

Special rules: Helping more people access financial support at end of life

Liv (00:09)

Why should healthcare professionals see special rules as more than a benefits issue and as an important part of holistic end of life care?

Ash Lillis (00:17)

We have this amazing thing that we can do for people. And we often feel quite powerless when someone has an incurable disease. And this is something so positive and enabling

Liv (00:27)

Hello, I'm Liv and my pronouns are she, her.

Emma (00:30)

And I'm Emma 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, sharing practical advice, clinical insights and real experiences to help you support people living with cancer.

Liv (00:46)

If you enjoyed 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 completing the short survey linked in the episode description or by emailing [professionalspodcast at Macmillan.org.uk](mailto:professionalspodcast@Macmillan.org.uk)

Emma (01:04)

Do you know about Macmillan membership? If you haven't heard, Macmillan membership has been designed to support professionals at every stage of your cancer learning journey. Whether you're a specialist working directly with people living with cancer or a member of the wider workforce who encounter cancer as part of your role, the membership provides access to a growing range of resources, learning opportunities, professional networks and practical tools designed to build capability and confidence. To find out more about membership, visit membership.mcmillan.org.uk You can also find the link in the episode description.

Emma (01:39)

This episode contains conversations about life-limiting illness and end of life which you may find upsetting or triggering. Listener discretion is advised.

Liv (01:49)

Just a flag before we get into the episode, throughout the conversation, you'll hear us refer to the special rules for end of life. These are the arrangements used in England, Wales and Northern Ireland. While Scotland operates a separate system called Special Rules for Terminal Illness, our conversation is still relevant to professionals working across all four nations of the UK.

Liv (02:07)

Hello and welcome to the Cancer Professionals Podcast. New research funded by Marie Curie and led by researchers at King's College London has highlighted a concerning gap in access to

financial support for people approaching the end of life. More than one in three people who die from a life-limiting illness in England and Wales don't receive the benefits they would be eligible for under special rules for end of life.

Inspired by this important research and the policy work that's followed, this episode explores why these missed opportunities occur and what professionals supporting people with cancer can do to help address them. Joining us are Ash Lillis, a National Clinical Advisor at Macmillan, and Steve Marshall, a specialist palliative care social worker. Can we start by asking you both to introduce yourselves please and your connection to the topic. Ash, can I come to you first?

Ash Lillis (02:51)

Sure, thanks Liv. I'm Ash Lillis. I am a doctor working as a consultant in acute medicine, four days a week in North London. So that means I run the admission wards for people who become acutely unwell with all sorts of diseases, including cancer. And I've been working at Macmillan for nearly 10 years as a clinical advisor, really focusing on the experience of people with cancer when they get acutely unwell.

A lot of times I'm meeting people who are in their last year of life and I'm recognising that we're not so good at exploring that with patients and that they might be missing out on non-means tested benefits that could make a huge difference to that valuable time they've got.

Liv (03:34)

Thank you. And Steve?

Steve Marshall (03:37)

My name is Steve Marshall. I'm a palliative care social worker. I work at King's College Hospital in South London.

and I've been doing palliative care social work for about 30 years and one of the things I've done over the years as part of my role is to support people accessing benefits and helping with their finances in general. And I also, in my current role, am connected to College London through the Cecily Saunders Institute where I'm based and what happened was over lunch one day I was talking to some academics and saying I wasn't really sure who had access to the special rules and whether there was any consistency about who we do SR1 forms for and that's where the research that we're going to talk about came from and we were able to put together a bid and Marie Curie kindly funded the research and that gets us to today.

Liv (04:29)

Yeah, thank you so much and thank you both for joining us. as we've mentioned, we're here today to talk about special rules and SR1s. Steve, can you firstly tell us what special rules are?

Steve Marshall (04:39)

Yeah, they are basically a fast track to benefits for somebody who is in the last 12 months of their life. And to generate that fast track, a clinician, a CNS or a medical professional has to complete an SR1 form and send that into the DWP. And once the clinician has done that, that then enables the patient or would support from their family or would support from a benefits advisor to actually access increased benefits. So in the case of people under state pension age,

would be personal independence payment and for those over state pension age that would be attendance allowance and it's a significant amount of money for people. PIP personal independence payment is a £194 a week and it's not means tested so people can still be working, it won't affect their pension, it's £114 a week currently for attendance allowance and it's just a fast track way of people accessing those benefits. They don't go into the same pool as other people applying for the same benefits. They kind of jump to the front of the queue. I support people with that all the time and in my experience they often have that benefit in their account within two to three weeks of having made the application. So it is really quick way of them accessing it.

Liv (06:00)

Brilliant and yeah that amount of money as well sounds like it could make a huge impact to and really help people. And why were special rules introduced?

Steve Marshall (06:10)

Well, I think special rules were introduced even before my time. And it was the Association of Palliative Care Social Workers lobbied because unfortunately people who were eligible for attendance allowance or PIP were dying before they actually received the benefit because they went into the same system as everybody else. So there needed to be a way of actually highlighting those people who really needed to be fast tracked for that benefit. that's when the special rules were created but over 30 years ago.

Liv (06:40)

Yeah, brilliant. And you mentioned that for a lot of people that means they'd get those payments within two to three weeks. Why is that shorter timeframe so important when somebody is facing a life limiting illness?

Steve Marshall (06:52)

Well, first of all, think I hear anecdotally that, you know, if you're applying for personal independence payment or attendance allowance outside of the special ward, so if you have a disability, that can take six to 12 months to be processed. So a lot of our patients don't actually have the benefit of that six to 12 months to make those applications. And also just being unwell is expensive and having cancer is expensive. So it can really help with people's quality of life at the end of their life. just very simple things like, people often need to have the heating on all the time because they're cold because of the treatment that they're having or just because of their illness. They might need to have new clothes because, the clothes they were wearing previously don't fit them anymore because they've lost weight. often people are expected to come back into hospital for outpatient appointments and things like that.

Having a attendance allowance or PIP can really, really make a big difference. just to cite an example, I have a friend who has recently just had breast cancer treatment, which she's come through successfully, so she wasn't under the special rules. She had 85 appointments throughout her cancer journey, and a lot of those appointments weren't near to home, so she had to travel huge distances for chemotherapy or just to see a surgeon and then combined with that, often people's income may be reduced because, particularly younger people, because of their illness and if they don't have statutory sick pay. So PIP and attendance allowance can make a huge difference to people at a really difficult time in their life.

Liv (08:19)

Yeah, and absolutely really relieve some of that pressure on them. And Ash, in your role and from your experience, what difference can access to this support make for the people you support?

Ash Lillis (08:29)

Well, what I would say is that I often are meeting people who are acutely unwell. So a crisis has happened, they've ended up in hospital. Sometimes that's because they've had a new diagnosis of cancer or heart failure or a degenerative neurological disorder and absolutely everything in their life has been turned upside down by this diagnosis period. I've met people who were working one week and then have a serious and incurable diagnosis the next week and one of the things that people think about immediately is how am I going to make ends meet? It's not often what's going to happen to me, my medical needs, it's how am going to look after the people that I care for, how am going to get to work and get paid. So there's something about being able to offer something and say, this is not hopeless, this is not something that you have to worry about and go through six to 12 months of waiting and wanting something we can do as healthcare professionals to help you in a period that is really, really difficult. And I would say that we could do a lot better in thinking about those financial needs when we meet people who get a diagnosis as a healthcare professional. We don't like asking people about finances because we don't know what to say about it. We know what to say about your disease or what symptoms you might have.

So we could offer them some support, but we don't feel confident in talking to people about finances. And this could be something that could make those conversations just a little bit easier in saying there is something that we can do to help.

Liv (10:15)

Thank you, yeah, and that brings us quite nicely, I think, on to talking a bit more about the research that you were involved in, Steve. So you mentioned kind of how it came about. Can you tell us bit more about the research that you were involved in and what were some of the key findings that came out of it?

Steve Marshall (10:31)

Absolutely. So there were two strands. There was a qualitative strand and a quantitative strand. So the Qual strand I worked on particularly, and we interviewed patients and family members about the experience of applying for benefits. And we also did some focus group with healthcare professionals. And then the other side of the, and bearing in mind I'm not a quantitative researcher, so we'll have to, I'll have to explain this in a way that I understand. So apologies for those people who understand stats.

We got data from the ONS and were able to look at people when they died, what they died from, and seeing whether or not they were getting benefits, what benefits they were getting at the end of life. We took out people who died from traumatic or sudden deaths, because obviously that would be, you wouldn't expect them necessarily to have a attendance allowance or PIP. However, we were looking at people with chronic illnesses. And one of the main

outcomes certainly from the qualitative work was that understanding of healthcare professionals, their understanding of the special rules was quite limited or there was some preconceptions, misunderstandings about the special rules and there was some hesitancy about applying them to their patients and then what was interesting about the quant work was the diseases that were particularly, and I was very surprised Approximately about 90 % of people with a neurological condition, so MND or those sorts of conditions were getting benefits at the end of life, were getting PIP attendance allowance. then, but down the other end of the spectrum, around about 40 % was people with HIV and people with liver disease. And cancer came somewhere in between. Cancer was about 60%. So only 60 % of people who died from cancer were getting PIP or attendance allowance. And I was really surprised by that. And I'd be interesting to know what you think about this Ash, because I always think in my work, so I work in a hospital where palliative care, so we work with people with cancer also with other conditions only about 35 % of our patients have cancer. I think it's generally easier to prognosticate to say how long someone has to live in cancer there and that was my assumption was that the cancers would be up there at the 90 % end but in fact they weren't they're about around about 60 % so I was genuinely very surprised by that.

Ash Lillis (12:45)

It was interesting because when I first saw the results of the Marie Curie research, I probably wasn't surprised, but that's because I kind of live in this world of talking about prognosis and oncology specifically and why it's difficult. So prognostication is one of the trickiest things to do. So that was a health care professional saying, I think this is about how long I think you might live. We are not very good at it so there's plenty of research that says that healthcare professionals are very good at predicting someone who might die in the next week but less so within the next months and less so and less so all the way up to a year. So we also feel really uncomfortable about saying something that isn't true so we kind of go well I'm not I'm not sure so I'll just err on the side of not saying anything.

And the thing about cancer is when you think about prognostication, there's kind of three different ways of chronic diseases that give you an idea on what the trajectory of the disease is. So there's some that are much more straightforward to prognosticate. And one of those is degenerative neurological disorders. So the majority of people with motor neurone disease, you will be able to relatively accurately predict that they will die within 12 months with cancer, you probably can do that more effectively because of the stepwise progression of lot of cancers.

But with new treatments and with our discomfort in saying, there isn't more treatment for you. We're not good at saying that. You know, that classic thing that we often hear in cancer is how long have I got is that question to a, to a healthcare professional. And that healthcare professional says, well, I'm not sure it depends how you respond to treatment. But actually I've done some research and people who are sick with cancer and end up in a hospital bed, no matter the stage of their treatment, what treatment they're having, their age, their comorbidities, they're very, very sick and about 70 % of people who have an acute cancer admission will have died within 12 months. But when I went out to oncologists, so the people who are talking to patients about cancer and said, what do you think is the average mortality, the length that someone will survive after a cancer admission to hospital, nearly all of the healthcare professionals I talked to who guessed that over 50 % of them would be alive at 12 months. In fact, most of them said 70 % of them would be alive at 12 months rather than 70 % of them would have died. And maybe that's a level of optimism if you work within a treatment

focused specialty. And maybe it's about the way we talk generally and hoping that, we will do better and we don't want to give up hope.

But I would say that this research is really clearly saying us that there's an urgent need to have those conversations with people because they might be missing out.

Steve Marshall (15:47)

Yeah, If I could just come in there as well, Ash, is that I think the DWP, the Department of Work and Pensions, who make the special rules, I think they understand that it can be very difficult to prognosticate. And for that reason, the criteria that they use is, as you as a healthcare professional, is very clear, would you be surprised if this person died in the next 12 months? And that's it. And they're not asking for anything more specific.

Yes, today you might say, well, actually, yes, I wouldn't be surprised if this person died in 12 months, but maybe in six months time, things might have changed and they might have had some treatments and whatever. the other thing is that they don't punish people and they don't punish clinicians if they get it wrong. It's really very much, would you be surprised today if your patient died in the next 12 months? And if you answer no to that, then they expect you to do an SR1 Form. And that's as simple as it is and that's really a message that we're very keen to get across from this research is that from the focus groups that we did was that people were really worried about filling in an SR1 form because they knew that it was hard to really be sure about the prognosis that someone had. But then when I went back to them and said, well, actually, would you be surprised? They were like, no. So then I was like, well, then you do an SR1 form.

Ash Lillis (17:06)

And isn't it great to have something that's so straightforward in terms

Steve Marshall (17:09)

Yeah.

Ash Lillis (17:10)

of a question. So this isn't a question that DWP have plucked out of the air. The surprise question is a really well validated tool for healthcare professionals to say start thinking about future care planning and what are the other needs, what are the goals of treatment. If you answer yes to the surprise question would you be surprised if your patient died in the next 12 months? That is giving people permission to say it's not wrong if they survive. You don't have to be absolutely certain. It's, on the odds of my experience and seeing a lot of people with a lot of diseases, would I be surprised? No, okay, well let's go forward with the process.

Steve Marshall (17:58)

And I think...The other thing, one of the other things that came out of the discussions we had in the focus groups was that people thought that they would, they would be come back if they got it wrong. So if that patient 12 months in a day, they would get in trouble. But the other thing that people were worried about was that actually it might in some way hinder that patient's income and hinder their benefits. That if they as a clinician got that wrong and then they lived over 12 months, that would then be taken away from them or somebody would get in trouble about that. And that's not the case at all. In fact, the special rules cases are only reviewed after three years. And I've been doing this for a long time, And certainly in my current job, I've only had two,

and we do lots of these I've only ever had two that have come back after the three years where the DWP has come back to us and said, this person is still alive and is still getting its benefit under the special rules. What's your thoughts about that? And in both cases, I spoke to the clinician involved and they both said I wouldn't be surprised if that person died in the next 12 months and so we just had another SR1 form and it was as simple as that but no there was no comeback nobody got in trouble. The DWP I think does understand that it's hard to be accurate and then sympathetic to that.

Emma (19:09)

And that's really reassuring to hear that there isn't that comeback, that you can use that judgment to really support yourself as a professional, to think about initiating those conversations, to think about whether somebody would be eligible and benefit from completing a special rules. And I think you've really highlighted between you both those challenges that clinicians can feel in identifying whether a person may die within 12 months and how comfortable somebody can feel making that judgment. And we've talked a little bit about the barriers in terms of asking yourself those questions. And I just wondered whether... in your experiences, what are those biggest barriers that professionals may experience or feel that prevent eligible people from accessing support through the special rules process? And Ash, I wondered whether in your experience and with the clinical work you do, whether you had some thoughts on that.

Ash Lillis (20:08)

It's a societal issue we feel pretty uncomfortable with talking about death and dying and that is kind of where all of this comes from because this conversation is linked to the fact that somebody is so unwell that they are probably coming to the end of their life and

We all struggle with having those conversations. People call them difficult conversations. People call them challenging conversations. But actually, probably for me and Steve, as people who work in acute and palliative care, it's actually one of the parts of the job that I really enjoy because you can really change and empower people to think about what the next months and years might look like by giving them this information. I often say it's not my prognosis, it's a patient's prognosis and we can share uncertainty with them. But lots of healthcare professionals, we don't like to be uncertain, we don't like to sit in that discomfort, we like to offer answers to people and this is one of the areas where there's no easy answers. So one of the barriers is difficulty in sharing uncertainty with people and not wanting to kind of...

I get very, I keep thinking about people talking about taking away hope is one of the themes that you hear from people who have said, I wasn't sure if I could have that conversation. And actually most people, especially people who have got a diagnosis of cancer, especially a cancer that may be treatable, but not curable, they've thought about death and dying. They've thought about what that looks like and we just have to give them more space.

What I would say is we often need a push and a pull to do something in, well in life, but in medicine especially. And for a lot of professionals, there isn't enough of a push to have a difficult conversation about prognosis and end of life, because actually it just feels like it's, you know, it's difficult. I'm not sure what it will change, but here we've got a really clear push to do it. Because if you don't have a conversation with someone, even in the highest possible terms about the fact you wouldn't be surprised if they died within 12 months, they're gonna lose out on really important benefits and finances, especially in the current economic climate for lots of

my patients who are living in inner city in cost of living crisis. This is something they're gonna miss out on if you don't have a conversation. And I did some research 2024 with Macmillan around some of the barriers, especially around people who've been sick enough to be in hospital with cancer. And we asked a focus group of oncologists, registrars and consultant oncologists. And then we asked a focus group of generalists, physicians, GPs, nurse consultants in palliative care, the same questions. And we said, given 70 % of people who having acute oncology admission are likely to die in a year, would that be a time that you think is a good time for a conversation about future care planning, which is where this would fit in. And really interestingly, the oncology focus group said, well, if a scan showed progressive disease and I didn't have more lines of treatment, then of course it's time to think about that. But our generalist nurses and doctors said, well, goodness, yeah, you're sick enough to be in a hospital bed. That's really serious. We should definitely have a conversation. So there's something a bit strange about cancer versus some other diseases where it feels like talking about prognosis might change something for people and we nearly we really need to kind of democratise it and say actually you know if if your patient maybe in the last year of life it's not for you to hold that away from them especially when there's this thing that could get the non-means tested benefits within a couple of weeks and really change their experience of the next months.

Emma (24:18)

And I think that's been really highlighted with Steve explanation of actually how much that monetary value is and the real difference that that can make to somebody's life. And I think what really resonates with me, Ash, is when you talked about that uncertainty and sharing in that uncertainty. And that can be a really difficult conversation to have. And it can feel an uncomfortable place for professionals to potentially sit in that moment.

And Steve, you talked a bit earlier about the misconceptions and the misunderstandings around special rules. And you've talked a bit about that there isn't that kind of comeback. There's no negativity in filling in and completing that form. And I wondered whether you might have any further insights into actually what are those common misunderstandings or misconceptions that professionals have around the special rules process, or if you've got any further insights into that.

Steve Marshall (25:12)

Yeah, I mean, think it's definitely confusion about or concerns about getting in trouble if you get it wrong. I think that's a huge barrier to it, which we've mentioned. But I also think I think I was going to mention the hope as well, which Ash talks about. I think particularly in oncology, I think there's sometimes a worry that actually to talk about the fact that this disease, we might not be able to cure this disease or we might not be able to control this disease is almost like seeing this giving up hope. So therefore to talk about the fact that I wouldn't be surprised if you died in the next 12 months will almost make it happen in some ways. We have this phrase that we use in palliative care, hope for the best, prepare for the worst, which I tried to avoid using, but I think that's a prime example of it where, you know, we hope we'll get you through this oncology treatment, but we need to also be prepared that that might not be the case. And actually, you might not respond to treatment. you were nodding very vigorously there, Ash, so I feel like we're talking the same language.

Ash Lillis (26:10)

Absolutely. There's a really interesting program that Macmillan funded up in Harrogate and it was called Thinking Ahead and it was run by palliative care, an online training program and teaching kind of group for people who have been diagnosed with incurable cancer. So that's anybody whose disease would not be cured, but could be controlled for many years. And they could go to these sessions and it was 12 online sessions for you and you know, people who are in your support circle and you learnt about eating well with cancer, exercise with cancer, you know, what you could do safely, learning about, you know, cooking really well when you're going through chemo, but also making an advanced care plan, making a will, making a plan for when things don't go right. And the feedback on that, they've had hundreds of people through that. And the feedback was, it was great. People have come back and done it again because what they got was all that information to try and plan for the future and one of them was about your finances where they talked about special rules but the team who ran it said the biggest barrier to referrals to even finding out who could come and get and just self register for the program was that someone had to tell them that their disease was incurable.

And actually they were really struggling with their cancer centre and they were like, it's free, people can come. And that the biggest barrier was that their oncologist had to tell them that their cancer was incurable. And then they got all of this support for free. So there is a really difficult barrier to get over. And I'd say to healthcare professionals who are listening is saying, actually, you don't have to be an expert in this with people who meet patients. I am not a cancer doctor.

But I can say if I'd be surprised if someone died in a year and you don't need permission from every professional looking after somebody to complete a special rules You can do that with them. it's not a palliative care job It's not a GP job is any of us can do this and actually what I've learned through the conversations with Stephen Reed in the Mary Curie research was Goodness, I you know, I could really change things for some of my patients and I never completed a special rules form or told someone to go and do one if you're feeling comfortable to have that conversation and you answer yes to that question just crack on.

Steve Marshall (28:39)

Yeah.

Emma (28:39)

Yeah.

Steve Marshall (28:40)

I agree. mean, and Emma, you were asking about barriers and I think that's one of the things is that one of the barriers would be that actually people not thinking it's necessarily their responsibility that they're the healthcare professional that should actually complete the SR1 form. I mean, again, the DWP is very clear on this. You can either be a doctor with a GMC number or a clinical nurse specialist, but you don't have to be a clinical nurse specialist in palliative care. You can be a clinical nurse specialist in anything, in heart failure, but actually if you as a clinical nurse specialist feel that you wouldn't be surprised if your patient died in the next 12 months. You are within your rights to fill out an SR1 form. You don't have to ask a doctor. and I believe in many cases, actually, those CNSs know their patients perhaps better than their medical colleagues do. I think that's one of the barriers as well. I think the other barriers are people, Ash mentioned it earlier on, talking about people's finances is difficult.

If we're very British about this, we don't like to necessarily ask. But I think other barriers are that people feeling that they're opening up a can of worms that they don't feel that they can then contain or know what to do with. So if they ask someone about their finances and somebody says, yeah, I'm really struggling financially, they don't then quite know where they send them to or what to do or how to advise them about that. So I think people are genuinely avoid asking about finances because they just don't want to have to have that conversation in a busy clinic and don't quite know then what to do with it. But I think certainly the message that I'd like to get across is that from a healthcare professional's point of view, filling out the SR1 form, that's what we need, that's what we need CNSs and doctors to do. And then actually the rest of us, so people like me in social work or people in welfare benefits, we'll help the person actually access that benefit. We can do that. We're relying on you as the expert to say, I wouldn't be surprised if this person died in the next 12 months. And I think that's one of the limitations that we found is that people weren't quite having that. Those conversations and not quite realizing that they were the ones that can actually open things up for people.

Emma (30:49)

And I think that really shows the importance of these discussions forming part of that holistic care, that this goes hand in hand with not just physical symptoms and emotional wellbeing, but it's actually part of that bigger picture of what somebody can benefit from, what support's available, and it can really unlock so much more for somebody.

Marie Curie Advert

Emma (31:10)

Before we continue, we'd like to take a moment to recognise the research and policy work that's inspired today's discussion. I'm delighted to be joined by Becca Stacey from Marie Curie. Marie Curie funded King's College London to investigate how many people with a terminal illness are missing out on the benefits they're entitled to. Becca has then used this research to pull together a policy briefing outlining how the special rules could be reformed and better promoted and embedded within clinical settings to ensure more terminally ill people are able to access benefits via this fast track route. Becca, would you like to tell us more about the research?

Becca (31:47)

Yeah, sure. So at Marie Curie, we are committed to ensuring that everyone affected by terminal illness receives the care and the support and the information that they need. And so through funding this research, what we really wanted to better understand was why some people might be missing out on the benefits that they are entitled to and identify some practical opportunities to try and improve access to and awareness of the special rules and this is essentially because when it does work well, the special rules can be one of the most effective parts of the benefit system. So it can enable terminally ill people to get support as quickly as possible. And that can be really key to providing financial dignity in the final period of someone's life. But as it stands, the potential of this mechanism isn't being fully realized. So what we'd really like to bring light to is the importance of this research and thank those who are involved in conducting it and to all the healthcare professionals and partner organisations who helped us in developing the policy and the practice recommendations around how this mechanism can be accessed by more terminally ill people.

Emma (32:53)

We're really pleased to be highlighting this topic today and would you like to tell us more about the work that Marie Curie does?

Becca (33:00)

Yeah, course. So alongside providing expert end of life care and support, Marie Curie also funds and champions a lot of research and does a lot of policy influencing and campaigning for change in this space, as well as developing resources to help professionals be able to deliver the best possible care and support for patients and families when they are terminally ill.

Emma (33:20)

We'd like to thank Becca, Mary Curie and the wider research team for their contribution to this important area of work.

If you'd like to learn more about the research and the resources available we'll include links in the episode description. Now let's continue with the conversation.

Episode continued...

Emma (33:35)

Steve, I wondered from your experience, when a special rule is explained well, and people can really understand what it means and the benefits that you can get from somebody completing a special rules form with you. How do people and families typically respond to that?

Steve Marshall (33:53)

Yeah, I find that actually being able to, kind of work from a hierarchy of need. think that actually if we can help people with their finances and their benefits and other practical things, that then takes you on to another level when you can begin to support them emotionally and everything. And as Ash said, that often when people are told that they have a condition, a cancer that might be life limiting, their main worry is those practical things. What are we going to do about the children? What am I going to do about my finances, how am going to pay my bills? and certainly in my work, there's never been any negativity around the special rules. But you remember, I do actually work in palliative care. So people have already been told that they're going to be referred to palliative care teams. My work happens at a slightly different stage to Ash's. I mean, that might be something for you to, respond to that Ash.

Ash Lillis (34:41)

Yeah, and I think it's often difficult to find the moment when it isn't a cancer diagnosis. So often with a cancer diagnosis, there is a point of diagnosis and then there is a point of say progression or acute illness when I see people where there's kind of an opportunity and we have that kind of approach to some holistic needs assessments.

But for lots of other diseases, it's really difficult to find that time when I support people and see them when they're having acute exacerbations of heart failure or COPD or living with severe frailty or dementia.

it's often difficult to say when are we here? And I think the surprise question really gives you a little bit of an in to do that for non-cancer diagnoses. And if you're struggling with it as a healthcare professional in cancer or not in cancer, we've got fantastic Macmillan information services and centres within so many hospitals. And this is one of the things that they are doing all the time is helping people to access appropriate benefits.

So even if you're sitting in the community heart failure clinic and you just complete the first bit of the SR1 and you print it out and give it to someone and say just go on down to the Macmillan information service, they'll be able to signpost your patient to how to get the rest of the information on the form and send it off. This doesn't need to be you doing the whole part of that. As Steve said, there's lots of people who are really ofay and really good at managing the financial and benefits side of things. All you need to do is have a conversation and start that form. then you can, and we're really clearly seeing that saying that from Macmillan is we are supporting people living with cancer and other conditions. So go down and ask for that support. And the team is down there will be able to support all different kinds of disease processes and different patients.

Steve Marshall (36:35)

Totally. I was just going to say that also, mean, yes, absolutely we want people like Ash. To do the SR1 forms and then pass it on to us. For those of us that fill out the forms and actually do that bit and help people get attendance allowance or help people get PIP, once we've got an SR1 form, it's really, really easy. The attendance allowance we can now do online on the .gov website, I can do one in about five minutes. PIP is still a phone call, but again, I can do that phone call in 15 minutes. So it's not an arduous form. If the patient or the family want to do it themselves, as well if they just want to do it on paper and send it in. Again it's actually very very easy because you've got the SR1 form all the questions in the application about your care needs about your mobility all those sorts of things they don't ask about that at all you just jump to the end of the form so once we've got the SR1 form it's really easy for us to help people get those benefits.

Emma (37:30)

That really shows the difference it makes, doesn't it, in terms of not only the turnaround time but actually the kind of the completion rate, how quickly you can get through that. It makes a massive difference thinking about how we've reduced the gap in the number of people accessing financial support and the fact that we as all professionals have a role and responsibility in that.

Is there any other practical steps that you can talk to that people can really be thinking about within their own practice that would support reducing that gap and supporting people access that financial support in a more timely manner?

Ash Lillis (38:07)

For me, would be very much speaking to our CNSs who are the absolute backbone of those holistic needs assessments at point of diagnosis and throughout their cancer journey. And just remembering that it is holistic and we want to include those finance questions and...

Don't feel that you need to talk to someone else about prognosis. If you are working within, say, gastric cancer or pancreatic cancer, where, most people are diagnosed with advanced and incurable disease, where the surprise question would be, yes, for nearly all of the patients. So make sure that you ask at that point, that you fill in the form and you set someone up to have that. Now, isn't it great that someone might live longer than 12 months? But the earlier we do that in that disease process, we really, really can make a big difference and hopefully people are hearing that it is not an onerous thing to do and we can do it in a very light way. It doesn't have to be a conversation about every bit of advanced care planning. I often say to people is...

It would make it a lot easier for me if people came into hospital when they're on cancer treatment having had a conversation about what it would look like if they got more and well. They don't have to have a care plan with every single bit in it. But if they've been able to have a think and write down and discuss what life would look like if and when they deteriorate it makes it a lot more easy for me to have those conversations with them. It's really hard when nobody's talked to people about that and they end up in A & E and I would say that the special rules give you an in to have what you might feel is really difficult conversation but you're also getting something positive for patients.

When I was thinking about special rules and thinking about how it might change things, I thought of a patient that I looked after last year and he was a man in his 50s who had still been working when he was diagnosed with advanced lung cancer. He was a single parent, co-parenting two teenagers and he was absolutely distraught at this diagnosis found it immensely difficult to accept the fact that his cancer was progressing despite treatment and I must have met him in the emergency department three times in six weeks as his oxygen levels were falling and he was still trying to work through this and would just not engage in any conversation about death or dying or future care planning and actually what changed the picture was when one of the lung cancer CNS sat down with him in A & E and talked about money and said you can't keep working like this I can fill in this form and get you non-mean tested benefits and one of the question is you know very light touch would I be surprised if you died within 12 months and he said I wouldn't be surprised and that actually both got him some benefits which really helped him in the coming it was just weeks. But also it opened a conversation and by the next time I met him he let the Palliative Care CNS come and talk to him. And it was interesting that that was the bit that opened the door.

Emma (41:33)

Yeah, Wow. It shows, doesn't it, how powerful it can be, somebody initiating that conversation. And like you said, it doesn't have to be that sudden deep dive into the conversation. It can be very light touch and that surprise question and just really opening that up, but the benefit and the impact that can have on an individual that that story really shows that.

Steve Marshall (41:56)

One of the strategies that colleagues of mine have employed in other trusts, in particular, a team up in Bradford, is that they've just put the SR1 as part of a checklist that they have when someone's being discharged from hospital. They've just kind of made it routinely part of that. So, you know, do we need to let district nurses know? Do we need to let community palliative care know? Who do we need to let know? Do we need to do an SR1 when this person's discharged from hospital? So it was as simple as that. It's had a big impact because it's just part of the things that they tick off. And I think, you know, I would certainly encourage colleagues

listening to this to actually think about ways that they can just put that on whatever checklist they've got, or does it need to just be something that they discuss at their MDT, or does it need to be something that they discuss in their morning meetings? It just needs to really become standardised. think that we should just, it's as person eligible for an SL1, and if they're not, then you move on to the next thing, but if they are, then we do it. And I think that's how we can potentially stop these people falling through the net.

Emma (42:56)

That sounds like a really great practical takeaway for people to think about. Is that something they can embed in their practice, in their processes? And we've talked a little bit about that uncertainty and having those conversations and uncertainty in terms of filling forms in. And I wondered if we could touch on actually for professionals who may not feel that they're experts in this topic or fill in SR1 forms on a regular basis.

What support is there for professionals who might not be sure how to do this? Is there education and training available? Is there any kind of resources you could recommend?

Steve Marshall (43:31)

I mean, I think it always a default setting for everything is the Gov website. I think the Gov website is really, really good. And that's got very clear, explains the special rules and it explains how you should, you know, the criteria is and how you can go about submitting an SR1 form and it's got the SR1 form on there for you to be able to access as a clinician. The other things you can do is look at the Marie Curie website where our research is on and also on and we'll include this in the notes.

Kings where the research was conducted. We have a page on the research called the actual study was called the take up study and there is a five minute video of me explaining about the special rules and how to apply them as well. So it's and it's literally five minutes but also I would always be very happy to be contacted if people would like me to come and speak to their teams as well about completing SL1 forms. I'm always happy to do the five minute research and then discuss how that might people might embed that into their practice. So there's lots of ways that people can learn about the SR1 form and the special rules and I really don't want people to be frightened by them. It's really easy, the form is really easy isn't it Ash, it's two pages. It's not very detailed, it's not going to be, you know like as healthcare professionals we often fill out forms that are pages and pages and the amount of detail that is wanted, that's not the case with this at all. It's very light touch and my colleagues can do them in about five to ten minutes per form so it's not going to be an arduous task for anyone.

Emma (44:59)

really valuable thank you. Ash have you got any additional resources?

Ash Lillis (44:59)

Yeah. Yeah, I would just...

Yeah, well, it's it's more to reinforce what Steve was saying because his little five minute video is absolutely brilliant. Like I had a read. I've now sent it around to my whole team of acute medics. said, this is five minutes. Have a little read. And then as someone who hadn't done an SR1 form, I went through the Gov website as a new user. Really super simple. So I think that's

that's my one thing. Have a read. Have a listen to that video. and just next time you're with a patient who'd be eligible, just give it a go. It's really, really quick and simple.

Liv (45:39)

That's really helpful. Yeah. Thank you both for sharing that. Ash, I just wanted to come back quickly to, I think that that story and that example you shared has really highlighted how this is more than just a conversation about benefits and actually like you said earlier, it's really about empowering patients as well to acknowledge the stage that they're at and kind of process what's going on for them. Steve, was there anything else that came out within the research of kind of examples of the impact that having these conversations and people being able to access SR1 and the special awards earlier, is there anything that came out within the research?

Steve Marshall (46:14)

Yeah, I think one of the things that's really interesting is how much it can benefit people. And, you know, we've discussed attendance allowance, we've discussed the amounts of money. The SR1 is even more powerful than that. It can actually help people. if you're on pension credit or on your own universal credit, it can actually get you increased money for both of those benefits as well. I've used the SR1 form in various different ways. I've used it to help people access their pensions early, their life insurance. It can be as simple as things like a blue badge, or it can also help people access carers allowance. So if you're caring for someone that gets PIP or attendance allowance, can then, some people are able to apply for carers allowance. it's primarily about those two benefits, attendance allowance and PIP, but actually it's a more powerful tool. And lots of other organisations will see it as evidence that a healthcare professional, and I keep banging on about this, but it's saying that the person is very likely in the last year of life and therefore it opens up other avenues for them financially as well.

Liv (47:21)

Yeah, that's really helpful. Thank you.

Emma (47:23)

So I'd just like to bring us to our final feature, but before we do that, I just want to kind of acknowledge that all of those resources, the links and the research will make sure we're included in the episode notes so people can go and find out more and access those videos and those resources to be able to really build their confidence in having those conversations. So that brings us to our final feature. And this question, I'll come to you first, Ash and it is to ask you what would you like listeners to take away from this episode?

Ash Lillis (47:58)

For me it is just listening to what we said there about the fact that the SL1 form can really enable and improve the quality of life for people who have a life-limiting condition that may or may not have a prognosis of less than a year. And the only people who can unlock that for them are their healthcare professionals. And that is a doctor or a CNS. We have this amazing thing that we can do for people. And we often feel quite powerless when someone has an incurable disease. And this is something so positive and enabling so just recognise the power of that and have a read have a think and make sure that we're the ones supporting our patients to get this really important benefit.

Emma (48:48)

Thank you Ash and Steve same question for you, what would you like listeners to take away from this episode?

Steve Marshall (48:53)

Yeah, I would like reiterating what Ash said, but also just, think we should all, every single patient that we see, we should ask ourselves, would I be surprised if they died in the next 12 months? I think we should just do it almost by rote. And absolutely, maybe 90 % of your patients, you would be surprised. But actually, I think we need to ask it of everybody every single patient that we have and that, you know, across specialties, across cancer and other specialties as well, know, non-cancerous diseases as well. But I think it really just comes back to would I be surprised if this person died in the next 12 months? I really need to be asking that of all of my patients.

Emma (49:32)

Thank you both so much and I think as well it's just highlighted for me that actually even if you're not a CNS or a doctor your role could be asking, has this person had that conversation? Is this something somebody's asked of you and signposting to those relevant professionals? And I want to thank you both for sharing your knowledge, your experience and insights today. It's been such an insightful conversation and I know I've taken so much away from it. And in particular for me, this conversation's really highlighted that access to financial support is not just about benefits. It's brought home the difference that timely financial support can make for people living with cancer and life-limiting conditions and those close to them. It helps to reduce stress. It empowers people to focus on what matters most to them. Hearing about the importance of special rules, the barriers that can prevent people from accessing support, and the practical step healthcare professionals can take to ensure eligible people don't miss out has really reinforced that this is an important part of holistic care and recognising opportunities and starting those conversations can make such a meaningful differences. So I just wanted to thank you both Ash and Steve for joining us on the Cancer Professionals Podcast.

Steve Marshall (50:45)

pleasure.

Liv (50:46)

You've been listening to the Cancer Professionals podcast, which is brought to you by Macmillan Cancer Support. If you're a health or social care professional working in cancer care, visit membership.macmillan.org.uk to find out more about Macmillan membership, which includes a range of education and training resources and access to our learning hub. For links to the resources mentioned, see the episode description.

Emma (51:07)

Coming later this month, we're really excited to bring you a special trilogy of episodes focusing on fertility, sex and pregnancy. We'll be exploring the challenges, opportunities and conversations that healthcare professionals can have to better support people affected by cancer across these important aspects of life.

Liv (51:24)

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

Emma (51:36)

I'm Emma.

Liv (51:36)

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