The Cancer Professionals Podcast

From helpline to lifeline: The power of acute oncology

Episode transcript

(Intro music)

Paul (00:10)

How confident are you in recognising and responding to an oncological emergency when every minute counts?

Naomi (00:17) – clip from episode

Because we're using more and more of these drugs in more sites of cancer, we are having to manage these complications and it can be quite difficult and we need lots of specialist input but for me, this story is about real recognition of Peter knowing something wasn't quite right, phoning in, which was the right thing to do. Phoning back when the symptoms were worsening and us having the ability to bring him straight in to be seen and for our helpline team to recognise that these symptoms were a concern with the treatment that he's received.

Paul (00:51)

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

Carly (00:54)

And I'm Carly 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.

Carly (01:09)

If you enjoy this episode, please subscribe, rate, and share with your colleagues and friends. We'd also 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.

Paul (01:30)

This episode contains conversations about lived experience of cancer and oncological emergencies, which you may find upsetting or triggering. Listener discretion is advised.

(Intro music fades out)

Carly (01:41)

Hello and welcome to the Cancer Professionals podcast. So in this episode today, we will explore a crucial but often overlooked area of cancer care, which is acute oncology. And acute oncology is all about rapid expert responses to cancer related emergencies. So conditions that can be life threatening if not identified and treated quickly. These can be sudden complications caused by treatment, disease, or any new cancer diagnosed as an inpatient. And this specialty plays a vital role in saving lives and preserving quality of life. And you might remember we released an episode on acute oncology last year where we were joined by Donna Monroe and Dr. Verna Lavender. And in this episode, we're very lucky to be joined by two very special guests, Naomi Clatworthy, who is an acute oncology nurse consultant and Peter Cook, who will generously share his personal experience of an oncological emergency known as Triple M which we'll talk about in this episode a bit later.

Welcome Naomi and Peter to the Cancer Professionals podcast. It would be great if we could start with you both just briefly introducing yourselves and telling us a bit about you. Peter, can we start with you?

Peter (03:02)

Yes hello, my name's Peter, I'm 77, obviously retired and now live in North Devon.

Carly (03:09)

Lovely, thank you. And Naomi?

Naomi (03:13)

Hi, I'm Naomi, an acute oncology nurse consultant in North Devon. So I work in the Northern Site, so part of the Royal Devon University NHS Trust, but part of the Northern Site and lead the acute oncology team here. But I'm also a UKONS board member and UKAOS board member as well.

Carly (03:33)

Lovely, thank you. So Naomi, one thing we wanted to start with is asking, could you share a little bit about why now is an important time to talk about acute oncology?

Naomi (03:48)

Yeah, thank you. mean, think every time, all the time is a good time to talk about acute oncology and I think I've been in this specialty for 10 years and it's definitely picked up in pace and awareness and significance of this specialty itself. So I can give you a bit of history if you like about where it's come from, if that's helpful.

Carly (04:07)

Yeah.

Naomi (04:08)

So acute oncology was first used as part of some recommendation, the NCAG recommendations based on the NCEPOD report that looked into deaths within 30 days of chemotherapy treatment. And what it found was that patients that attended acutely unwell were really poorly managed in hospital and also out in the community. So we were giving these patients really horrible treatments that caused lots of nasty side effects then just sort of told to go and sort of manage these with no sort of mechanism for them to contact any specialists to how to manage sort of the side effects. So based on this NCEPOD report, these NCAG recommendations, so National Chemotherapy Advisory Group recommendations were formulated and within them, one of the points were to have a helpline for cancer patients on treatment in place to contact 24/7. So lots of hospitals around the UK have a helpline in place and have done for quite a long time for cancer patients to contact if they have any symptoms or side effects from the treatment that they're receiving. A number of other recommendations that every hospital with an ED department should have an acute oncology service in place. And so they've been developing over time. There is a little bit of variation in terms of how they are set up within each hospital. But every hospital should have an acute oncology service in place. It's vitally important.

So now is a really important time because we're seeing a whole host of new drugs being used. Patients are living for longer with cancer, which is amazing, but also they do have a number of complications that can continue to go on for a long period of time.

And so there needs to be a service to be able to support these patients. So if they do present acutely unwell in hospital, there's a team, a specialist team able

to support them and advise the inpatient teams on how to manage these patients. But also there's a mechanism for patients to contact a helpline really quickly to be assessed by a specialist team that can then point them in the right direction of where to be, whether that's a continuing monitoring on the helpline with these patients or if it's an assessment within a same day emergency care or ambulatory assessment unit or if it's an attendance to the emergency department if that's your pathway. But that mechanism needs to be there for patients to be able to access this support. There's lots going on in acute oncology and I'm sure we'll get into that and talk about it a little bit more within the UK and actually wider internationally as well. It's being seen as a vital subspecialty within cancer and there is a lot more investment now than ever before which is fantastic but we need more and more sort of recognition of how important these services are and so certain areas have had a lot of investment but there may be others across the UK that maybe haven't.

Carly (07:06)

Lovely, thank you. And so can we come over to you, Peter? So of course, the reason that you're here to join us today is to talk a little bit about your experience and share what had happened. So would you be happy to firstly, share a bit about your cancer diagnosis if that's okay, if you're comfortable to do so?

Peter (07:18)

It was just over a couple of years ago I was diagnosed with a tumour on my right kidney which actually turned out to be a grade 4 tumour. So I was told that really there was no option but to remove the kidney. So I was called into Exeter General and about a week later had the operation.

Then after a period of convalescence I was asked to come in and have a CT scan and then to see the oncologist to get the results of that. When I saw the oncologist she confirmed that although the operation had been successful, unfortunately there was still cancer present on some of my lymph nodes. So what was then decided was that really they would start me off on a course of immunotherapy together with some chemo drugs. So I came in and had my first infusion of those in acute. This was the start of my journey with acute really. Yeah, I came in and had my first infusion, went home all fine for a couple of days and after a couple of days I was finding I was getting this chronic pain that came up through my back into my neck and what was getting worse was the fact that I couldn't seem to hold my head up. I was okay if I was laying down but as soon as I got up in the morning as the day went on my head started to drop further

and further and I just couldn't raise it. So I did then phone Acute Hotline. They initially asked me to speak to my GP who basically prescribed painkillers.

They didn't touch it so after a short period of time I did phone acute hotline again and they called me in to see them face to face. I had a series of blood tests and what they confirmed was that after this first course of immunotherapy that my bloods had completely all shot up sort of off the scale and they were a bit worried that I might end up having heart failure.

Carly (09:40)

Gosh.

Peter (09:40)

So really what I had to do was obviously they stopped everything and put me on a course of steroid infusions to try and bring the blood levels down. So I used to come in every so often to the acute and have these infusions. Gradually as my bloods did start to drop they sort of weaned me off a period of time, they weaned me off the infusions and then put me on steroids tablets together with some other drugs.

After a period of time gradually the bloods started to go down to sort of normal levels so then what they did they called me in every fortnight to have blood tests and also asked me to have I think I'm right in saying asked me to have a CT scan and a visit to the oncologist every three months to see what was happening. That's basically what I've been doing over the last two years. Only in that, over the last two years obviously as things have gone back to normal, my fortnightly visits to acute have extended out to once a month. So that's at the moment, that's what I'm doing. I'm coming into acute once a month for my blood test and I'm getting an appointment for a CT scan and to visit the oncologist every three months.

Carly (11:09)

Wow, so let's say lots of support and coming in a lot, lots of regular support.

Peter (11:14)

Well yeah they've obviously ended up like my family, I know them so well.

Carly (11:18)

That's lovely. That's really nice. But it must have been so scary for you when you were, did you say you were at home and then you, that was when you started having the symptoms?

Peter (11:29)

Yeah. Yeah, I was, yeah

Carly (11:31)

And I'm interested to know what sort of timeframe was it between you noticing that you were, know, when you said you couldn't, felt like you couldn't hold your head up, what was the time between then and actually coming in?

Peter (11:44)

Yeah, it was really only after that couple of days. I mean obviously when I was taking the steroids the one thing that didn't go for quite some time was my problem with my head. I had that for quite a while even although my bloods obviously started to come back more to normal levels I still had the problem with my head and I believe what was said to me was that with immunotherapy even only being one dose that could actually last for some time which it did. I'm pleased to say that eventually it did go off. Because that really took, from my point of view, after the operation, all the trauma and the operation, that really was the worst part of my life, trying to live with that all the time, you know. Because you couldn't really go out anywhere or anything because, you know, you felt so bad. I couldn't even, you know, I used to go shopping with my wife and she used to leave me in the car and, you know, go and do the shopping. That's not us, we always did everything together. So, yeah.

Carly (12:36)

Yeah, of course. It sounds really life changing, doesn't it? To not be able to do like you said, the day-to-day things like even be able to go around the shops.

Peter (12:51)

It was.

Carly (12:59)

Naomi, could you talk a little bit from a more clinical perspective about actually what Peter was experiencing and what was happening to him at that time?

Naomi (13:08)

Yeah, so Peter received two drugs. So one was an intravenous infusion that was an immune checkpoint inhibitor. And then it was also receiving another drug, an oral drug, which was a tyrosine kinase inhibitor, which is a targeted therapy. And so he had the infusion and then some tablets to take at home as well. And actually, like Peter described, he actually hadn't had very much, it was post his what we call first cycle and a few days afterwards I think initially phoned the helpline with some I think was described as pain when we've looked back through, looked back through his records to find out exactly what happened but just a bit of pain and so at that point Peter would have been assessed and according to what he was describing in his symptoms, the advice was probably to go and seek further assessment, but with a GP, which is fine. So we use the UKONS triage tool to assess our patients and that is widely used across the UK and has been also translated into other languages. So used internationally. And that is a risk assessment tool that is grading symptoms, green, amber and red. And then from that will allow us to have a specific action. So when we're grading, if a patient's mainly green when we're asking them questions, then it's more sort of advice over the phone and to stay at home and we'll put a few supportive measures in place.

If any of the symptoms trigger an amber, if it's just one, it means that we'll bring them back the next day just to check on this symptom actually and see how things are going. If they score two ambers of the symptoms, that equals a red. And so a red is an assessment. Depending on what they are will depend on where they are directed to. So if it's a red, for example, chest pain, that would go straight to our emergency department. We wouldn't send anywhere else.

If it was a red for say a temperature and maybe another symptom, we would advise exactly to come in as well, but that may vary from place to place. For us, it would be into our assessment area. We have sort of an oncology same day emergency care ability here. So we would bring the patient straight in to us. That might differ again from place to place, but that would be for us. So I think on initial assessment, Peter would have been an amber and as it felt like it was sort of a musculoskeletal type complaint, he was advised to go to his GP and speak to his GP. But would have been for us what we call a call back. So we would always follow those calls up just to make sure that everything is okay. But actually, Peter himself, I think his symptoms were worsening. So he described his not being able to lift his head up from his chest contacted us for further assessment. Even though he's being assessed by a medic, a GP, actually symptoms are worsening, something's not right here. We need to bring him in for further assessment. So like I say, here we have the ability to bring patients straight into us to be assessed, which is what happened with Peter. And so our

acute oncology service here has a number of staff, nurse specialists, advanced clinical practitioners, we also have doctors working in the team as well and so he was able to come in and be assessed by our team which found actually his symptoms were quite concerning and like Peter explained a number of tests were completed and actually the thinking at that time was that unfortunately this was an immune mediated reaction caused by the immunotherapy based on the results that we were seeing. And actually Peter was diagnosed with what we call triple M which is actually a really rare adverse event to treatment. So triple M is myocarditis, which is inflammation of the heart muscle, myositis, inflammation of the skeletal muscles, myasthenia gravis, which is a neurological disorder that can cause this muscle weakness that what he was experiencing. So like I say, this is extremely rare. In fact, it was the first one that we'd actually seen here in our hospital. And so it needs quite rapid treatment and intervention and support. And again, because this is so rare, it's not something that we had ever seen here or in combination seen here. We needed a lot of sort of specialist input. So we know we've got guidelines, we use our UKONS guidelines here, which contain the Clatterbridge immunotherapy guidelines that are widely used. And so straight away we started very high dose steroids with Peter and did admit him as an inpatient for further monitoring because we were really, really concerned about him.

And actually that was the first time that I met Peter because I came in the day after and it was a weekend so we have a seven day service here and I was able to see Peter on the Saturday and that's when I met him for the first time. And so he went on to have, like he's described, sort of what we call a weaning dose of steroids over time but actually Peter also needed some further immunosuppressants, had something called tacrolimus and mycophenolate as well, didn't you? So what these drugs are doing are dampening down the immune response.

The way that immunotherapy works is stimulates the body's immune system to target the cancer cells and hopefully kill them, that's what we want it to do. But unfortunately, a complication that can occur is that we over-stimulate or the body's immune system we've over-stimulated and then starts to unfortunately attack normal healthy cells and tissue that causes this sort of immune response and different complications can happen. So we're now seeing more and more of that in patients, maybe not the severity that Peter had, but yes, because we're using more and more of these drugs in more sites of cancer. We are having to manage these complications and it can be quite difficult and we need lots of specialist input from different areas. But for me, this story is about the real recognition of Peter knowing something wasn't quite right, him phoning in,

which was the right thing to do. Phoning back when the symptoms were worsening and us having the ability to bring him straight in to be seen and for the helpline team to recognise that these symptoms were a concern with the treatment that he's received. And I'm sure Peter had a pre-treatment education session before he started treatment that would have explained to him what he needed to do, who he needed to contact and in what circumstances.

Peter (20:13)

Yeah, that's right. Yeah, I did.

Naomi & Peter (20:26)

And so that's critically important as well. I do say this, that that needs to be, it's so vital that those sessions are completed before patients start treatment so they know exactly what they're looking out for and who to contact in case they need to.

Carly (20:30)

Yeah, and that's so important there, such an important takeaway healthcare professionals know to ensure that the people that they're supporting also know how to do that so that people like you, Peter, were able to call in and get the rapid response that you needed.

Naomi & Peter (20:47)

Yeah, that's right.

Carly (20:49)

When we're talking about that, being able to respond to this in a really quick and rapid way, how did that timely care that Peter received, if this is okay to touch on, impact his recovery?

Naomi (21:04)

I mean hugely. This would have been an oncological emergency that I'm describing and we could have had a completely different outcome, I'll be very honest, if we hadn't started treatment so quickly with Peter and that assessment and recognition from the team that reviewed him here on the unit had within their mindset the differentials, the different things that could be going on with Peter and actually for someone to pick up and recognise that actually these investigations need to be completed to identify what's going on and I think with standard treatments that we were using previously and sort of standard investigations and blood tests actually probably that the normal blood set that

we would do usually when patients come in a little bit unwell probably wouldn't have picked up the issues that Peter had actually because what we were testing for were these cardiac enzymes, things that would pick up muscle damage. That's not in a routine set of bloods. So that history taking, knowing what treatment Peter's received was vitally important.

I suppose seeing him being seen by a specialist team actually was key because actually I suppose if you've entered the emergency department, those sorts of things might not have been done as far up the top of the list as everything else. I think they would have got there, but maybe not as quickly as we would. And so I think that's why it's so important to have a specialist team involved. And I think if we generally see patients, the highest number of complications and reactions occur from these treatments within the first six months. That's what we generally see. However, people can have reactions to these treatments months, if not years after they've received the treatment and so that's why it's vitally important that if patients are having concerning symptoms, anything out of the ordinary, that they can call in and speak to a team for further investigations and assessment.

I've had situations before where a patient who nearly a year out of treatment had quite a severe rash and actually it was caused by his immunotherapy that he'd had a year previously and so he required steroids and treatment for a period of time. So I think even after patients have almost, you some of our patients are discharged, then they need to know that actually there could be a reaction a bit later on and to know to contact us and it might be that we go no it's fine don't worry about it we'll bring you in we'll assess you and no it's fine you know carry on but you know it's worth it's worth the teams being asked the question but of course not everywhere has the same resource unfortunately and so again I would say you need to know what's available within your area and local pathways that are in place and this is why we are trying to raise awareness about acute oncology and the importance of the services and that investment is needed in this speciality for patients.

Carly (24:14)

Yeah, yeah. And that experience you shared, Peter, just brings it to life perfectly how important and how vital it is, this service. So thank you. Thank you so much for sharing.

Paul (24:28)

Peter, if I could just ask a question, kind of, you know, after listening to your story of what happened, in your experience of using this service, what made the biggest difference to you?

Peter (24:43)

Basically being able to speak to people that understood what I was talking about. mean obviously you can only go so far with a GP, GP is fine, but as my GP said to me, he said a lot of this, he said I don't understand it because it's so specialist. Obviously that is the main thing really, that they understood what I was saying and were able to as Naomi said, react to it so rapidly really because I'm not sure what would have happened if they hadn't done that to be honest with you.

Paul (25:21)

Naomi, just coming back to you, I know you've touched on a little bit about the oncology services already in some other things you've said. Can you perhaps say a little bit more about the different service models that exist around the UK?

Naomi (25:36)

Yeah, no, of course. we started the service here in 2015 with two part-time nurses working five days a week. Skip forward 10 years, and we have nearly 20 staff now in our team covering a seven-day service. We manage the helpline for patients, we look after all the in-patients. So we're in a small district general hospital in Barnstaple. We don't have oncology and hematology wards, in-patient wards. So if a patient's admitted, they actually are anywhere in the hospital. But we see them every day. So our acute oncology team will also go and complete in-patient ward reviews and support the teams looking after them in an advisory capacity, but very fully involved in their sort of treatment and management. And so we have a number of patients that we review every day as well. And then we also have what I've described, this same-day emergency care model, where we have the ability to bring patients in here to be seen, assessed very quickly, hopefully treat, formulate a plan of care, and then hopefully discharge home. So actually we want to manage these patients as an outpatient and not be admitted into hospital, so we're preventing hospital admissions. And we know and this isn't just here it's around the country as well actually cancer patients are more likely to be admitted into hospital if they go to an emergency department than if they're seen by a specialist team and so we looked at our data for last year and in all the patients that we see over the year we admit six percent of the patients that we see. That's very, very low actually. So a lot of patients we see and we're seeing over 150 a month in that model, we don't

admit very many at all. If we do admit, then we need to admit them. And what's great about this hospital is we're able to sort of have admitting rights onto a ward. So patients, if they do need to be admitted, they will go straight to award bed, is fantastic and again I know not everyone is able to do that but we are here which is great for our patients.

Our service also covers this non-specific symptom pathway and our cancer of unknown primary team, malignancy of unknown origin team which is patients that are admitted into hospital acutely unwell but then are found to have a cancer during that hospital admission and now as the sort of diagnostics takes place, we may find the site of cancer, but we also may not. So we may take tissue samples and still not be able to necessarily find where the primary site of cancer is. And so that's called a cancer of unknown primary. And so our team support all of that work as well. And then we also look after patients on immunotherapy. So these immune checkpoint inhibitors, which Peter received, our team also look after that group of patients.

So it sounds like we've a huge team but we cover a lot here and not all acute oncology services necessarily will cover all of that but we do here and we're a really valued team I would say in the hospital and that's probably how we've been able to successfully not only with our data showing the activity but also with experience from patients being so you know, so positively, but then also staff as well, recognising how valuable our input is and the expertise. You know, I have all of the staff in our team, Peter will say are amazing. You know, really highly skilled and knowledgeable, I have to say. So, and everyone's actually been here for quite a long time. I don't have many people that leave the team because they love working within this area.

Peter (29:15)

I've been coming for over two years as I say and it's the same people that I can see so they've been here probably longer than that

Paul Middleton (29:23)

Again, just thinking of your experience, how important is that for you that, you know, those people, the people there are the same people that you recognise and you have spoken to before. How important is that for you?

Peter (29:38)

Yes, it makes such a difference that you're seeing the same people all the time and obviously you get to know them but you you're comfortable with them. You can ask them anything and you know that you won't get fobbed off. You'll get

an answer, hopefully the right answer. You'll get an answer. Yeah, it means everything. means everything.

Carly (29:56)

Yeah.

Naomi (29:58)

We have fantastic... I've talked about the nurse specialist and the advanced clinical practitioners, but we have assisted practitioners as well in our team and also inpatient support worker actually, but they actually deal a lot with Peter, liaising with him, reviewing his symptoms, triage him, more than probably our registered nurses now. And so we have a really sort of diverse varied sort of team and the members within it but all really vital to ensuring that we're monitoring and safely triaging Peter.

Peter (30:31)

Yeah I mean every time I have my blood literally within a day or so I get a call from acute obviously just to let me know but hopefully everything's sort of okay going okay

Paul Middleton (30:42)

And we are aware, you know, there are variations of experience for people around the country. And Naomi, you mentioned the team have gone from two to 20. I mean, is that due to the increase in demand or because the team's remit has grown?

Naomi (30:58)

We do have a large remit, but I think it is demand. Absolutely. think so the data we've collected demonstrates the activity. And you know, we've always tried to here have in our mindset is how can we make this better for our patients? So if our cancer patients are going to have these side effects and treatment or complications, we want the best pathway for them. And so with all our thinking as we've looked at sort service development, that's been our main sort of question that we always ask, how can we make this better?

So we had an issue with patients that suffer unfortunately with abdominal ascites, so a buildup of fluid and that needs to be drained because it's very uncomfortable for patients. so years ago, this was quite a complex pathway. The patients would either have to be admitted into hospital or they'd have to travel an hour and a half to another hospital to have that procedure. So really poor

pathway for these patients. So actually we then were like what can we do and so looked around the country and actually there were other sites that were nurse-led in that the nurses were completing these procedures called a paracentesis. And so we implemented that here. So we now have a nurse-led paracentesis service so if patients do have this buildup of fluid rather than being admitted for days which is what was happening or they were waiting so that was so uncomfortable that they then have to come in as an emergency and have the procedure. We now have the ability to bring them in in a day. So they get scanned, we put the drain in and then they're drained and then they go home on the same day, which has absolutely transformed that pathway for the patients and improved the experience. It's better and they don't have to stay in hospital, so everyone's sort of happy. But that's an example of what we've been able to do here and that's why we have so many staff. But like you say, it's not the same everywhere. And I hear that all the time. I was with our South West group last week and you know that's probably the most frustrating thing is there's such limited resource in certain in certain places and investment because actually the potential to really develop these services and prove things for patients is there but it's just not put in place. So some services, acute oncology services don't manage the helpline actually it's managed by different teams that might be a ward teams, might be the chemotherapy units are picking up the calls in between their patients, which isn't ideal.

Part of UKAOS so that's the United Kingdom Acute Oncology Society have with lots of different people have been doing a survey, a four-nation hotline survey, looking at what's in place and getting feedback from all the teams. And then hopefully we've just produced a report, but we're hoping to put out some recommendations of actually how these helplines specifically should look because there is variation even in just the helplines, there isn't consistent services. Some are gold standard amazingly run very well but others maybe not so and need a bit of help and support and investment and actually we're hoping that by providing these recommendations of what should be in place for patients this will help support and then further investment in so these helplines are consistent across you know so no matter where you live actually it should be the same you should have the same response like you know Peter had the same ability, the recognition and we've got the standardisation in terms of the triage tool that's used and that's fantastic and we created online e-learning training. UKONS created this with collaboration with UKAOS. We had some funding from a great source that was able to put these e-learning modules together for staff. So everyone is trained and there's the standardised training, which is fantastic. So we have the tool and we have the training, but it is inconsistent in its

approach. So hopefully from this review, that will support investment and standardisation.

(Background music fades in)

Paul (35:01)

Here's Leigh to tell us a bit more about one of those e-learning courses which are available on Macmillan's Learning Hub.

Leigh (35:09)

Do you want to learn more about acute oncology? Macmillan's Level 1 acute oncology e-learning module is designed to give you the core knowledge required to recognise, respond to and support people experiencing acute symptoms caused by cancer or its treatment. Whether you're a call handler, healthcare student, community support worker or a clinician in primary or secondary care, this course is for you. You'll learn how to spot oncology emergencies, understand common symptoms and know when and how to act, all within your role. So if you want to build confidence and deliver safer, more responsive cancer care, start today.

If you have a Learning Hub account, just search Level 1 Acute Oncology or see the episode description to find out how to sign up to the Learning Hub for free today.

Paul (35:56)

Thanks, Leigh. Let's get back to the conversation.

(Background music fades out)

Paul (36:01)

I was just wondering, are there any kind of common misconceptions around acute oncology among healthcare professionals that you can perhaps unpick for us a little bit?

Naomi (36:16)

I think the importance and significance of what we do isn't fully appreciated and I think especially with the helpline about actually it prevents escalation of

symptoms and prevents admissions and is so vital. I mean patients report it, have described it to us like a lifeline actually. We call it a helpline and there's lots of different names for them. We found that in the report as well but it's a lifeline for patients because we're so responsive and we will try and help as much as we can with whatever it is that patients are calling in with. And when it's so difficult, think sometimes for patients to access GPs, we know that we often get a lot of calls and we're like, I'm not entirely sure this is necessarily for us. But I don't really care because I just think actually there's a patient there that needs help and needs support and advice and we can give that to them.

Paul (37:13)

Could you give us an example of somebody you've spoken to on the helpline or the type of questions that come in?

Naomi (37:23)

Yeah, so I had a patient recently that contacted the helpline and his main symptom actually was fatigue and nothing really else but just sort of fatigue and he'd had a PICC line inserted so that's a line that's put into your arm and we're able to give chemotherapy then through this line and he said oh we've got a little blister at the top of the dressing. I thought it sounds like you've probably had a bit of an allergic reaction it's not uncommon to this bit of line. To be honest he hadn't actually started treatment yet he was due to start treatment and hadn't but was phoning because he was a lot more pertinent.

So I wasn't concerned about a complication from his treatment actually but something didn't quite sit right and I said well you've had this PICC I've recently put in is it red is it you know sore? He said it's a bit sore and it's been bruised since I put it in again not particularly that concerning because it can hurt when they go in a little bit and be a little bit bruised but so I as it's red anything, so I've just got this blister on the top of the foot I think you know what do we do I could bring come on in and that's let's have a look and see and when he actually came in there was a green puss pouring from the PICC line site. I was like, my goodness me. This isn't normal. And he said, ~ I thought it was normal. And I said, no, that's not normal actually. ~

Paul (38:43)

Gosh.

Carly (38:44)

Gosh.

Naomi (39:05)

And so we then had to, we took lots of swabs and blood cultures and we took some blood from his line from his arm just to check and make sure the infection that we're assuming he has, which I think he has, is within his bloodstream. Unfortunately it was within his bloodstream because those blood cultures came back as positive and had a very very nasty bug within the blood and required lots of antibiotics and removal of the PICC line unfortunately.

He was fortunately very well but could have been very unwell and I suppose it was just I mentioned it to my team and I said you know it's really interesting that this person only presented really with fatigue that's why he was calling but actually something you know I thought I better just bring him in and have a look and actually if I hadn't that could have been a completely different story. Now he probably would have become more and more well and then eventually come in but at what point? And how much longer would he have needed an inpatient stay or complications and obviously we're talking now this is delaying his treatment from starting as well but he needs for his cancer.

So I suppose it was just an example of that triage call where you're not too sure but actually that ability to be able to bring somebody in to see and this is why it's so valuable having these assessment units where you have the ability to be able to do that is so important that patients can phone in with, we get quite a lot of temperatures, so patients if they have temperature, we always bring them into us, because obviously we're concerned, especially for chemotherapy, of what we call neutropenic sepsis. So we know blood counts are affected when patients have chemo, especially during the first few days, first couple of weeks or two weeks and they can become neutropenic and neutrophils are a type of white cell which help fight infection and when you don't have those on board it can be quite difficult to get on top of that infection then complications can occur and then you can develop sepsis which is your body's response to an overriding infection in the body and so combined together being neutropenic and septic is not good.

And so we need to start antibiotics very quickly with these patients and so that would be something that we would pick up when we're triaging patients if they've got a temperature we would bring them in. We look after neutropenic sepsis patients basically or patients that were concerned about having this. Also we might get patient phone in with pain especially back pain we're also quite concerned about that something we call a red flag if they've got known disease or especially disease in the bones because we're concerned about metastatic spinal cord compression which is where the disease can unfortunately push into

the spinal cord and symptoms are pain, increased pain or neurology so tingling, numbness in the limbs or in the bottom, loss of sort of bladder or bowel are all concerning signs and what we call red flags for metastatic spinal cord. So those are just a few examples of what might phone in.

Paul (42:10)

If there are red flags, who can kind of refer, i.e. would the patient re-ring in themselves as you've kind of mentioned, or would a GP advise a patient to ring the helpline?

Naomi (42:22)

So we do have a UKONS primary care tool developed with Macmillan for healthcare professionals within the community, within primary care that does then prompt the reviewer to then tell the patient or themselves to contact the helpline. So that's been around for a few years. We're just reviewing it at the moment and updating it based on the fact that we've just updated our UKONS triage tool that we use in secondary care. So that's ongoing, but that would prompt healthcare professionals in primary care to contact the helpline with symptoms. And again, it's got a list of symptoms that patient may present with and then they're graded. And then according to how they're graded, will then initiate a response to then refer into the helpline. There's a very low threshold for referral in actually, but that's good. We want to know about it and like I say the symptoms sometimes can be so difficult to sort of work out that actually it does need us sort of specialists to be able to unpick slightly and yeah bring in for further assessment if needs be which is vital.

Carly (43:28)

So as you know, we have our regular feature, which are three questions which we ask of all of our guests. So the first question is, if you could go back in time to when you first received your cancer diagnosis, Peter, what piece of advice would you give yourself?

Peter (43:47)

Yeah, if I go back to the day that I was first diagnosed with stage 4 kidney cancer, I would tell myself this, breathe, don't let fear take over. You are stronger than you think and you will face this with more courage than you ever imagined. In fact my wife says I'm the bravest person she ever met, I can't totally agree with that but anyway. Take each day as it comes, lean on those who love you and never lose hope. Even on the hardest of days, life will change but it's still yours to live to the full. Trust yourself, you will face this with grace and grit.

Carly (44:31)

That was lovely, thank you. And Naomi, if you could go back in time to the start of your career, what piece of advice would you give yourself?

Naomi (44:42)

Yeah, probably a few things. think lots of people comment to you about what to do and I think it's probably don't listen to others, especially people that say you need to have this or need to have that or a certain amount of experience before you're able to move on to a new role and do this and do that and I think I was quite conscious of that but actually if you think you've got the skill set to be able to do something and also I think if you've got a passion for a certain area just go for it.

Carly (44:09)

That's great advice and actually great advice for any profession as well. So thank you.

So the second question is, what change would you like to see to improve the lives of people living with cancer?

Peter (45:21)

So if I could change one thing to improve the lives of people living with cancer, it would be to ensure that no one faces it feeling alone or unheard. Beyond medical treatment, people need time, compassion and real human connection. Support that treats the person, not just the disease. I would want faster diagnosis, easier access to cutting edge treatments and better emotional and mental health support systems for both patients and their immediate family. Everyone deserves dignity, clarity and hope from the moment they hear the word cancer.

Carly (46:01)

Lovely, thank you. And Naomi, what change would you like to see to improve the lives of people living with cancer?

Naomi (46:10)

Yeah, I mean, I feel like I should say more investment in acute oncology recognition of what acute oncology is. But actually for me, it's more supportive services. That's what I'd like to see. So we've got a great cancer and wellbeing unit here, Fern Centre, that has been so beneficial for patients. Lots of support services there. Lots of complementary therapies, access to counselling, that

psychological support. Which actually I think is really under invested and actually really does help people living with cancer, just as much as our side of things with the treatment, but actually that part is so important and that sort of personalised care aspect is really under resourced and so I think I'd like to see more support services in place for patients.

Carly (47:01)

Yeah, absolutely. And that really links into what you said, Peter, isn't it, about it goes beyond that medical treatment. It's about seeing that person as an individual and supporting them in lots of other ways in addition to that.

And so the last question is, what would you like listeners to take away from this episode? Peter, we'll start with you.

Peter (47:22)

Right, what I was thinking was that I want listeners to take away that behind every cancer diagnosis there is a person who still lives, loves and inspires and even in the hardest of times there is resilience and hope.

Carly (47:39)

Yep, thank you. Definitely not gonna cry again. And Naomi?

Naomi (47:44)

I want people to know about acute oncology so if you didn't know about it hopefully you've known a little bit more and if you don't know your local service hopefully you're going to find out a little bit more about it and ask questions about what is available within your area and then it's everyone's business so everyone should know about acute oncology actually. It crosses multiple specialities now in terms of who we're reaching out to and having support from with various sort of complications. So if you don't know about it, go out and ask the question and hopefully today we've given a little bit more of an idea of what acute oncology is like here for us.

(Outro music fades in)

Paul (48:19)

Naomi and Peter, thank you so much for joining us today. Your insights and experiences have helped bring acute oncology to life in a way that's both powerful and practical. And Peter, a huge thank you for being so honest with us today and to help us understand how rapid response can make such a

difference. So again, Naomi and Peter it's been a real privilege for us to have you on the podcast today. Thank you.

Peter (48:48)

Thank you.

Naomi (48:49)

Thank you.

Carly (48:52)

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 (49:13)

If you enjoyed this episode, follow us so you don't miss our next conversation where we'll be talking about menopause and cancer with Dani Binnington, the Founder of Menopause and Cancer and best-selling author of "Navigating Menopause After Cancer" and Professor Richard Simcock, Chief Medical Officer at Macmillan and Consultant Clinical Oncologist, to help us better understand this topic.

Carly (49:38)

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Paul (49:53)

I'm Paul

Carly (59:54)

And I'm Carly and you have been listening to The Cancer Professionals podcast by Macmillan Cancer Support.