Transcript

The complexity of pancreatic cancer with Pancreatic Cancer UK

Intro music

Paul (00:10)

What does it really mean to face a cancer that's often diagnosed too late? And how do families navigate the uncertainty that comes with it?

Nicci (00:18)

We hear this a lot about this lead up to diagnosis. And like I say, often it can be back and forth to the GP with these kind of vague nondescript symptoms that can be put down to lots of other things, so. Like things with back pain, is it muscular or those bowel symptoms and changes you know, is it IBS? So these are the kind of things that we hear.

Paul (00:40)

Hello, I'm Paul and my pronouns are he/ him.

Liv (00:43)

I'm Liv and I go by she/ her. Welcome to the Cancer Professionals Podcast, a podcast from Macmillan. In this series, we chat to a wide range of guests, including health and social care professionals to lift the lid on current issues faced by the cancer workforce.

Paul (00:56)

If you enjoy this episode, please subscribe, rate and share with your colleagues and friends. We'd love to hear from you- please get in touch to ask questions, give feedback, or even to suggest topics you'd like us to cover by emailing professionalspodcast@macmillan.org.uk or by filling in our short survey linked in the episode description.

Liv (01:18)

This episode contains conversations about death and bereavement, including a personal account of losing a partner, which you may find upsetting or triggering. Listener discretion is advised.

Paul (01:29)

Welcome to the Cancer Professionals Podcast. Today we'll explore the complexities of pancreatic cancer and the realities of supporting people affected by it. We're delighted to be joined by Nicci Murphy from Pancreatic Cancer UK to share clinical insights and Alison who is generously sharing her personal story of supporting her husband who was diagnosed with pancreatic cancer. So to get us started could I ask you both to introduce yourselves? And Nicci, I'll start with you.

Nicci (02:00)

Thanks Paul, and thanks for having us on the podcast. My name is Nicci Murphy and I am a clinical nurse specialist working at Pancreatic Cancer UK. And my background is in palliative care prior to the role that I was in now. I worked actually for Macmillan in a busy hospital in the North west. And prior to that, I was in district nursing. So I've spent a lot of my career working with people who have a diagnosis of pancreatic cancer.

Paul (02:28)

Thank you. And Alison, could you introduce yourself?

Alison (02:32)

Hi, I'm Alison. My husband Aiden was 57 when he was diagnosed with pancreatic cancer in October 2024. Sadly, it was too late for any treatment at all and he died 11 weeks later at the end of December 2024, 30th December.

Paul (02:50)

Thank you. And there will be an opportunity for you to tell us a bit more as we progress through the episode. So to kind of get us started, Nicci, are you able to maybe give us an overview of pancreatic cancer and why it's often diagnosed so late?

Nicci (03:08)

So pancreatic cancer is when someone has a tumour in their pancreas and we know around 10,000 people are diagnosed each year and 95 percent of those people will be diagnosed with ductal adenocarcinoma which is the most common type of pancreatic cancer.

So sadly, pancreatic cancer has got the lowest survival of all common cancers with a five-year survival of less than 7%. And shockingly over half of the people diagnosed will die within three months of diagnosis. We also know a lot of people won't get to treatment. So seven out of 10 people diagnosed don't receive any active treatment. And only one in 10 will receive potentially curative surgery.

So, you know, that gives an indication of what a challenging background to pancreatic cancer. And unfortunately, those statistics haven't changed for many years.

Paul (04:05)

Yeah, they're quite harsh statistics, aren't they? Definitely. So could you maybe just explain in a bit more detail why it's often a complex lead up to a diagnosis?

Nicci (04:09)

A lot of people don't actually know what their pancreas is or what it does. Your pancreas is an organ about the size of your fist that lies deep within your abdomen, tucked behind your stomach. So it's difficult to get to and often it can cause symptoms at a later stage. And that is one of the big challenges with pancreatic cancer is we know that they often symptoms don't get picked up. So for around 80% of people, they'll be diagnosed at a later stage, so stage three or stage four. Your pancreas has two jobs- the exocrine function, which is where your pancreas makes enzymes that help you to break down the nutrients in your food. So it plays a really important part in digestion. And also the endocrine function, which is the regulation of hormones in your body. So lots of people will have heard of things like diabetes and that is a condition related to your pancreas. So it has got two very important jobs, but it's, like I say, it's something that people often don't know about until there is a problem. So often people will have quite vague symptoms that are very similar to more common conditions. So it's not unusual for us to hear on our support line at Pancreatic Cancer UK, people who've been back and forth to the GP on a number of occasions with those kind of vague symptoms of abdominal pain, changes to their bowel habits, just feeling generally unwell. Yeah, so it's challenging and at the moment we don't have a simple test to diagnose pancreatic cancer which obviously makes it even more complex and difficult to manage.

Paul (05:59)

And could you maybe just explain a little bit more about what some of those key challenges are in terms of symptoms and that kind of thing?

Nicci (06:06)

Yeah, of course. So people who have a problem with their pancreas often have lots of complex symptoms. Again, because I mentioned about that big role that it plays in digestion of food. So it's not unusual for us to see people lose weight and they can lose weight quite quickly. And that's weight loss without trying. So they can be eating a normal amount of food, what is regular for them. But actually the weight is, they're just not maintaining their weight.

They will often have abdominal pain which can radiate round to their back and that can be under the rib cage or lower down and it can be difficult pain for them to describe. People often have changes to their bowel habits so we often see people have or describe something called steatorrhea. So that's a type of diarrhoea where there's a real sense of urgency to go to the toilet. It's very yellow in colour, it's difficult to flush and often you can see oil in the toilet bowl and the reason that happens is because people aren't absorbing fats in the food that they eat so it just passes through their body, and again that's why people experience that weight loss that I mentioned before. So there's lots going on, lots of difficult symptoms and as I said often by the time people get to a point of diagnosis they can have had these symptoms for quite some time.

And then it's difficult to get on top of those symptoms and to manage them well. And so we often see people being diagnosed where they've been pretty unwell for quite a long time. And then that again, makes it more complex to get people to treatment because they might not have a performance status which enables them to have things like chemotherapy.

Paul (07:47)

And in terms of kind of the complexity with some of those kind of symptoms, is there anything else you want to add on that?

Nicci (07:59)

I think it's incredibly difficult for the person, it's incredibly difficult for the health professionals who are supporting people with pancreatic cancer because like I say, often these symptoms are uncontrolled for a period of time and then as a lot of health professionals who work with people with pancreatic cancer will be able to testify, it's then difficult to try and get on top of it. So pain, like I say is particularly challenging and that pain can be complex in that it can be neuropathic pain, which can be difficult as well to get on top of. So often, you know, people will have lots of, like I said, digestive problems. So this is where we need the input from dietitians to help to manage those symptoms, but not everyone is referred to a dietitian. And because there's a long run up, to being diagnosed, it can take a good length of time for someone to go through that process of getting to a CT scan, waiting for results, then perhaps they might need further investigations or a biopsy. It can take weeks. And in that time, not everybody is then getting the support with those symptoms. So it continues and they become more and more unwell.

So time is against us. It can take a long time to diagnose pancreatic cancer in a way that we don't always see with other cancer types. So from someone first going to the GP to then being referred under a two week wait for a CT to then waiting for the results of that, it can take weeks and that also adds to that challenge.

Paul (09:32)

And I think, I mean, it sounds incredibly kind of complex and, you know, alongside that complex kind of lead up to diagnosis, does it, and this is quite a hard question, I think, really, does it also depend on where you are in the country as to what type of support you might get? Because we do hear of, you know, differing resources.

Nicci (09:36)

Absolutely.

Yeah, it absolutely does depend on where you are in the country because as you said, Paul, there is huge variation across the country as to what is available. Often, you know, health professionals working in HPV cancers or upper GI cancers, a lot of clinical nurse specialists will be working alone, a large caseload of patients who all have, like I said, difficult, complex symptoms that need to be managed. So yeah, there is variation of where you are and what's available. We know in places where there is a specialist centre, the support is actually very good, and often there is a dietitian and someone will be referred for dietetic support, which is vital. And then in other areas, not so much. So yeah, that again is a challenge as to where that support kicks in.

Paul (10:47)

You mentioned weight loss earlier on. Could you maybe tell us a little bit more about, that is and what that means?

Nicci (10:54)

Yeah, absolutely. So this is a really common thing for people with pancreatic cancer to experience. So as I mentioned, most pancreatic cancers are something called ductal adenocarcinoma and they usually the head of the pancreas. So we describe the pancreas as having a head, body and a tail. So most tumours occur in the head of the pancreas and this is the part of the pancreas where those digestive enzymes are made that help to break down the nutrients in food.

So when that's not working correctly, people experience something called pancreatic exocrine insufficiency or PEI for short. And that can happen in lots of conditions. So we know people with pancreatitis can experience this or even things like Crohn's disease, but it's particularly prevalent in people with pancreatic cancer. So because they're not producing those enzymes to break down food, they're not getting that absorption and they experience lots of symptoms like losing weight very quickly without trying, lots of wind and uncomfortable bowel symptoms, having to dash to the loo after eating, feeling full very quickly when they eat. But the important thing to know is that it's diagnosed early.

We don't wait around with people with pancreatic cancer to test for PEI. We know that it's likely that they're going to have it. And so we start them on something called PERT pretty quickly. Now PERT are capsules, the Pancreatic Replacement Enzyme Therapy, and they're capsules that are taken when you eat to make sure that you're- they basically mimic what a healthy pancreas would do. So it would mean that you would then absorb the food that you eat and they're crucial.

And unfortunately, you know, we still hear of patients not being prescribed PERT or not being given enough or told how to take them correctly. So it's just something really important to look out for. And I would encourage health professionals who are involved in caring for people with pancreatic cancer, that that is one of the first questions that they ask. Have you been prescribed PERT and do you know how to take it?

Paul (12:56)

Great, thank you.

Liv (12:58)

So, Alison, we are so grateful that you've joined us today to talk about Aiden and share your story. I wonder before we kind of talk a bit more about Aiden's diagnosis, whether you could just tell us a little bit about him.

Alison (13:12)

So Aiden was a, he was a massive cyclist that's that was that whenever anyone who knew Aiden you know mentioned his name what the picture is he was a cyclist, he cycled hundreds thousands of miles a year. You know holidays were- now I'm going to watch the Tour de France and taking his bike and whenever we replaced our car, he had to make sure it would take the bike and you know, it was a big passion in his life. He was also very intelligent. He'd originally started in research himself. He'd been a biochemist, but he spent vast majority of his career as an IT programmer, software programmer, and he was extremely highly skilled and highly regarded. He always gave his time. He was always generous with his time with colleagues at work and with other people. He loved puzzles.

One of the things we used to enjoy doing, we'd go to the pub on a Saturday afternoon and we'd do the crossword together. He used to love doing Sudokus at night in bed. He was just really easy going. And we'd been together nearly 30 years, married for just shy of 25. Sadly, we just missed our silver wedding anniversary. And yeah, it was a real shock.

Liv (14:35)

Yeah, thank you so much for sharing that. Yeah, he sounds a great guy. I wonder if we could move on to talking a little bit about Aiden's diagnosis and kind of what led up to his diagnosis and what kind of symptoms he experienced.

Alison (14:46)

Okay well Aiden probably a year or more before his diagnosis he'd had vague, vague symptoms. Aiden was really really fit and because he was really really fit he he could tell when something wasn't quite right, when he wasn't feeling quite as well. He'd had a bit of mid-backache, feeling a bit of indigestion he'd he got pain actually lower down not not as high up, more a little bit lower down his torso and that you know and I'd actually said you need to go to the doctors, you need to go to the doctors, and he actually supposed to have been sent for a scan that we never received the letter because we never received the letter and it wasn't followed up. Nothing happened and that was nearly a year before he was finally diagnosed and you just think of all that waste of time. and then as time goes on, you know he'd still be moaning on about these back pains see the thing is because we weren't aware of the symptoms. example, I'd often go into the bathroom after him, I'd be moaning at him, he'd not flush the toilet properly, because the stool would be floating. But I didn't realise that could be a symptom. If it had been blood, I would have known very well- oh crikey, that's something to... And then eventually, I think- he had diabetes. That's another thing, he was type 1 diabetic.

I think about 18 months, a year before he got diagnosed he'd had his diabetes check-up and the nurse, the diabetes specialist had said- oh, that's, I don't know anything about that you know it's not my, you know so there's a real need I think to get, for some connection between the different medics and so eventually we got to the Summer and he kept complaining about chest pain, and I was like- well Aiden, you know, you really need to get that sorted. Anyway he did go and he got sent by the it was a practice nurse he got sent to A&E, they only did an ECT scan that came out fine, they checked his lungs they found what they found markers for DVT- not DVT, they did find something but they didn't follow it up, they said we'll give you another scan three or four weeks, I think it was for a clot, they found some clotting factors, there was something and they'd found something, a small clot in his lung but they never checked him lower down despite the fact he had other symptoms, they never CT scanned his abdomen, they only checked his lungs and so this was sort of like end of June, early July.

So, you know, and they said, oh, it's probably muscular pain. You're probably, you know, from your cycling and all that. So we went away and he was still kept complaining, but I think he was, you know, at that point we were thinking, is it something to do with his heart, with his diabetes? We never thought for a minute there was anything, you know, like where it turned out to be.

Alison (17:40)

And then we went on holiday in September. He was still well enough to go on holiday and we enjoyed the holiday. Although even when we were away, he sort of bypassed things like bread and said he felt a bit bloated and then start complaining like, you know, I don't feel that greatly bloated and stuff and so he wasn't eating quite like he was. He did lose some weight just before the holiday but because he was so fit and slim anyway, it wasn't really noticeable on him like it might have been for someone who was a lot bigger. Because he was always very skinny really, to be perfectly honest. He had that, you know, that physique.

So about month before he was diagnosed maybe less we went back to A&E. They basically said- it's just, you know, because he was getting pain his main complaint at the time was then was he was struggling to walk he was getting pain in his legs he was getting breathless he was even just going upstairs which was so unlike him.

You know, I knew that he couldn't cycle as far. He was struggling with his cycling, which again was very unlike him. And that, be fair, had been going on a couple of years that he hadn't been quite up to cycling as much as he had been. So he had been there all the time, but he was dismissed out of A&E about three weeks before he finally got diagnosed. Being told it was just muscular pain, was nothing wrong with him. You know, we knew there was something more serious that needed checking out, you know, and Aiden through his work his work had a Bupa cover, and he had a private GP appointment and he talked about the pain in his legs and that he was really struggling to walk and it hurt when he walked, and he got referred to a private vascular surgeon who did an ultrasound of his legs so there's nothing wrong with his veins but because he was so slim they moved up to his torso and then they said it looked and that they didn't spot anything on pancreas but they did spot something on the lymph nodes I think at that point he was worried the possibility might have- what is it- the lymph, the other one is it, that's the one- lymphoma. And he's also started having night sweats at this point as well. So this doctor has for him to go straight to the assessment unit bypassing A&E. So we went back to, we went there and the first doctor we saw said, you know, there's nothing wrong with you, your scan came out okay. Yeah, so he's had another CT scan of his lung at this point and it had gone down a bit. We did finally see another doctor who took it more seriously and admitted him and did lots of tests. And they found things like gallstones and other stuff amongst other things, but he did finally get a CT scan on the Friday and that would be the 11th of October. We had the CT scan on the Friday and then on the Monday we got called and said- you know there's a mass and it was in the tail of the pancreas where it looks have started. Tail and the body sorry, it looks like it could be cancer.

And so we were sent over to the MDT scan, MDT team. At that point, we had a massive wait. We had a real wait and Aiden was deteriorating all the time. In fact, between him finally getting to see a specialist from the MDT team and getting that phone call, he ended up back in hospital from the GP trying to get his pain under control. And his weight then did start going down and his appetite started going down as well.

He'd always been able to eat quite well. And so he never, he was always told it was suspected pancreatic cancer because he never was deemed to be well enough to get a biopsy. When we first, when we eventually saw the specialist, they said, oh, you've lost some weight. We think at the moment it's too much of a risk to get, to do the biopsy because he might get pancreatitis. Try and put some weight on him in a couple of weeks. But it didn't happen, he just continued to go down. Even right up until November they were still saying- suspected pancreatic cancer they weren't saying it definitely is because we didn't have the biopsy but you know we did find out later yes it was the more common type but unlike most it started in the tail which I understand if caught early enough it's in the tail it's a more successful outcome but it's also less likely to found early enough is that correct I think. But I just think of all the missed opportunities when it could have been picked up when he mentioned things to other doctors like his diabetes specialist, and they never thought- that might be worth checking out so yeah so by the time we finally found out what we were dealing with it was far too late for anything. We just got palliative care. So, yeah.

Liv (22:28)

Gosh, yeah, it sounds like there were so many challenges that you faced as you were kind of, like you say, trying to get that diagnosis and get to the root of what was causing all these issues.

Alison (22:37)

Hmm.

Liv (22:38)

And what did you notice about how Aiden was coping with the kind of physical and emotional effects of the illness at that time?

Alison (22:46)

He was very quiet for a lot of the time. When he first got diagnosed, initially, you know, he went into like his business, always tried to make sure everything was sorted out and everything was in order. He was more worried about, you know, he was worried about telling his mum and dad. He didn't want them to come see him. He didn't want them to know for ages. You know, he didn't want them to know what was happening.

He was, he seemed to be more worried about me to be perfectly honest. I mean, he was still fighting it. You know, right up until the end, he was still saying, well, you I might get some chemotherapy. I might, you know, he was still trying. But nothing, it's, yeah. It was heartbreaking to see someone who'd been so active and so fit and so full of life, just to go down so quickly.

Liv (23:30)

Yeah, no, yeah, we're so, so sorry to hear about what happened to him.

Nicci (23:35)

It's hard to go back over it, isn't it Alison?

Paul (23:38)

Yeah. I wanted to ask why it took so long for Aiden to get diagnosed?

Nicci (23:45)

It's, it's so frustrating and it's sad because Alison and Aiden's story isn't uncommon when, you know, we hear this a lot about this lead up to diagnosis. And like I say, often it can be back and forth to the GP with these kind of vague, nondescript symptoms that can be put down to lots of other things. So like things with back pain, is it muscular or those bowel symptoms and changes that Alison spoke about, you know, is it IBS? So these are the kind of things that we hear.

Ad

Liv (24:20)

This conversation really shows how complex pancreatic cancer can be. So many early symptoms are subtle or missed.

Paul (24:25)

Yeah, and that's why having the right information is so important for healthcare professionals.

Liv (24:30)

If you want to learn more, the Learning Hub has a range of resources including on pancreatic enzyme replacement therapy and palliative care.

Paul (24:37)

That's incredibly valuable. Access to this kind of information can really improve care and support for everyone involved.

Liv (24:44)

Exactly. Whether you're looking to deepen your clinical knowledge or understand the experiences of people living with cancer, head over to the Learning Hub after the episode. You'll find the link in the episode description. Everything's free and really easy to access. Pancreatic Cancer UK also has a range of resources for healthcare professionals to help you provide the best possible care for your patients.

Paul (25:02)

Okay, let's get back to the discussion.

Nicci (25:06)

I wanted to touch on what Alison said about the diabetes because that is a big one. You know, if someone has had diabetes for a long time and their blood sugars have always been stable.

if we see suddenly those blood sugars changing and a big fluctuation, that is a sign that potentially something's going on there. And we would encourage anyone who supports people with diabetes if they see a sudden change in blood sugars, particularly alongside things like weight loss and pain, that's then investigated further. So a CT in that situation would be appropriate.

The pancreas is really difficult to see and so with an ultrasound often if people have got abdominal pain the first port of call will be an ultrasound but the ultrasound often won't pick up masses on the pancreas because it can be occluded by bowel gas so they don't always get a good visual of the pancreas on an ultrasound. The next step is usually a CT, and that's very good, visualising the pancreas but because people present at the GP with often quite vague symptoms we don't have those kind of quick screening tools to use, which is why not everyone will get to the point of having a CT. Even when they do, the results can take two weeks. It can take even longer in certain circumstances. Then it might be that they need to do more investigations. So it's not unusual for people to have an endoscopic ultrasound or an EUS, or they have to go for an ERCP.

And then that can take time waiting for that appointment and then waiting for the results of that appointment. And in the meantime, someone is becoming more and more unwell. And like we saw with Aiden, you know, those symptoms just escalated during that time. So when it comes to the point of trying to get a biopsy, which is an invasive procedure or getting, and you need a biopsy, sorry, I should say to get chemotherapy. They won't do it- in very rare circumstances, but typically it won't be done. Chemotherapy won't be given without a confirmed histology. That then when people get to see an oncologist, they're just so unwell, actually chemotherapy isn't the right step forward.

Alison (27:13)

Aiden actually never got referred to an oncologist, unbelievably really. People still find that hard to understand. Yeah.

Nicci (27:19)

Hmm. Yeah. Yeah. It is, it is hard to understand. That's why early detection is everything because if we're picking these cancers up earlier and we're getting these symptoms under control much quicker, then it means people are going to be in a better position to have life extending treatment or curative treatment like surgery.

Liv (27:45)

And I wonder if we could move on to talking a little bit about the support that's available to people. Alison, what support did you and Aiden access at that time while she was going through this from kind of charitable organisations, other organisations, what was available for you?

Alison (28:00)

Well initially we didn't get huge amounts of support at the hospital because we were waiting for the MDT team and a friend of mine who's a nurse, she suggested Pancreatic Cancer UK and I rang their helpline so from quite early on I got really a lot of support from one of the nurses there, and we got information from her that we would never have, that weren't forthcoming from the hospital. It was a consultant we were referred to actually, who mentioned about PERT. It was suggested, what were the best pain colours for Aiden's symptoms. And so we were actually saying, oh, this is what we've been suggested, rather than them telling us this is what would be recommended, which seemed quite shocking really.

Alison (28:44)

So the most support we got was from Pancreatic Cancer UK. Aiden also accessed cancer specialist through his insurance at work. But that was it really.

Liv (28:55)

Nicci, could you share a little bit more about Pancreatic Cancer UK's services and what you can offer people affected?

Nicci (29:02)

So we are a charity that is, we run a nurse-led support line for people affected by pancreatic cancer, so that's anyone who's concerned about any symptoms they might have, to people who've been diagnosed. We speak to lot of family members, anyone really like say who's been affected and we also speak to health professionals who will contact us ask us certain things. So as well as the support line which is a phone service we also speak to people via email and WhatsApp. And we also have something called Circles, which we're really proud of. It's quite a new service and it's a peer support service. So it's where people can talk to, we have different groups and they run over WhatsApp and Facebook and people can speak to other people affected in a similar situation. So for example, there's a group for people who are having or have had surgery.

There's a group for family members and we've had a really good sign up to those. So we know that that peer support is crucial. We know that people need it and they want it. So yeah, that's another thing that we offer to people.

Liv (30:09)

Brilliant, thank you. I wonder if we could ask as well about kind of referral to other services, so other parts of the NHS as well. So in terms of obviously Alison mentioned that they weren't referred on to oncology. does that happen a lot for people affected by pancreatic cancer? And also I wanted to ask about referrals to palliative care as well.

Nicci (30:26)

So we do hear of people who don't get to the point of where they're referred to an oncology team. And I think that particularly is a very difficult position to be in because we know that that support often kicks in when that referral is in place. And that's where a clinical nurse specialist will come into play. You have a good clinical nurse specialist involved in your care and they're an absolute vital part of that whole pathway. We know that some people won't always get referred to a clinical nurse specialist, but there is so much support out there for people to access. It's just knowing about it. And I think as health professionals, we sometimes forget that people haven't been in this situation before. So they might not be familiar with Macmillan. They might not be familiar with ourselves, but there's so many charities that offer support locally and nationally for all kinds of types of cancer, but also for different things.

So some people need practical support. They need to speak to people about finances. They need help with benefits or they want emotional support as well as clinical information. So there's a huge wealth of information and I think we need to be passing this on to patients and their families. And it might not be for everyone, but I think it's really important to know about it and to know that that support is there.

Yeah, I'd just encourage anybody who's working with people who have been affected by cancer to find out what's around you, find out what's available and just share that information because when it's good, it's absolutely fantastic and I think it's a vital part of people's support.

Paul (32:01)

I think that's really kind of useful to know. Is there anything else from a support to professionals point of view that we haven't mentioned? Because you did mention quite a lot there.

Nicci (32:13)

So at Pancreatic Cancer UK, we also offer lots of information and education for health professionals who are working with people with pancreatic cancer. So we do webinars where we bring in guest speakers from dietitians to clinical nurse specialists to talk about particular areas of interest, and we record those webinars and we upload them on our website so you can find them on our website under the health professional section. And we also run courses, so we have an introduction to pancreatic cancer course for perhaps someone who's new in post but I think it would benefit any health professional who does look after people with pancreatic cancer.

And we've recently launched a diabetes course, which is really exciting because people with pancreatic cancer can experience a very particular type of diabetes called Type 3C diabetes. And a lot of health professionals aren't familiar with this type of diabetes. So we have a course there on our website and they're all CPD accredited and free to do. So it's definitely worth a look.

Alison (33:20)

Can I just add something? When we were talking about clinical nurses, we were actually, when we finally got to see the specialist, which was a surgeon, not an oncologist, we did actually get assigned a clinical nurse, but she only worked part time and there was no one to contact. We weren't given contact. I mean, she was very nice and don't get me wrong, know, she was very helpful when I went to get hold of her, but she only worked part time and we got no guidance of- what to do out of hours, what to do at the weekends and in the period between Aiden going back into hospital for, when he was in hospital for like several weeks then just came home for the last week and a bit and that bit when he was at home and I was having to deal with all his pain and night sweats and everything there was there was nowhere for me to turn to out of hours. I felt very much stuck on my own, it was horrendous.

Paul (34:10)

Yeah, does sound horrendous.

Nicci (34:11)

Yeah, I think that really highlights that importance of primary and secondary care. We know that if people are at home, then they need that support from community teams as well as their team at the hospital. So this is where GPs, district nurses and palliative care teams really come into play. You know, the evidence tells us that the earlier palliative care are involved in these situations, the better the outcomes.

You know, helping to manage someone's symptoms, but also it can help to prolong life. And I think palliative care can be a frightening word for people, so it's really important that we explain what it is and we explain that it's not just about end of life care, but it's about keeping people well for as long as possible and also helping them to make decisions about what's important to them and their families. So I would certainly advocate for anyone with a new diagnosis of pancreatic cancer- consider a referral to palliative care, even if they're going to have active treatment, even if they're going to have chemotherapy, I think it's really important that we are referring to those specialist teams because we've talked about the complexity of pancreatic cancer. If we have the right health professionals involved in care, we know that the outcomes are better.

Paul (35:26)

That sounds like sound advice there. Could I just move us on slightly- if you could maybe talk about any new or emerging developments that might be coming.

Nicci (35:40)

So when we're talking about the challenges of diagnosing pancreatic cancer, one of those challenges is that we don't have a simple and easy test to use, and often there can be lots of investigations which are time consuming, leading up to someone being diagnosed.

Now we know that early detection is the key to getting people to potentially curative surgery or having treatment. So as a charity, we have funded research into something called a breath test, which is taking place at Imperial College by Professor George Hanna. So there was a phase one study which has been completed and the results of that were really exciting. So we're now into phase two stage of the trial. So there's going to be over 6,000 participants who are going to be recruited from people who've been referred for a two-week pathway, so who have those vague symptoms of pancreatic cancer. And what the breath test does is it detects volatile compounds in your breath can pick up even really early-stage cancers and it could be an absolute game changer because the hope is that you know in the next few years, this will be a really simple to use test that GP surgeries will have access to there. And then if there's a flag, if that comes up with, you know, this could potentially be a pancreatic cancer, we can get people into that system much quicker. So it, yeah, It's a really exciting bit of research.

Paul (37:11)

That sounds amazing. Yeah, so perhaps we look forward to hearing more about that.

Liv (37:15)

So finally, have our three questions feature. We ask all our guests on the podcast three questions to close each episode with. So Nicci, I'll start with you if that's okay. And our first question is, if you could go back in time to the start of your career, what piece of advice would you give yourself?

Nicci (37:31)

I think I would give myself- just listen. I think as nurses we are often very task driven, we have a natural desire to fix things and when we can't fix things we can feel a bit powerless but actually the power of just giving someone space to speak and to share their story and to tell you how they're feeling and really listen is vital.

Liv (37:54)

That's great advice, thank you. And Alison, if you could go back in time to when Aiden was first diagnosed, what advice would you give yourself?

Alison (38:03)

I would ask the doctors as much information as possible what the next stage is, what can we do. I would try and rush, rush maybe is the wrong word to use, but to try and push things to happen faster than what they. Because at the time, you know, just like, oh, someone will get in touch with you and over the next few days it didn't happen and we then started chasing things up. And I think what I should have done, you know, if I go back and say, well, who do I need to contact? What happens next? What timescale am I looking at? What can we do to speed it up? Anything that could have shortened that time to give Aiden any chance at all.

Liv (38:36)

Yeah, thank you. Thank you for sharing that. And the second question is, what change would you like to see to improve the lives of people living with cancer? Nicci.

Nicci (38:44)

So for people with pancreatic cancer, faster diagnosis, earlier detection, getting people into the right services at the right time, involving those teams like palliative care to manage symptoms.

Liv (38:58)

Yeah, that's so important. Thank you. Alison, what change would you like to see to improve the lives of people living with cancer?

Alison (39:05)

Better communication and information with all the medics really. Of course there's the things that Nicci has already contacted from a medical point of view, faster diagnosis and everything else. But think from our point of view it was the lack of communication and really being felt that we're on a limbo. A long time we felt we were on our own.

Liv (39:22)

Yeah, that must have been so, so difficult. And finally, what would you like listeners to take away from this episode, Nicci?

Nicci (39:30)

I think just if you are caring for someone with pancreatic cancer that you be aware of those things that can have a huge impact. So PERT being a big one, if someone is losing weight very quickly and struggling with those symptoms of pancreatic exocrine insufficiency, the sooner that they are started on PERT the better. And we know not everybody is prescribed PERT if they're not on active treatment, but actually it makes a big difference very quickly.

So absolutely familiarise yourself with PERT and what it is and what it does and bear that in mind when you're supporting anyone pancreatic cancer. And the same for type 3c diabetes. These are things that we don't always know very much about because not a huge amount of patients will experience them, but it's really important to be aware of those signs and symptoms. And that's where you can access the information on our website to find out more.

Liv (40:23)

Thank you. And Alison, what would you like listeners to take away?

Alison (40:27)

I'd like this to be more joined up thinking because when we found out what Aiden's diagnosis was, we looked at the symptoms. He'd had them for quite a long time and we'd seen different people and nobody had joined the dots together and come up with a possible explanation. The first time we heard pancreatic cancer was when he was diagnosed. So think the thing for would be to have an overview, to don't just think in your speciality, to think wider and work together more. Greater awareness throughout.

Liv (40:57)

Mm. Yeah, lovely. Thank you so much. And hopefully, hopefully this episode will help in some way in doing that of really kind of spreading the word to as many professionals as possible about how important that is for everyone to be aware. Thank you so much.

And that brings us to the end of the episode. So thank you both so, much for joining us today. Nicci, for sharing so much information about the complexity of pancreatic cancer and the importance of really having the right teams involved at the right time and as early as possible. And Alison, thank you so much for sharing Aiden's story. It's been a privilege to hear about him and we're so, sorry hear about the experience that you've had. It has really powerfully highlighted the human impact that this complexity has on real people's lives. So thank you so much for sharing.

Paul (41:51)

Thank you.

Outro music

Liv (41:52)

You've been listening to the Cancer Professionals Podcast, which is brought to you by Macmillan Cancer Support. If you work in health or social care, visit macmillan.org.uk/learning to find out more about our Learning Hub where you can access free education and training. For links to the resources mentioned, see the episode description.

Paul (42:09)

If you enjoyed this episode, follow us so you don't miss our next conversation. We'll be joined by Judith Neptial, co-founder of From Me To You- The Art of Survival, and Israel Eguaogie from iAssist Northern Ireland to explore how cultural responsiveness transforms cancer care from knowing to doing.

Liv (42:30)

We'd love you to rate our show and share with your colleagues. Get in touch with us by emailing professionalspodcast@macmillan.org.uk. New episodes are released on the first and third Wednesday of each month.

Paul (42:40)

I'm Paul.

Liv (42:41)

And I'm Liv and you've been listening to the Cancer Professionals Podcast by Macmillan Cancer Support.