



Emma: What does it mean to be living with cancer during a global pandemic?

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Hello, I'm Emma B, and welcome to Talking Cancer. You might have listened to Series 1 of the podcast earlier this year when I met with some really extraordinary people to have honest conversations about living with cancer. Things have changed a little since we last met, I think it's fair to say, and at times it feels like we're living in a new world entirely. That's why Macmillan have teamed up with Boots to bring you a very special Coronavirus series, Talking Cancer to address some of your most common concerns around living with cancer during a global pandemic.

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Marc: You need to look after yourself, too.

Rosie: Would you mind if I put my loved one who's in the carpark on speakerphone or you can ask to record the consultation?

Marc: Discussing it with your doctor or a consultant, and asking the questions. There are often options that you won't think of.

Emma: Today, I'm joined by Macmillan's Chief Medical Officer, Rosie Loftus, and Boots' Chief Pharmacist, Marc Donovan, to talk about the services available and practical advice you'll need to navigate this new normal with cancer. We're Macmillan, and we're Talking Cancer. Rosie, Marc, it's lovely to have you with us. Really nice to have you along. Now we're recording this on the 11th of September 2020. I'm being specific about the date because lots of people are-- We're trying to give people some answers when the guidance feels like it's coming from a frequently changing landscape, sometimes on a daily basis. Let's start at what is the beginning of many people's experience with cancer.

We know because lots of people are getting in touch with Macmillan at the moment, because they're either being diagnosed with cancer over the phone, or receiving information about treatment via a phone call, and that must be incredibly hard to take in when you don't have a loved one or a carer there with you for support. Rosie, I'm going to start with you. What kind of advice can you give people who are preparing to potentially receive information about a diagnosis or treatment, difficult treatment over the phone?

Rosie: Thanks, Emma. As you say, we've had a huge number of calls to our support line about this. As we all know, receiving a diagnosis of cancer is frightening in the best of times. It turns your world upside down in a matter of seconds. When you add on the extra pressures of what's happening in the world at the moment with COVID, this just amplifies all those feelings. At a time when you're thinking you're going to be receiving a diagnosis, you might not actually have your head in a space where you might be able to think about some practical things.

Actually, patients tell us that some of these things are really, really helpful, and sometimes actually give them that feeling of being able to take a bit of sense of control back. I think some of the top tips we heard from people are making sure that you've got yourself a quiet and a comfortable space. Some people will be in house shares. Also, do you need it to be confidential. Planning ahead for someone to be with you. Again, patients have told us that actually, sometimes actually doing this in their own home has increased the opportunity for them to have somebody with them. Write down your questions and your queries and what it is you want to hear from the consultation.

A really small thing, but actually, again, lots of people have said it to us is that when hospitals phone, sometimes it will come up as one of those withheld numbers. We're also used to those nuisance calls at home. Do recognize that that might be the case so that you don't miss the call. Ask them if it's possible for you to record it. Remember, the other person at the end of the phone, they can't see you, so they don't know how you're feeling in response to what they're saying, and they don't know what you're hearing and actually what you're understanding. If you have got questions, you don't understand stuff, do feel free, do feel empowered to ask for that clarity.

Emma: Marc, from the pharmacy world's perspective, it must be a very challenging time for you to be able to keep track and keep up with the changing landscape and the recommendations. Has it been a challenge for you to stay helpful to people receiving diagnosis in this time?

Marc: Yes, I think it is difficult. We understand people are anxious both for themselves, for their families. We have stayed open on high streets, of course. I've been able to provide advice for people who are affected by cancer and those who are caring for people who are affected by cancer. We are navigating a new world, too.

Emma: Both of you have mentioned this new normal, this new world. I know as a former GP, Rosie, video consultations are fast becoming the new normal. That has its own stresses. You mentioned confidentiality. There's, "I'd be wary about that, possibly." Also, there are lots of people that really aren't very tech-savvy, that might be super stressed about setting up a system like this or right through to being able to talk to somebody intimately, a GP over a Zoom call or a phone call about symptoms. Rosie, what's your advice? How can you reassure people that this might not be quite as invasive and traumatic as it sounds?

Rosie: It's been an absolute sea change in a way of consulting. Many of us, as you said, I'm a former GP for 30 years, and I've been using the telephone in consultations for quite some time in specific instances and for specific circumstances. The scale of the change in the way that we're we're consulting and the speed it's happened has just been, as you say, quite phenomenal. It's a new way for all of us. I think we're really learning, we're treading carefully and there's not a one-size-fits-all.



Some people have told us actually that they've quite appreciated the access to their GP and the efficiency that it gives them, but it's not going to work for everybody. It's really important that people find their individual way. The video adds another layer on to that. I'm certainly not the most tech-savvy person in the world. I'd get a youngster from my house to help me with that. You might want to do a dry run with a friend, even. I think it's still also really important to say that if it's not working for you, you need to tell the clinician it's not working for you.

You need to feel empowered to say that, but definitely feel okay to say, "Look, there are things I need to tell you, I feel I need to see face to face." At Macmillan, we're working on some top 10 tips. We're working together with both patients and professionals so that we're not making assumptions about what is working for people. We're hoping to put those on the website very shortly. Do lookout for those.

Emma: That sounds absolutely perfect. Marc, it's come at such a tragic cost, obviously, with COVID and the pandemic, but are you seeing any benefits in store with pharmacists having more time to speak to people? Are there any upsides in your world?

Rosie: I think, as Rosie said, the way patients interact with GPs and other healthcare professionals has changed quite dramatically. Patients can access the GP practice in a slightly different way. I think that has provided opportunities for pharmacists and GPs to work closer together, and we would want to encourage that. GPs can refer people into pharmacy, send their prescriptions electronically, ask our pharmacy teams to provide further advice or feedback into the GP practice.

Some of the interactions that we're having through our pharmacy teams on the high street of course, and during the height of the pandemic. We launched online Boots Macmillan Information Pharmacy service. We have over 2,000 Boots Macmillan Information pharmacists that can advise on a day-to-day basis any matter and we work closely with Macmillan to refer them into the Macmillan website and support lines too, and the Boots Macmillan information pharmacist scheme where we have over 2,000 information pharmacists in our stores.

Over lockdown, we've launched an online Boots Information pharmacists service hosted by shielding pharmacists where people can make an appointment either through boots.com/Macmillan or through the Macmillan support line and talk to some of our pharmacists online about their concerns, about the support that they can get through our pharmacy teams and where to find other support as they go through their experience with cancer.

Emma: Rosie, can you maybe give us some clarity as well on if you are going to appointments? Is there a blanket rule at the moment about being able to take somebody with you or not, or does that differ from center to center, hospital to hospital?

Rosie: Really important point. Again, something we've been fed back on a regular basis because, in the main, it is still that hospitals are saying that actually they don't

want people coming through their doors that don't absolutely need to be there. However, of course, all hospital buildings are set up slightly differently. The way that you enter them and the route that you take might vary depending on the location. It may well be that in some circumstances, those rules are slightly laxer but in the main, it is the case. I had a friend who's visited a hospital recently. Again, she was really worried about this situation. Then actually when she got to the consultation, there was the opportunity to say, "Look, would you mind if I put my loved one who's in the car park on speakerphone so that they can be part of it?"

Or you can ask to record the consultation or actually then also say again, I talked about McMillan's cancer nurse specialist who may be there and involved in that conversation. It may well be that you could say, "Or would you be happy to speak to my relatives? I haven't managed to take everything in that you've said to me today." I suppose one tip is also just to make sure that when you're in that appointment, just make sure if there are any of these annoying bureaucratic consent rules that you have actually completed those so that actually your loved one will be able to talk to the professionals

Emma: Picking up on that as well, Rosie, in that guidance information that you are likely to get when an appointment is booked for you, would it explain there as well what you should or should not have been doing with regard to shielding measures or isolation measures before going into an appointment?

Rosie: Absolutely. The most important message is that whatever information is sent to you for your individual appointment, that you make sure you follow that because nobody wants the fact that your care or your treatment couldn't be delivered, because you haven't followed the guidance and the guidance will vary depending on where you're going and what you're going for. Obviously if you're going to be staying in hospital and having treatments, interventions, it may well be you have to have a COVID test 72 hours before.

May well be that when you come home, you also have to self isolate, but I can't say highly enough how important it is you follow the guidance that is given to you for your individual appointment.

Emma: Marc, when you get a cancer diagnosis, there's new language, there's new structure, there's new routines, there's new buildings, there's new doctors and faces. Then there's now new guidance's we've been talking that changes on a daily basis. It's a huge amount to take on board and I think as well that there are people who are understandably very wary about being outside, in the public, going to the pharmacy to pick up whatever they're picking up, being in hospitals.

What's your advice to somebody who sees this and just goes, "This is all a bit scary for me."

Marc: Well, I understand it's scary. It's part of my job to keep up with the guidance on a day to day basis. I really struggle with it to be honest, it's really difficult. I understand the anxiety, I understand the nervousness. Everybody has a bit of that.



As Rosie said, hospitals and GP practices have changed to make it significantly safer. In our pharmacies we've made significant changes for it to be safer to access as well and it's okay to ring up ahead of the appointment, understand the changes that you'll see and how you can prepare for that appointment as well.

We're here to help and make you as comfortable as possible and every healthcare professional will aim to do that. Ask questions, get prepared, talk, and share how you're feeling and people will be able to support you.

Rosie: I know with my GP now, repeat prescriptions and online ordering of medications and there's some delivery systems as well. There are structures around aren't they? Which means you don't have to go into a busy high street and a busy store to be able to keep up with your medication to keep up with the information that you are supposed to be receiving.

Marc: Yes. We'll help people in whatever way we can. Every pharmacist will do that. I'm sure on every pharmacy team. Whatever's right for you, if you're nervous we can deliver the prescriptions to you. We can have the prescriptions transferred automatically from the GP to a pharmacy on the high street and sort it from there. We can also talk over the phone or indeed online for any questions that you have about your medication too. There are solutions.

Emma: Marc. That's great to hear.

Rosie: Just to add in terms from obviously there's also support from McMillan. Quite early on in the pandemic we also set up a befriending scheme, and you can look at the website to see this, this offers connecting with someone who we try to match people. It's a telephone buddy scheme and you'll get contact over a 12 week period.

Emma: My dad, has been self isolating since about 1992 but that's just as he doesn't like people mostly. Everybody is different. You did mention though Marc, that it was really important. I'm glad you bought that up. This is wrapped up with mental health as well, is that it is, I guess at this time when you get a very overwhelming piece of news and there are restrictions that are changing on a daily basis, it would be quite easy to sort of retreat Rosie, the benefits of staying active and communicating. However you do that I'm sure can't be underestimated.

Rosie: Absolutely, Emma. I think we all know, don't we, the benefits of staying active for all of us. Actually when you've got a significant illness, the benefits of exercise both for your physical and your mental well being.

For people, who've had a cancer diagnosis, waiting to go through treatment or going through treatment, actually keeping up your physical and emotional strength is just absolutely vital. There are things you can do without, we always say you don't have to jump up and down in Lycra. There are things that you can still easily do within your own house, actually there's a part on our COVID hub on our McMillan website that actually talks about looking after yourself at the moment. There is a video on there.

Sometimes people are really worried about, what is it safe for me to do. People think maybe they do need to sit on the city, because they're going to do themselves some harm. Number one, if you are worried, check in with your healthcare team and your pharmacist just to reiterate, there are simple things you can do within the home and it's really vital that you do that and keep up your strength.

Speaker 4: Questions about cancer. Boots and McMillan are by your side from the moment you're diagnosed through your treatment and beyond. Our Boots, McMillan information pharmacists are on hand with specialist support from helping you make sense of your diagnosis to advice about living with cancer, you find them in your local Boots pharmacy or online via video appointment, visit boots.com/mcmillan for more information, subject to pharmacist availability.

Emma: Now, we've talked a lot about people getting in touch with McMillan because they've been diagnosed with cancer over the phone or had to attend appointments on their own. We've got a short clip from an amazing woman called Ruth, who was diagnosed with breast cancer during lockdown just weeks after her little girl was born. She's got some tips for others who are in the same position as her.

Ruth: Hi everyone, I'm Ruth. I was diagnosed with breast cancer in April this year during the Coronavirus lockdown, it was quite difficult getting a diagnosis during this point and not being able to take somebody with me, but there was a few tips that I found through the way that really helps move that process for me.

Firstly, if you're going into an appointment on your own, I find it really useful to see if you could have someone join on a call with you and put them on speakerphone in the room. I found this really useful for moral support, but also bringing somebody else into that process with you and then they're also able to take questions, take notes and be another pair of ears for when you're getting a lot of information in a lot of cases.

Secondly, if you're going in for surgery, find out whether you're going to go into the anaesthetist room first, or if you're actually walking straight into the operating theater. Mentally preparing yourself for the latter can need a little bit more of thought and visualization just to get you into that right head space of walking yourself into an operating theater. Thirdly, take a good book or TV shows to watch when you're on your own waiting really does help pass the time. Then the final tip I've got really is a lot of hospitals have security on the doors at the moment to limit the number of people going through.

Give yourself time to get yourself into security and through it with an appointment letter or a text, just to help that smooth running as you're going into your appointments and hope it all goes well.

Emma: Of course, so many people are going through difficult situations like Ruth many have been writing into the McMillan support line, Rosie, Marc, we've been working through some of the most common questions coming through to McMillan's support line, but lots of people concerned about delays to treatment or to tests which

might diagnose them with cancer or their treatment cycles being shortened. What are your words of wisdom to give to people who are worrying about those things?

Marc: Well, you're right, Emma, we're seeing more and more people coming to our pharmacies with concerning symptoms really that they haven't been able to access the GP or consultant. Clearly we would encourage them to do, and I've had personal experience of this actually over the lockdown period. My father-in-law sadly has been diagnosed with colorectal cancer during lockdown.

Emma: I'm very sorry to hear that.

Marc: Yes. For weeks and weeks and weeks, it turns out that he was ignoring these important symptoms and talking to him, he was thinking that the GPs were closed. We've already talked about that. They haven't been, and Rosie was saying that there's more appointments available for people to talk to their GP. He thought that they were too busy or in fact he was not allowed to go outside because he's over 80. When we got to the place where he could access some of the support that is available, I was really impressed with how it was handled. The GP and the referral. He had to have some COVID tests before going into some of the appointments to have some scans.

Results over the phone like we've been talking about. Then talking to the consultant about a plan of action and a discussion of whether to go for treatment now or whether to delay it a bit later and he started some treatment for it. I'm fascinated by how many people who perhaps would ignore those symptoms, which are really vitally important to raise and get in support. The healthcare system is still working and there's no real delay getting access to what is normally then, in fact, as Rosie said earlier, it can be quite efficient and quick but there's clearly lots of anxiety. You need to take the conversations about all options really, and all action plans. I'd encourage people who perhaps are thinking, "Should I delay treatment," or worrying about how you can manage the treatment that they're currently in?

You have to make a decision which is right for you. That's really important, and discussing it with your doctor or a consultant and asking the questions. Being prepared like Rosie has said earlier and getting all the information together. I think there are often options that you won't think of, but others will and I think that's really important.

Emma: I'm really glad that you brought that up, actually, Marc, and we wish your father-in-law a speedy and healthy journey. Rosie, Marc mentioned there about being a very personal decision. Some people who have been going through diagnosis and treatment had to make really tough decisions about whether to continue or whether to hold back and wait until it is, "safer for them to do so." Marc talked briefly about that. How can you add to how people best weigh up what's best for them in that situation?

Rosie: We are learning all the time. We're learning much more about COVID, we're certainly learning a lot as a number of academic people up and down the country

doing really clever stuff. We're learning about the interaction of COVID and cancer and what is safe and what treatments are and aren't safe to continue. There are plans now for restoration recovery in all of the four UK nations. We're influencing, our very own chief executive lender has had direct conversations with Matt Hancock about this. We're influencing at the top level, and we're working with the workforce who are tirelessly endeavoring to get as many treatments back online.

Again, coming back to what Marc said, it is about those individual conversations about what is best for you and those conversations, you and your healthcare team know yourself best. That's where to have those conversations.

Emma: Marc, as you know with a cancer diagnosis, there is the individual, but there are partners, children, wider family, in this time, what's out there for people who are trying to support their loved ones. I know Rosie, you can probably help with this as well.

Marc: It's tough being a carer, isn't it? The first thing I'd say, you need to look after yourself too, and there's definitely support out there if you haven't found it yet. The Macmillan support line is a brilliant resource and the website is a brilliant resource too. Family members, loved ones, you need to be strong and be able to share the online community groups on the Macmillan website which you can gain support and strength from, and talking to people about it is really important.

In our pharmacies, through our Boots Macmillan information pharmacists, and our pharmacy teams, we often talk to the carers actually, rather than the people who are directly affected by cancer. The carers perhaps haven't been in the conversation, need to understand a little bit more about what treatments are and what these medicines mean so that they can ask questions and we're here to help. I'm sure other healthcare providers are there to help too but it's important to look after yourself.

Emma: Rosie, it's a relevant question, I think, in a relevant subject for us to end on then. There've been so many changes to the guidelines and rules. Where's the first place, where should people turn if they're really still not sure what measures themselves and their family need to take?

Rosie: There's a particular part of the Macmillan website which is our Coronavirus hub. We try to respond to the content on there in response to the questions that come through the support line and obviously we are updating it on a very regular basis. However, we do also make sure that we've got the gov.uk links on there because sometimes as we know, announcements are made on a Saturday evening. Again, coming back to you and your individual care be guided by your healthcare teams and the information that is being sent to you about any specifics that relate to you. I think those would be the things that I would suggest in terms of making sure that you have got absolutely the right information that is personalized for you.

Emma: Rosie, Mark., thank you, so unbelievably helpful. There's so much in there to take away. It's been a pleasure speaking to you both, take care. Thank you.



Marc: Thanks, Emma.

Rosie: Thanks, Emma.

Emma: My thanks again to Rosie and Marc for taking the time to speak with me today. For more information on the topics discussed in this episode, make sure you head to our website, [Macmillan.org.uk/talkingcancer](https://www.macmillan.org.uk/talkingcancer) for resources, advice, and support. It's also where you can find out more about donating to Macmillan. In our next episode, we're talking about managing your mental health through the pandemic. Subscribe if you'd like to hear that and every new episode whenever it's ready and if you enjoy the series, why not give us a rating or a review? It helps others find the podcast more easily. I'm Emma B, and Talking Cancer is a Macmillan cancer support podcast.

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