Pancreatic Cancer: A Patient’s Perspective

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UK expert for the HCP Pancreatic Cancer Euro Index

Let’s drive earlier diagnosis
## My route to diagnosis

<table>
<thead>
<tr>
<th>June 2006</th>
<th>Not associated with weight gain, no family history</th>
<th>Told to alter (already healthy) diet &amp; monitor</th>
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</thead>
<tbody>
<tr>
<td>Diagnosed with new-onset type II diabetes</td>
<td>Prescribed Gaviscon</td>
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<tr>
<td>Mid-June/July 2007</td>
<td>Diagnosed with dyspepsia</td>
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<tr>
<td>Mid-Aug 2007</td>
<td>Prescribed Buscopan</td>
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<td>Pain on eating – stopped eating + change in bowel habit + back pain</td>
<td>Told ‘yes’</td>
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<tr>
<td>Asked GP if fit to travel (family holiday)</td>
<td>Spent week ill in hotel room</td>
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<tr>
<td>End July</td>
<td></td>
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<td>End July/July 2007</td>
<td></td>
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<tr>
<td>June 2006</td>
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</tbody>
</table>
My route to diagnosis cont...

Severe pain – home visit – out of hours GP

Suggested pancreatitis & told to go back to GP

Given morphine injection for pain

GP: discussed my pain on ‘phone to surgical A&E team

Decided pain not bad enough to be admitted to hospital

GP prescribed Co-Codamol

Took myself to A&E – they suspect gallstones

Told needed US – no-one available

Sent home with Tramadol

3rd week in Aug

Next day

Bank Holiday Monday
My route to diagnosis cont...

Next day

Back to GP: US requested ➔ Non-urgent – would be 4-6 week wait ➔ Asked for private referral

4 days later

Chased private referral ➔ GP had sent to consultant's NHS secretary by mistake ➔ I had to chase for 2 more days to get appointment

Appt with Consultant HPB surgeon ➔ Admitted to hospital straight away ➔ Morphine patches & Voltarol suppositories to manage pain
30th August 2007

Tests revealed 5.5cm mass on pancreas

Luckily confined to the pancreas

Surgery planned for week later

Before diagnosis:

Fit and healthy non-smoker, not overweight, no family history and rare attendee of the GP practice
Distal Pancreatectomy & splenectomy

8th September 2007

- Successful but close to margins
- Histology revealed Stage 2b adenocarcinoma
- (1 lymph node affected)
- Followed with 6 months chemotherapy then 5 weeks of chemo-radiotherapy
My situation is unusual

Most patients diagnosed too late:

Only 10% dx in time for surgery.

50% patients never heard of pancreatic cancer.

70% of UK population doesn’t know where pancreas situated.

Average life expectancy 4-6 months

5-year survival only 4% (no change in 40 years)

Pancreatic Cancer Action Patient Survey 2015:

Before referral for tests, 40% patients visited their GP 4 times or more.

1 in 10 had 10+ appointments

61% of patients said their GP initially dismissed symptoms
After treatment: late effects

**Confirmed diabetic Type 3c:**
Currently controlled through insulin.

**Spleen removal:**
Antibiotics for life – erythromycin (allergic to penicillin)

**Peripheral neuropathy:**
Due to cisplatin chemotherapy

**Early-onset menopause**
Opted not to have HRT

**Diet (mostly) normal:**
Have to watch the carb intake.

But difficulty digesting meat and have so far avoided the need to take enzyme supplements – but do have bile malabsorption.
Dealing with my diabetes

- My diabetes considered a ‘side-show’ to the pancreatic cancer
- Was initially managed with gliclazide and diet
- Glucose control has gradually declined
- New regimen included gliclazide plus night-time humulin and evening meal humulog.
- Still lack of control. Gliclazide reduced and metformin added to the insulin regimen.
- Now – gliclazide removed, metformin (slow release) daily, humulog at breakfast & dinner, humulin at bedtime.
- Future: complete control by insulin??
34% of people said they were too embarrassed to go to the doctors.

Only 31% knew the location of the pancreas.

25% of people said they were too busy to go to the doctors.
European pancreatic cancer facts and stats

- 4th biggest cause of cancer death in Europe – if no action taken, it will be the 2nd leading cause of cancer deaths by 2020.

- It has the lowest survival rate of all cancers (<7% to 5 years)

- Huge variation in survival across Europe

- Median survival rate (metastatic pancreatic cancer) 3-6 months

- Patients with pancreatic cancer lose 98% of their healthy life expectancy at the point of diagnosis (Carrato et al, 2015)

- Pancreatic cancer receives <3% cancer research funding
Pancreatic cancer one-year survival rates vary across Europe

Eurocare 5: European 1 year relative survival rates for pancreatic cancer patients diagnosed between 2000 - 2007

Country/Region

Bulgaria 16
Northern Ireland 19
Scotland 20
Malta 23
Latvia 23
UK average 23
Eastern Europe 23
Czech Republic 23
Wales 23
Slovakia 24
Netherlands 24
Slovenia 24
Estonia 24
Denmark 24
England 24
Ireland 24
Lithuania 24
Norway 24
Poland 24
Croacia 24
Spain 24
Finland 24
European Average 24
Sweden 24
Southern Europe 24
Portugal 24
Austria 24
Central Europe 24
Italy 24
Iceland 24
Germany 24
Switzerland 24
France 24
Belgium 24
Also variation in 5-year survival rates
There have been huge improvements in survival for most cancers...

Sadly the same isn’t true for pancreatic cancer

Source: Cancer Research UK
Pancreatic cancer only gets 3% of overall cancer research funding in the UK

Annual research spend by tumour site 2002 - 2014 (NCRI data)
If diagnosed in time

Survival increases ten-fold...

Surgical resection “Whipple’s procedure” or distal pancreatectomy & splenectomy followed by adjuvant chemotherapy can increase survival by up to ten-fold
Symptoms

Signs & Symptoms of pancreatic cancer

- Low mood or depression
- Diabetes (new onset and not associated with weight gain)
- Indigestion (not responding to prescribed medication)
- Pale, smelly stools (that don’t flush easily)
- Jaundice (yellowing skin, possible itchy skin)
- Mid-back pain
- Pain on eating
- Upper abdominal pain
- Fatigue
- Unexplained weight loss

DO NOT IGNORE THEM!
If you persistently experience one or more of these symptoms which are not normal for you, contact your GP straight away or call the NHS 111 Service

Let’s drive earlier diagnosis
What we do

Fund clinical research

Provide Medical Education

Signs & Symptoms of pancreatic cancer

Symptom Awareness

Provide Patient Info
• Washroom panel adverts in over 220 shopping centres, network rail and service stations and online advertising.
• Gender targeted.
• National coverage.

45 million impacts (potential views) over 4 weeks.
Currently 5 booklets in Understanding Pancreatic Cancer series:

1. What is pancreatic cancer & how is it diagnosed
2. Surgery for operable pancreatic cancer
3. Treatments to control the symptoms of pancreatic cancer
4. Chemotherapy and how it is given
5. Diet & nutrition for pancreatic cancer
6. Pancreatic cysts & cystic tumours (written with UCLH)
7. Recipe book - High protein, high calorie recipes for those experiencing cancer weight loss

All booklets available to hospital units and patients FREE of charge!
Thank you!

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