#PCUKStudyDay

Pancreatic CANCER UK

Supporting people with pancreatic cancer in the community

11th June 2025
9:30 – 11.00am
Via Zoom Webinar

#PCUKStudyDay

Welcome and introduction

Nicci Murphy
Clinical Lead and Pancreatic Cancer Specialist Nurse, Pancreatic Cancer UK

An introduction to us

Nicci has been nursing for 20 years and started her career as a district nurse, going on to specialise in palliative care, both in the community and in a hospice setting. Nicci then moved to secondary care, working in oncology in a city hospital providing support to individuals and their families affected by a cancer diagnosis, including pancreatic cancer. For the last five years Nicci has been part of the nursing team at Pancreatic Cancer UK working on the support line.

Simon has been a registered nurse for over 20 years starting his career in specialist surgery within an acute NHS hospital before moving into Community Nursing. For the past 15 years Simon has worked as a specialist nurse within hospice care in both the community and inpatient settings. His main focus has been in palliative care supporting people with life limiting illness, including those living with pancreatic cancer.

Aims of this session

Overview of pancreatic cancer

The impact of a pancreatic cancer diagnosis

Physical and psychological symptoms

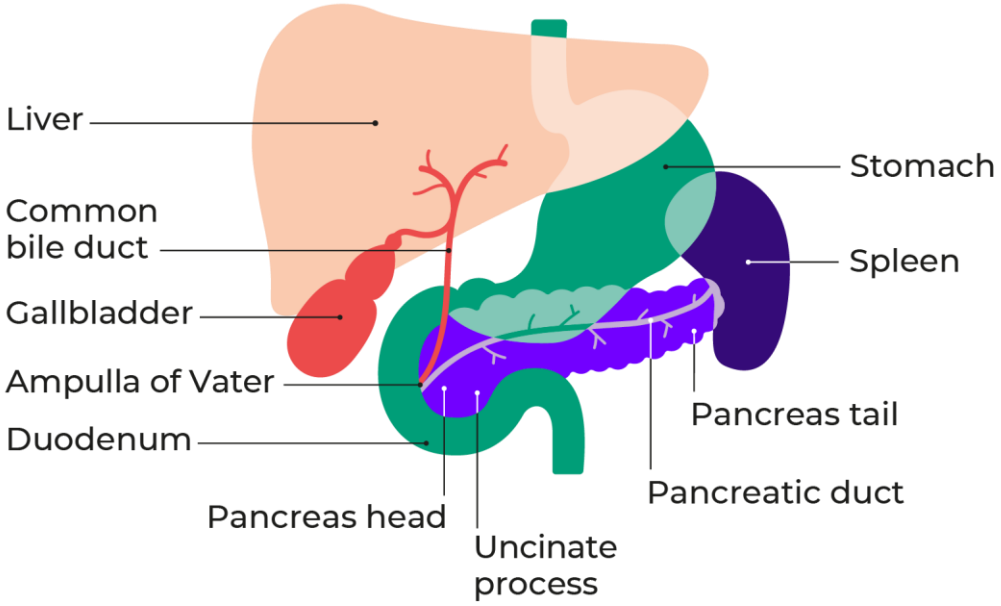
How to support your patients in the community

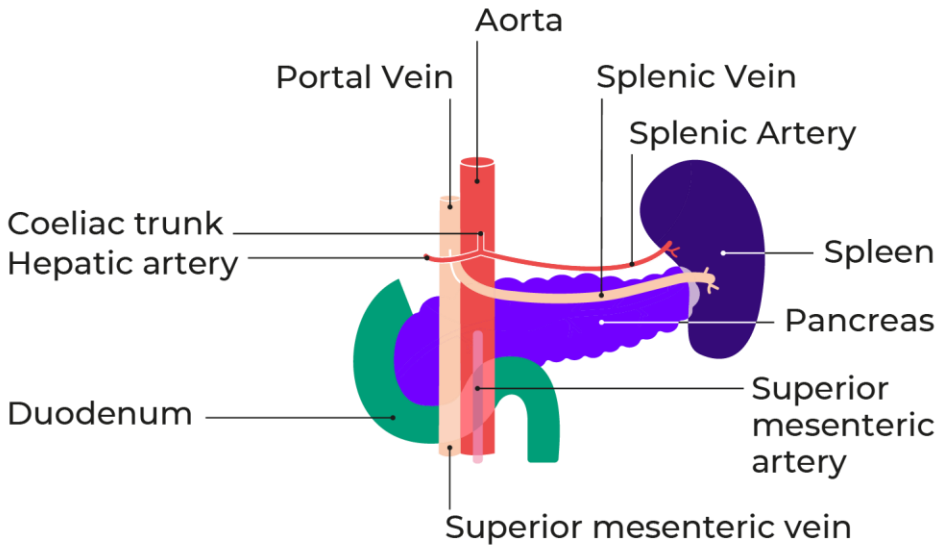
Poll

In your experience, what is the most challenging aspect of supporting someone with pancreatic cancer?

- Symptom management
- GI issues/ Pancreatic Enzyme Replacement Therapy (PERT)
- Psychological/emotional support
- Supporting loved ones

Diagrams to show the pancreas with surrounding organs and blood vessels





Pancreatic cancer: the facts

Deadliest cancer

5th biggest cancer killer in the UK

One in four people dying within a month

Less than 7% survive past five years

Late diagnosis

It presents with vague and non-specific symptoms

80% diagnosed at stage 3 and stage 4

Over half of pancreatic cancer patients are diagnosed in A and E

Limited treatment options

7 in 10 people with pancreatic cancer do not receive any active treatment (e.g. chemo or surgery)

Surgery is high risk - up to 3% mortality and up to 30% morbidity

High rates of recurrence

Complex and severe symptoms – people too sick to receive treatment

What people affected by pancreatic cancer tell us

‘[He was] passed around like a rugby ball. 6 hospitals for 6 procedures’ - Pancreatic Cancer UK Transforming Care workshop participant

‘Continually chasing test results and telling the story over and over’- Pancreatic Cancer UK Transforming Care Workshop participant

‘I didn’t have anyone to call, and his pain was just getting worse’ -support line caller’

‘When my Mum was discharged from the hospital, she was told someone would be in touch, we still haven’t heard anything and that was two weeks ago ’ -support line caller

Pathways following diagnosis

Patients will typically sit in one of three pathways:

Operable
Small percent of patient group, significant surgery, usually in hospital for up to 2 weeks, full recovery expected to take a year.

Borderline Resectable
May be on systemic treatment in attempt to downstage the tumour (location and size dependant) for surgery

Inoperable
Patient may be offered treatment such as chemotherapy or for palliative care only.

Psychological Distress

Higher risk of severe psychological/emotional distress

Multifactorial with financial, spiritual, social, cultural and physical components

Prior and or current mental health issues may be exacerbated by the diagnosis

Pre-existing issues such as learning difficulties and neurodivergence may bring unique communication and support needs

A proactive rather than reactive approach is needed. Medication such as antidepressants can help

Providing timely, individualised and sensitively communicated information is key

Utilisation of support networks with early advance care planning is vital

Pain

Pain is common often complex and multifactorial

Huge impact on quality of life affecting sleep, appetite, relationships and psychological wellbeing as well as limiting treatment

Different types/combinations of pain: eg neuropathic, nociceptive (somatic- skin/muscle, visceral- internal organs), tumour, bone and psychological/emotional. Total pain

Comprehensive and ongoing assessment is essential- consider pain assessment tools

Early recognition and intervention is key including referral to specialist services such as palliative care

Pain

You can go straight to a strong opioid for pain control

Morphine remains the gold standard but won't tackle all pain equally

Neuropathic pain medication- adjuvants eg Amitriptyline, Gabapentin, Pregabalin

Steroids, NSAIDs, benzodiazepines and antidepressants such as Duloxetine can also be helpful

Polypharmacy and tablet burden need to be considered along with careful assessment of efficacy- if it doesn't help then stop!

Prescribe daily laxatives to avoid constipating effects and consider anti-emetic if opiate naïve.

Nerve blocks and standard treatments such as radiotherapy may also be considered

Don't forget non-drug options such as TENS, distraction therapies, hobbies, pets, psychological support

Jaundice

Jaundice can present at any point, from pre diagnosis to end of life

Symptoms to look out for: yellowing to skin/eyes/ itchy skin, pale stools, dark urine

Treatment is usually a stent (if able to tolerate procedure/ symptom management)

Follow up with bloods- (bilirubin) but be aware can take up to 14 days to return to normal levels.

Important to refer on quickly for assessment, unable to have chemotherapy until jaundice resolves

Poor prognosis if untreated

Nausea and Vomiting

As with pain detailed assessment is key!

Multifactorial- treatment, pain, disease, obstruction/stasis, infection, constipation, psychological/emotional distress, GORD, candidiasis and the medications we give! Mechanical and/or chemical picture

Anti emetic choice- need to fit the drug to the cause, some combinations are counteractive and the route is important with SC sometimes necessary particularly in palliative care

Quality of life- Impact is massive, it affects mood, sleep and ability to withstand treatment

Loss of appetite- resulting in weight loss and aversion to eating can persist if symptoms severe. Can be due to altered taste from treatment

Practical help- cold foods (reduces smell from cooking), simple diet, avoiding strong flavours, avoid metal cutlery if metallic taste is a causal factor

Early referral to palliative/enhanced supportive care

Constipation and Diarrhoea

Constipation- treatment, opioids and other medications eg Ondansetron + Amitriptyline, immobility/reduced physical activity, reduced dietary intake and dehydration. Can be due to PEI

Diarrhoea- infection, treatment, PEI, overflow, SIBO, BAM and previous medical history

Steatorrhea- pale, oily, foul smelling (more than usual!) stools which are difficult to flush. Due to fats present in stool and a consequence of PEI from disease and/or surgery

GOO (Gastric Outlet Obstruction)

15 – 20 % of pancreatic cancer patients will develop GOO.

Caused by tumour infiltration from pancreas into duodenum, external compression or lymphadenopathy (most common in head of pancreas tumours)

Diagnosed usually via CT or endoscopy

Symptoms – ‘mechanical vomit’ high volume vomit with undigested food, nausea can be sudden onset and relieved by vomiting. Pain, weight loss and early satiety.

Anti emetics will be of limited or no benefit in full obstruction

Duodenal stents need careful management of diet- soft easily digestible foods

Bypass surgery (Gastrojejunostomy) only in a small number of patients if curative surgery is found not to be possible during the surgery and only if felt to offer significant potential benefit with symptom management

Other symptoms to be aware of

Ascites and Oedema

Fatigue

Pulmonary embolism (PE)- increased risk with gastric cancers

Gastrointestinal bleed (tumour location dependent)

To discuss in the next session:

Bile Acid Malabsorption (BAM)

Small intestinal bacterial overgrowth (SIBO)

Type 3C diabetes

Community Care

You may be involved in a pancreatic cancer patients healthcare at any point, from pre-diagnosis to end of life care.

Recognising the complexity of the disease and potential for rapid changes.

Good communication needed between primary and secondary care- community nurses, GP, Oncology/Surgery, dieticians, and palliative care.

Early referral to specialist palliative care teams due to high burden of symptoms

"***I was given little cards with the nurses' name and numbers on. I can ring them anytime. They'll send me a text asking me how I am. I've found them really, really helpful***." - Andrew

“It’s a lot more in-depth for us than it was before”

A multi-methods study of community nurses’ extended roles in palliative care

Dr Ben Bowers

Community nurses have a central role in home care

More deaths at home

Increased complexity

Less support

New & extended roles

Dr Ben Bowers

Kristian Pollock, Simon Etkind, Alison Leary, Stephen Barclay, Louisa Polak

Help us identify community nurses' contributions to end-of-life care

The Queen's Institute of Community Nursing

UNIVERSITY OF CAMBRIDGE
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