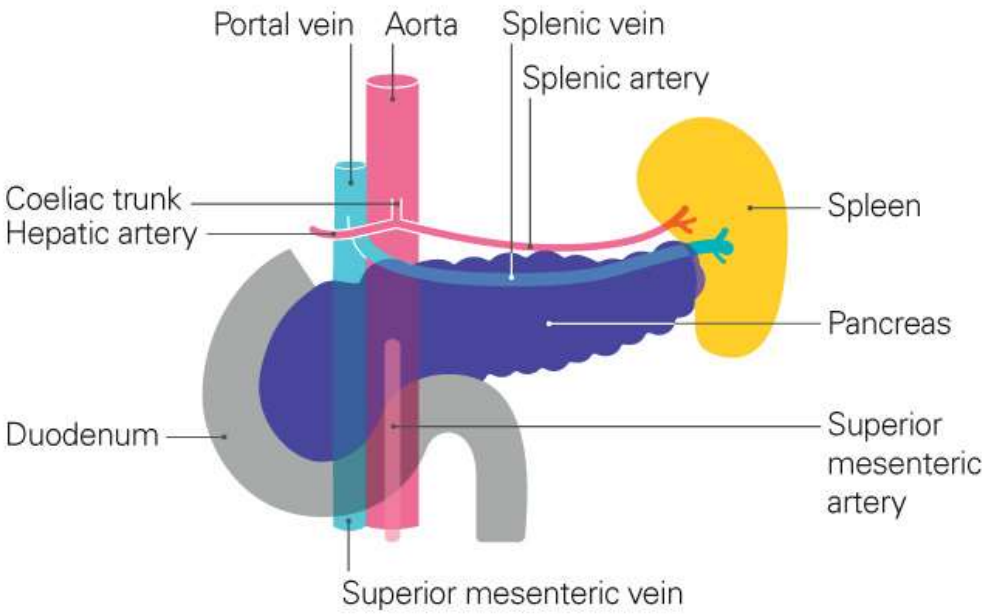
Pancreatic Cancer UK

# Treatment

Pancreatic Cancer UK

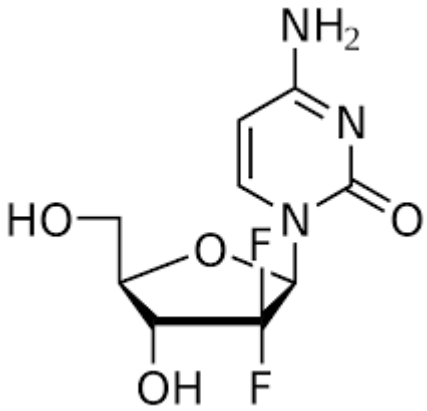


Pancreatic Cancer UK




- Whipple's operation (pancreaticoduodenectomy or PD)
- Pylorus-preserving pancreaticoduodenectomy (PPPD)
- Distal pancreatectomy
- Total pancreatectomy

Pancreatic Cancer UK





Chemotherapy can be used:

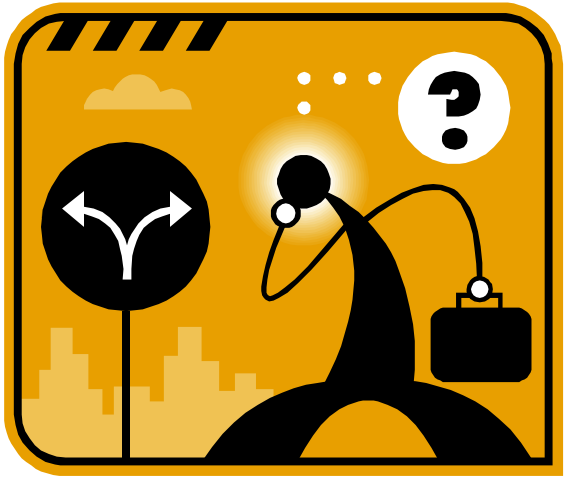
- Neo-ADJUVANT (before surgery to try to shrink the cancer so that there's a better chance of removing it)
- ADJUVANT (after surgery to try to reduce the chances of the cancer coming back)
- LOCALLY ADVANCED (to slow down the growth of cancer that has spread to nearby structures, such as the blood vessels around the pancreas)
- PALLIATIVE (when the cancer has spread beyond the pancreas to other parts of the body)

Pancreatic Cancer UK

- Radiotherapy is used to kill cells
- Can be given with chemo (chemo/rad)
- Given in neo-adjuvant, LA and advanced disease
- Being used more frequently in PDAC, studies continue

Pancreatic Cancer UK

# Clinical Trials



**Questions**

Who should we treat?

With how much drug?

How often?

In combination?

Is the drug working?

**How does the drugs make people feel?**

**Phase I**

First in humans – is it safe?

Maximum tolerated dose

Small numbers of patients

**Phase II**

Does the drug work?

Specific type of cancer

Involves more patients

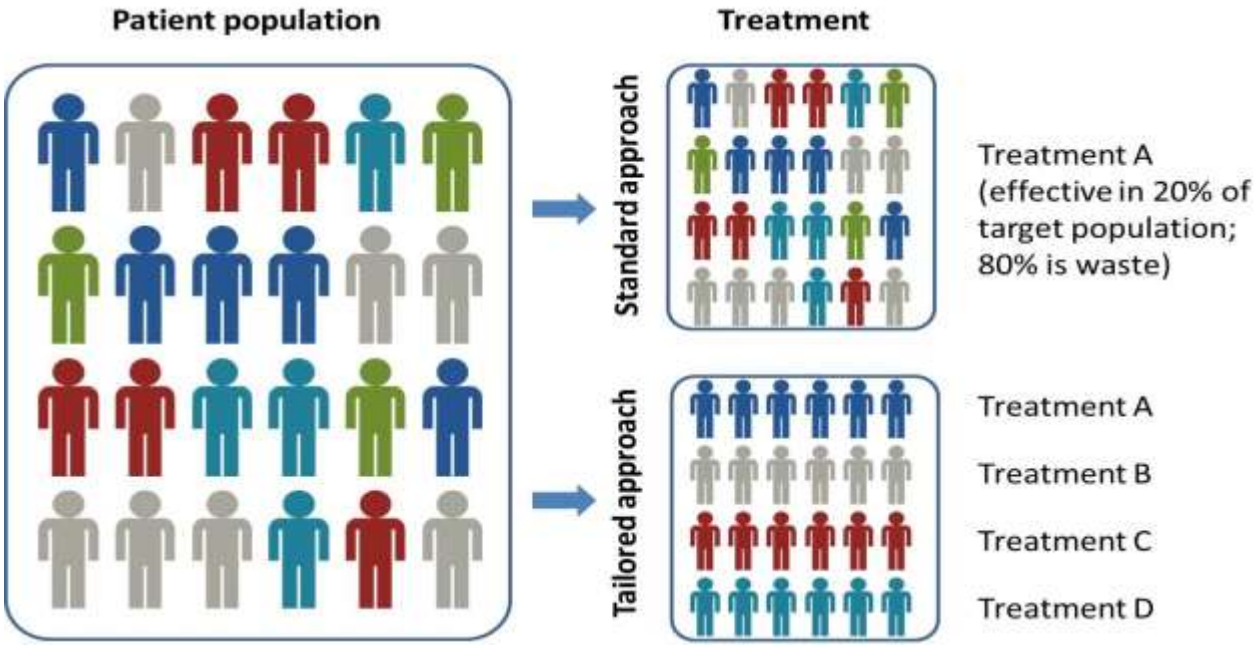
**Phase III**

Is the drug better?

Specific type of cancer

Involves 100s of patients

Pancreatic Cancer UK




PRECISION PANC

Personalising treatment for pancreatic cancer

Pancreatic Cancer UK

## Supportive Care

Should start at diagnosis in a lot of cases

Consider -

- Referrals and sign posting
- Financial support
- GP liaison
- Identify when entering last year of life
- Gold standard Framework
- Communications

Pancreatic Cancer UK

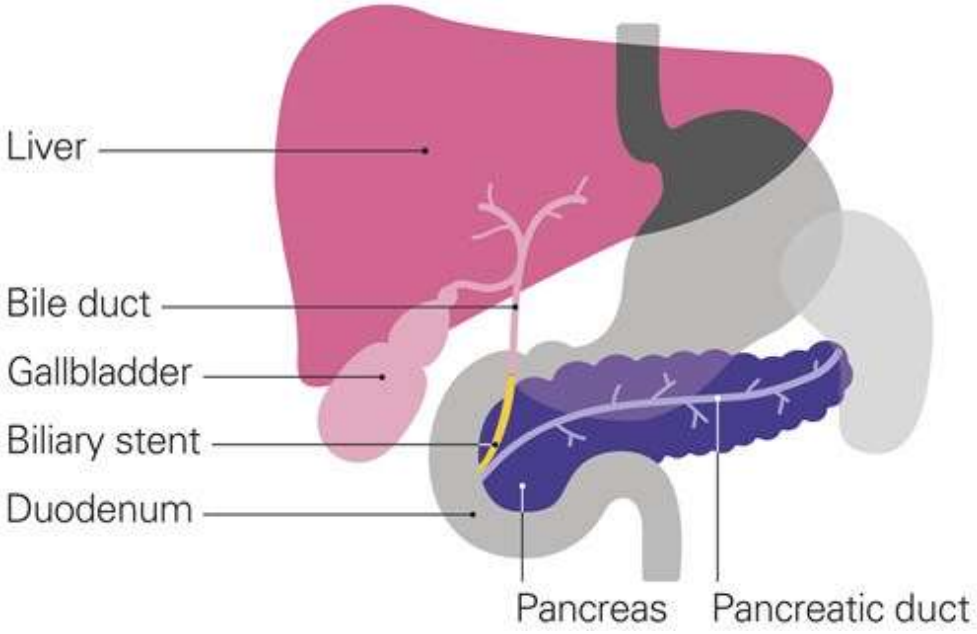
# On-going symptoms

Pancreatic Cancer UK

- Jaundice
- Ascites
- Gastric Outlet Obstruction
- PEI, diet & weight loss
- Fatigue
- Financial

Pancreatic Cancer UK

# Jaundice




- 75% of HOP present with jaundice
- Elevated bilirubin, yellow skin & eyes, dark urine, pale stools, itching skin
- Is associated with decreased survival
- Stent to improve symptoms, treatment options & QofL,

Pancreatic Cancer UK

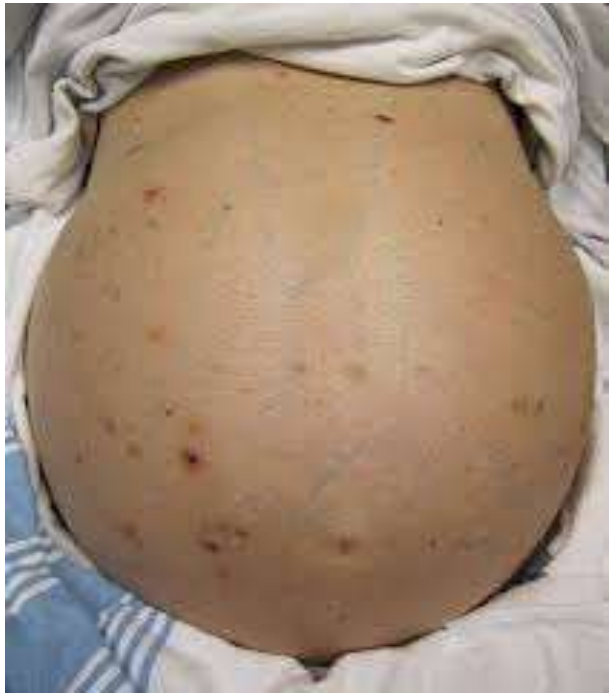
# Ascites

- Abnormal accumulation of fluid in the abdomen. Its often multifactorial, effects 20% of patients however more common in advanced metastatic disease

Symptoms

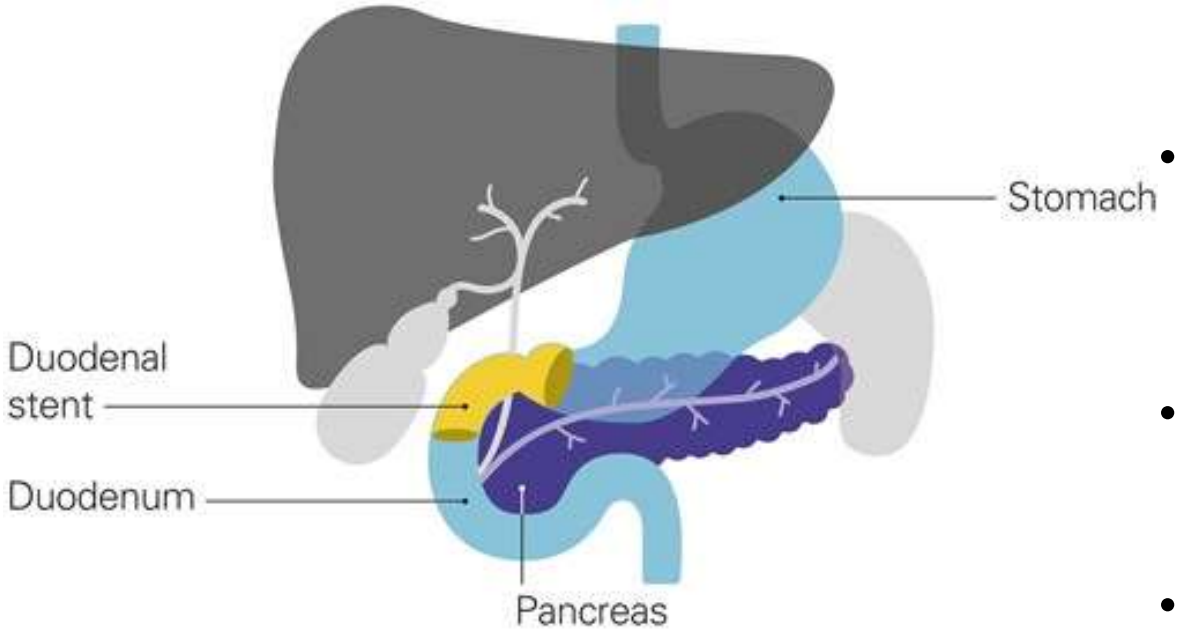
- Adbo swelling, discomfort and increased waist size
- SOB
- Decreased appetite, feeling full
- Indigestion
- Increased weight
- Fatigue
- Constipation, nausea & vomiting
- Ankle swelling

- Diuretics, drainage, comfort measures



Pancreatic Cancer UK

# GOO




- 6% of PC patients present with GOO
- Nausea and vomiting, dehydration, malnutrition and delay in treatments
- Goes on to occurs in up to 20% of PC patients
- Stenting improves symptoms, treatment options and QofL

Pancreatic Cancer UK

Pancreatic Cancer UK


# Diet and pancreatic cancer booklet

This booklet explains how pancreatic cancer can cause problems with diet, eating and nutrition.

It includes information on how to manage these problems including pancreatic enzyme supplements.

Pancreatic Cancer UK

# Diet

Nutrition Interest Group of the Pancreatic Society (NIGPS)

Supported by Pancreatic Cancer UK

## Type 3c diabetes and reduced

Nutrition Interest Group of the Pancreatic Society (NIGPS)

Supported by Pancreatic Cancer UK

## Type 3c diabetes and healthy living

: https://www.pancreaticcancer.org.uk/health-professionals/educational-resources/

Pancreatic Cancer UK

# Fatigue

## Advice

- Discussions on managing energy, breaking up of daily tasks
- Discuss on individual aims and goals and how to achieve them
- Exercise
- Diet
- Signpost to support
- Communications

Think

- Low Hb
- Low deficiency
- Is this reversible?

Pancreatic Cancer UK

# Finance

## Benefits and Financial Support

- Recognise the ‘price’ of a cancer diagnosis
- Financial issues can cause worry when someone becomes ill
- Ability to work can be effected, work just doesn’t mean employment
- Your patients may be able to claim benefits to help you in their situation.
- Your patients may also be able to get financial assistance from other organisations

## What can you do?

- Open & honest discussions, identify need
- Information & signposting
- Encourage self referral while continuing support those who need it.
- Macmillan information & benefits advice workers
- Maggie’s
- Recognise those who are eligible for support as they are in the last year of life (All special rules claims for AA, PIP and DLA are reviewed after three years)

Pancreatic Cancer UK

# What's missing?

Pancreatic Cancer UK

## Ongoing Symptoms

- Jaundice
- Ascites
- Gastric Outlet Obstruction
- PEI, diet & weight loss
- Fatigue
- Financial
- **Psychological**

Pancreatic Cancer UK

# Psychological Impact of Pancreatic Cancer

- National Cancer Patient Experience survey reports that access to information and support is poorer in pancreatic cancer (PC) than in other cancers
- Studies show that up to 96% of PC patients have unmet needs both physical (54%) and psychological (52%)
- With needs being very similar in those who have undergone surgery and those who have not
- Distress occurs more frequently in those with PC than in other cancers.
  R 30-70% at different points along the disease trajectory

Pancreatic Cancer UK

# Patient Survey

## The aims of the research

- Measure patient experiences – diagnosis and treatment
- Increase understanding of information and support needs
- Explore attitudes of health professionals, as experienced by patients

Pancreatic Cancer UK

# Patient Survey

## Why this research is so important and the aims

- Very little is known about patient experience and supportive care needs for people with pancreatic cancer
- Psychological burden of the disease is highlighted in data
- Positive experience of patient care and early supportive care have proved beneficial for quality of life, treatment success and survival
- We aim to ensure our services are evidence based and meeting the needs of patients

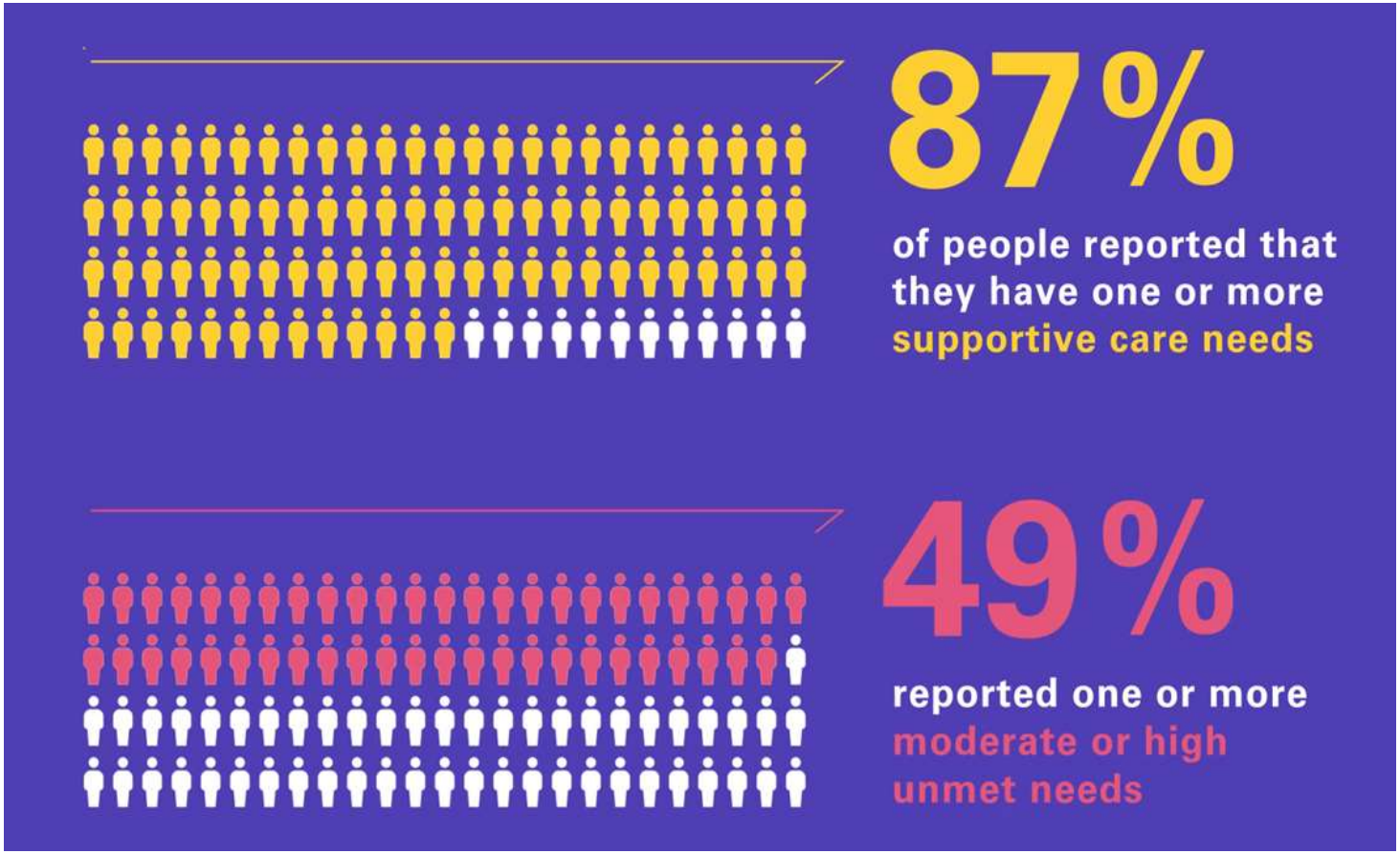
Pancreatic Cancer UK

# Patient Survey

## We had 274 participants (215 completed online; 59 paper based)

- Development included a literature review, utilising existing validated questions and cognitive testing with patients
- Anyone with a diagnosis of pancreatic cancer was eligible to take part
- Recruitment was via selected NHS Centres and online
- Survey was open between January and May, 2018

Pancreatic Cancer UK



Pancreatic Cancer UK

# Most common unmet supportive care needs (moderate/high)

| Rank | Label | n | % need |
|---|---|---|---|
| 1 | Uncertainty about the future | 185 | 31.4% |
| 2 | Fears about the cancer spreading | 186 | 30.1% |
| 3 | Not being able to do the things you used to do | 188 | 25.0% |
| 4 | Concerns about the worries of those close to you | 190 | 24.7% |
| 5 | Lack of energy/ tiredness | 187 | 23.5% |
| 6 | Anxiety | 192 | 22.4% |
| 7 | Worry that the results of treatment are beyond your control | 185 | 21.1% |
| 8 | Feelings of sadness | 190 | 20.5% |
| 9 | Being informed about things you can do to help yourself feel better | 191 | 20.4% |
| 10 | Feeling down or depressed | 196 | 20.4% |

Pancreatic Cancer UK

# Most common unmet needs unresectable (moderate/high)

| Rank | Label | n | % |
|---|---|---|---|
| 1 | Uncertainty about the future | 59 | 37.3% |
| 2 | Fears about the cancer spreading | 62 | 33.9% |
| 3 | Worry that the results of treatment are beyond your control | 58 | 31.0% |
| 4 | Concerns about the worries of those close to you | 62 | 30.7% |
| 5 | Digestion problems (e.g. bowel problems, bloating, wind, discomfort) | 62 | 29.0% |
| 6 | Being informed about things you can do to help yourself feel better | 63 | 28.6% |
| 7 | Anxiety | 60 | 28.3% |
| 8 | Lack of energy/ tiredness | 57 | 28.1% |
| 9 | Feelings of sadness | 61 | 27.9% |
| 10 | Feelings about death and dying | 63 | 27.0% |

Pancreatic Cancer UK

# Biggest current needs

**Symptom related:** bowel and digestion issues; fatigue/energy/sleep; pain management

**Treatment related:** better explanation of treatment options / timescales ; improved post-treatment follow-up; timely results; improved care co-ordination

**Psychological:** help to deal with anxiety/ uncertainty and how to stay positive; someone to talk to; support for families

**Prognosis:** clear and honest explanations; help to deal with fears

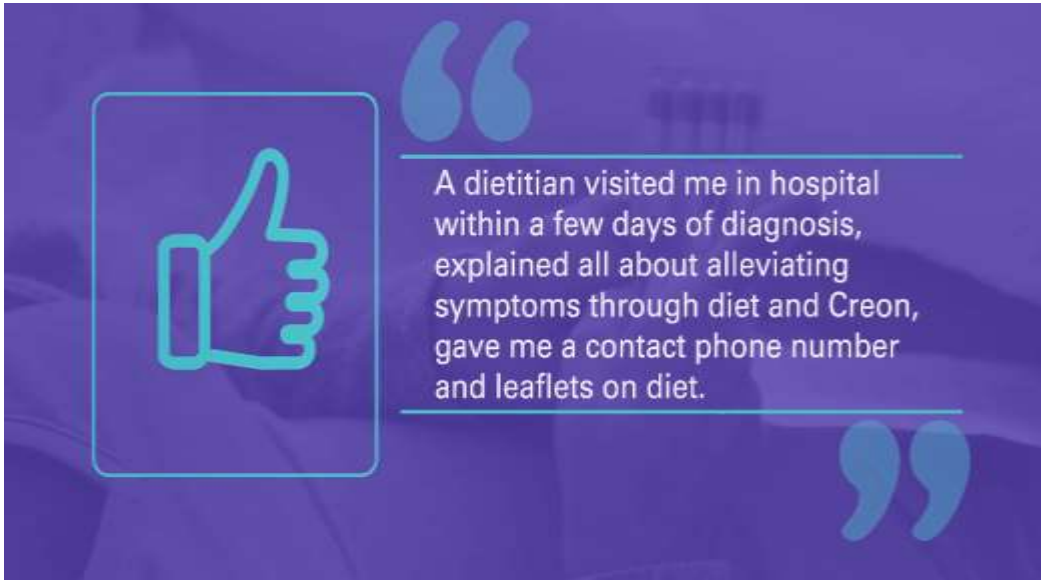
Pancreatic Cancer UK

# Diet

- A lot of respondents had been prescribed PERT

  **94%** resectable Vs **77%** unresectable
- **33%** of those prescribed PERT felt they had not been given enough information
- **20%** (52) had not been offered a dietician appointment
- Those least likely to have seen/been offered a dietitian were those diagnosed within the last 6 months ago (**66%)**
- Unresectable patients less likely than resectable patients to have been offered a dietician appointment (**62%** Vs **77%)**

Pancreatic Cancer UK





It can be a very lonely cancer.
There seems to be a lot of support for other well-known cancers. I feel cancer should be cancer, no matter where it is, and everyone should get the same support!

Pancreatic Cancer UK


# Thank you. Any questions?