



Emma B: What practical support is available to me during the pandemic and how can I access it?

[music]

Emma: Hello. I'm Emma B. Welcome to our coronavirus series of *Talking Cancer*, a podcast from Macmillan and Boots, where I get to talk to experts to get answers to the questions Macmillan is hearing the most. Today I'm joined by Macmillan's chief medical officer, the brilliant Rosie Loftus, and Boots' Chief Pharmacist Marc Donovan. To talk about the practical support available for those affected by cancer and how people can access that support.

Marc Donovan: I know our colleagues really value their ability to make a difference in people's lives as they go through their experience with cancer.

Emma: We'll also touch on the latest government guidance and what it means in practice for people living with cancer.

Rosie Loftus: If you are asked to attend an appointment, please do keep it and feel confident in doing so.

Emma: We'll also be hearing some top tips from Mandy.

Mandy: Things that keep you connected with people it's not the same as in-person, but it is a good substitute if these are your circumstances.

Emma: Now, we know that these recent changes may make some people feel very anxious and worried. Please have a listen back to Episode 2 of the podcast if you're looking for some guidance and helpful tips about managing your mental health during the pandemic. We're Macmillan and we're *Talking Cancer*. Rosie and Marc, Welcome back. Lovely to have you with us. Now, as in the other episodes we've recorded, I'm going to timestamp this and we're recording this on the 23rd of October, 2020. All the information that we talk about is correct at the time of recording.

In Episode 1, we discussed what people can do if they're struggling with the new often virtual ways of interacting with GPs, specialists, and healthcare professionals. The Macmillan Support Line team are still receiving some calls about this. I'd recommend that anyone worried about that particular issue listens back to Episode 1 for more informations, loads of great advice there.

However, for some people, physical appointments and treatments in hospitals, GP surgeries, and pharmacies are going ahead. Understandably, people may be feeling very anxious about the safety of this while COVID-19 is still very much present. Rosie, what precautions are in place in hospitals and healthcare settings at the moment and how are they making these environments as safe as they possibly can for patients?



Rosie: Yes, thanks, Emma. Great to be back. Thank you very much. As you say, we talked about some aspects of this last time. Obviously, it's totally natural to worry about going for appointments. All of us are anxious at the best of times when doing this. Of course, now there's all the added concerns and logistics on top of that, but everyone's telling me that, actually, they're really reassured by all the precautions that they see once they arrive.

Again, last time, we did talk about that shift from not quite so many face-to-face appointments and some telephone or video. That does actually help because that means there are actually less people going through the hospital. Of course, when you get there, you might have a timed entry, you might be asked to stay in your vehicle until your appointment time. Some places are even giving pager alerts out.

I know one of our Macmillan information centers that's close to one of the hospitals, in fact, right next door, they've opened up their car park to allow people to park there. Indeed, if you aren't traveling by car, they're also allowing people to wait inside and the hospitals just buzzing straight across when they're ready for the patient. Of course, there's all the cleanliness precautions, gel at the doors, PPE for the staff in particular, and then there are red and green channels in the hospital, areas where cancer patients will be kept well away from potential infection risk. Deep cleaning is just going on relentlessly.

I suppose I'd say there are so many precautions in place. The most important thing is that if you are asked to attend an appointment, please do keep it and feel confident in doing so. One last thing, just following up on some of the conversation we had last time about the challenges of not being able to take someone to your appointment. Some of that is lightening up a little bit in some particular circumstances, not across the board, but it's really important. Do ask because it might actually be possible that you can take someone to some of your appointments.

Emma: Actually, from a personal perspective, a friend of mine went for her yearly checkup post-treatment for breast cancer yesterday and the situation about taking people had changed. She was able to take somebody with her, not all the way-
[crosstalk]

Rosie: That's great. Yes.

Emma: Just you make sure you ask.

Rosie: Absolutely.

Emma: You did just touch on that lightly. Not everybody is able to be picked up from the front doorstep and dropped at the door of the hospital. For many people, public transport is the only way they're going to get to these appointments. That has its own level of risk and its own level of anxiety as well. What steps can patients take to ensure they are traveling safely themselves?

Rosie: Really understandable that you're going to be worrying about this. Actually, you might be worrying about it and feel, "I really can't bother people at the hospital or

File name: macmillan series 2 episode 4.mp3



my healthcare teams to talk about this." Actually, you absolutely should. It may well be that there are options that they can do to modify, something simple like changing times of appointments so you're not traveling busy times. Might be able to actually organize things so that, for example, a blood test might be closer to home. Please do ask if there are any options to explore.

If you do have to travel, then definitely follow the guidelines. Travel in a bubble where possible. If you've got to travel in a taxi, for example, wear a mask and open the window. Follow the guidelines which you will find online. I know also that some of our Macmillan information centers have been linking locally to see what transport services are available. Again, just where I started off with this, if you're worried about this, ask.

Emma: There's so much talk of what's online and there's so much information online. I know for some people who maybe don't have access to computers or are a little bit older, there are people on the end of a phone on there at the hospitals, at appointments, and people are willing to talk and explain through the processes that you might expect.

Rosie: Oh, very definitely. Again, I can only reiterate that our Macmillan Support Line is there also and we'll be able to answer these queries or direct you to any of our local services. Absolutely, people are available at the end of a phone, be that your healthcare team, or indeed the Macmillan Support Line. Absolutely, you don't have to go online, there will be someone at the end of a telephone line. Please, pick up the phone and ask.

Emma: I think when you have a cancer diagnosis, that is, again, creating levels of anxiety. Very basically, though, how does the shielding measure that was in place in lockdown marry with the new three-tier system that's been introduced by the government recently?

Rosie: I think the most important thing is that you do need to check the local restrictions and guidance for your area. If you've got any specific concerns about this, then do check in again with your healthcare team, they might be able to advise about any adjustments and be able to reassure you about precautions. We are advised that there will be a letter coming from the government to people who are on the extremely vulnerable list to explain to them what advice they need to take. That letter is imminent. I think it's really important at the moment with the rapid change we're seeing in different geographical areas that you make sure that you're up to date on what the local advice is.

Emma: Marc, yes, Rosie mentioned obviously for pharmacies across the UK, the changing restrictions and tier system is meaning that you guys as well are having to be quite reactive quickly to make the experience of being able to get into pharmacies or access to information from you guys available quickly and safely.

Marc: Yes. Hi, Emma. Hi, Rosie. It is confusing, isn't it? Tiers in England, firebreaks, lockdowns in Scotland, Northern Ireland, and Wales, it's very important that you stay



close to the local guidance and guidance on travel. Pharmacies are open as they have been all along through this pandemic and we continue to be open for advice. You can access your medication and there are rules and support on doing that. Feel free not only to access them physically on the high street, but also ring ahead and, to Rosie's point, pharmacies are available to advise if you have any questions on how to access medicine or get them delivered, or how to help order your prescription with your GP too.

Emma: Lovely, thank you. If there was one starting point that people can go to, what's your advice about the first starting point for guidance in your local area?

Rosie: Many people will have already been on the GOV.UK website which is updated regularly. Actually, you will be able to look for your local area on there. What I would also say is we talked when we were talking previously about the Macmillan COVID Hub, which has lots of information to support cancer patients through the pandemic. On that hub, you will find the up-to-date information, but also with a link straight through to the GOV.UK. Obviously, as we said last time, sometimes things get changed on a Saturday evening at ten o'clock, but you can get to the GOV.UK website from that Macmillan COVID Hub.

Emma: Marc, once again, the practical resources available to be able to access medication, from your perspective, where do people go immediately to find that?

Marc: You can contact your local pharmacy, of course. There will still be access and support for medication, access for food delivery slots are still available, et cetera, for those people who are shielding or are vulnerable. We also have launched recently a virtual Boots Macmillan Information Pharmacists, actually. You could go to boots.com/macmillan and book an appointment with a pharmacist to be able to help talk you through any concerns or questions that you have around medication or wider issues with your cancer experience.

We'd be able to help in that way, which is something that we started to bring in at the beginning of the pandemic earlier this year and something that many patients and carers too have begun to access. It's another way of accessing some of that advice. There's lots of ways and lots of support available, so look at Macmillan support helpline and website as well as the Boots website to be able to access that support.

Emma: Rosie, it's always a difficult conversation and subject matter, but we need to talk about a very sensitive area that people are struggling with, which is palliative care, and especially palliative care in the community and the difficulty in contacting the appropriate health care professionals. What practical steps can people take to understand more about their own or family members' palliative care options during this time?

Rosie: Yes, Emma, as you say, palliative care is so very sensitive at all times, and even more so and more challenging with all the restrictions present. I think the first thing I'd want to say is that for more than 30 years as a GP, I really can't emphasize enough how important it is to actually have conversations, understanding how very

difficult that is, but actually, it's really important. I don't mean they're just conversations with your health care team, but also with your family and friends. It's not easy starting those conversations, but over the years, I've seen the huge benefits as a result of those very open conversations.

In terms of practical, it's important to say that palliative care is still available, whether that's through district nurses, GPs, specialists, or at the hospice. Some of these services may be doing less face-to-face visits right now and trying, obviously, to reduce the risk and the spread of infection, but they are still there, they are still accessible, and they have so much to offer in terms of supporting with physical symptoms and also emotional and practical support.

Emma: It's a very isolating time without the pandemic, so to know that this is still available and with conversations and some persistence and support, that level of support is still there.

Rosie: Yes. Just to add that I think also, be really clear when you're engaging with these services about then what contact numbers are available to you and which ones to use when. In many instances, there will be a 24-hour line for you to access for queries, so do, again, ask to know where people will be at the end of the line. Again, of course, Macmillan website has lots of information relating to palliative care, some of it that would help you start those conversations. Of course, never forget that you can, of course, contact the support line as well.

Emma: Thank you, Rosie. Thank you, Marc.

[music]

Advertisement: Questions about cancer? Boots and Macmillan are by your side from the moment you're diagnosed through your treatment and beyond. Our Boots Macmillan Information Pharmacists are on hand with specialist support from helping you make sense of your diagnosis to advice about living with cancer. You can find them in your local Boots pharmacy or online via video appointment. Visit boots.com/macmillan for more information, subject to pharmacist availability.

[music]

Mandy: I'm Mandy, and I was diagnosed with breast cancer in 2011. During the first phase of COVID, I was classed as extremely clinically vulnerable, so I shielded at home for 100 days and didn't have much contact with anybody. I found it really hard to get a food slot to start with, but then through the local council, I was able to get a secured time slot on the supermarket of my choice. Also, they would check in just to make sure and make me aware that there were local charity groups setting up to do shopping if you needed it. The hospital had their COVID practice on point, so at arrival, clean masks, temperature check, COVID questionnaire.

Every visit, temperature again when you got to the department that you were going to. Hand sanitizers, I was sanitized to within an inch of my life during that particular period. If there's a service you need, if you can't find it, you need to be able to ask

File name: macmillan series 2 episode 4.mp3



someone. You get quite resourceful as your cancer experience goes on. For me, that's where Macmillan come in. You are the fifth emergency service. You're on speed dial. It is about making connections with people. The online forum on the Macmillan website, for me, they're secondary support groups. Stay connected with people, things that keep you connected with people. It's not the same as in-person, but it is a good substitute if these are your circumstances.

[music]

Emma: Some really useful tips there from Mandy. Marc, now this episode on practical support, you mentioned it earlier, actually, which I want to know a little bit more about because it sounds very exciting. It's the perfect opportunity, really, right now to delve into the wonderful support on offer from the partnership between Boots and Macmillan. Tell us a little bit more about that.

Marc: Well, yes. The partnership started, actually, in 2009. I was there at the beginning. It seems an awful long time ago, but I remember being really excited about this partnership as we started together. Macmillan's a wonderful charity, and as a pharmacist, the whole organization got behind the partnership. It was raising money through doing silly things of colleagues up and down the UK through all of our different stores. At one time, a number of years ago, I even ran the London Marathon. My legs are still recovering, actually, eight years on.

Emma: [crosstalk] [unintelligible 00:16:12]

Marc: [chuckles] It was. We were all behind this wonderful partnership and raised a lot of money, over 19 million so far-

Emma: Wow.

Marc: -with the Boots-Macmillan partnership. This partnership has created far deeper connections than just a fundraising partnership. Soon after the partnership started, sadly, I had a real close-up experience of the power of the partnership. My father was diagnosed with cancer, mesothelioma, a cancer of the lining of the lung, developed over many years through exposure from asbestos. He was diagnosed in April and sadly passed away the following March.

He was my hero. I loved him so much, and lots of other people loved him too. He had quite a complicated experience of cancer. It was painful. He was in and out of hospice, and there was lots and lots of messing around. I had been a pharmacist at that point for a number of years. I'd dealt with people affected by cancer on a day-to-day basis, I guess, but it wasn't until I was on the other side of that experience I realized that we could do better as pharmacists, as pharmacy teams.

Rosie just mentioned it earlier about the power of conversations, and I couldn't agree more. Dad didn't like to talk about things. He didn't complain about anything. He didn't want to worry any of us, really, but I do remember having a conversation with him about dying. Like I said, Rosie said it's so important to have. Many of our conversations when he was going through this was, "I've had a good day," or "A bad

File name: macmillan series 2 episode 4.mp3



day." Then occasionally, we had some opportunities just to talk a little bit deeper. I value those conversations.

I remember a conversation, it turned out to be two weeks before he passed away, I promised him something then that something good would come out of this experience that he was having. I saw how much of a difference that his pharmacy made in taking some of the hustle out of his experience. It's a whole load of things to cope with when you're going through cancer. I know the pharmacy didn't think that they were helping that much and having that much of an impact, but they really were.

We took that away and developed this Boots Macmillan Information Program just to take this partnership to a deeper, more connected level. Then recognizing that beauty and feeling good is important for people when they're experiencing cancer as well, we then developed the Boots Macmillan Beauty Advisor role as well. As of the end of August, we have over 2,000 Boots Macmillan Information Pharmacists, we have over 1,000 Boots Macmillan Beauty Advisors. They fundraise, they advise, they improve local connections with cancer teams and connect health care professionals too.

It's wonderful to see it grow. It's wonderful to be a partnership that is more than just fundraising because I know our colleagues really value their ability to make a difference in people's lives as they go through their experience with cancer.

Emma: What was your dad's name?

Marc: His name was Grenville.

Emma: Grenville. Thank you very much. A legacy, and such an incredible journey you and Macmillan have had together. Just tell us a little bit about as well the Boots Macmillan Information Pharmacists. I know that's a very specific role that has been created. What can somebody expect if they are hoping to have a chat or an appointment with one of these guys?

Marc: Well, they get extra training from Macmillan. A wider support pharmacist know about medicines and can advise around side effects and what to expect, but there's other things, isn't there? The fatigue. I was fascinated how to look after your skin if you're going through radiotherapy and what soaps to use. We've trained our pharmacists and our beauty advisors to help on those more practical, different areas that perhaps people who are affected by cancer don't want to ask their consultant about, that they feel or they hadn't and they remember later on.

Our Boots Macmillan Information Pharmacists are there to answer those questions, signpost to other services. They can get identified by a little Macmillan badge they wear in our pharmacies, or if you go on to our boots.com, you can find your closest information pharmacist for you to go in and have a chat to, really.

Emma: Do you need to make an appointment to go in, Marc? If you're there and you see somebody-- I didn't know that's how you identify Boots Macmillan Information Pharmacists, by the badge. I didn't know that, so that's great to know.

File name: macmillan series 2 episode 4.mp3



Marc: Yes, and you can go on to [boots.com/macmillan](https://www.boots.com/macmillan) and you can search where your local stores and we'll tell you whether or not that store has a Boots Macmillan Information Pharmacist or a Boots Macmillan Beauty Advisor. You don't need to make an appointment, you can just go and see them and they'll be able to answer your questions and signpost on and offer you further advice.

Like I said, through the pandemic, we've developed the role into a virtual information pharmacist. Now, you do need to make an appointment with that, of course, but you go online to make that appointment and then we'll connect you with a virtual pharmacist, like I said, and you can talk to them through an application, and see them, ask their questions. If you're afraid of going out or can't get out, you can still have the service. A number of people are finding that really helpful as they struggle getting out and about at this time.

Emma: Absolutely. I remember when my mom was sick, she was so concerned with her feet not being really dry and uncomfortable and we used to be in Boots the whole time making sure her feet were comfy. It's these things that-

Marc: It's the practical things, isn't it?

Emma: The practical thing.

Marc: The little things, they make a huge difference.

Emma: Make a huge difference, indeed. Rosie, Macmillan has got other partnerships as well in place to enable people with cancer to get practical support. What does that look like? What else is there that it might be worth exploring?

Rosie: We do have lots of other partnerships as well. We've partnered with Nationwide, for example, for over 25 years, and also Lloyds Bank, Bank of Scotland, and Halifax. The joy of this is that this is how we're able to help people with one of those worries. Finance is a huge worry for people going through cancer for lots of reasons. Macmillan has to train the staff at these banks so that they actually understand the specific impact of cancer on people's finances. Being trained in that, they can then offer their expert practical advice in relation to managing finances, personal banking, mortgages, credit cards. Again, there's more information about these partnerships on our website, so please do access them.

Emma: Marc, Rosie, as always, just so full of information and great, great advice and support. If I'm going to try and pin you both down to try and highlight the one piece of advice that you think is going to be the most useful for people who are finding themselves really struggling at the moment with practical support during this hideous pandemic. Marc, what would your piece of advice be?

Marc: I'd say talk to people. That's what I'd say. I think there's lots and lots of advice around. Lots of people don't know what that advice is or support is, but talk to Macmillan, talk to our pharmacists, talk to your consultant. Don't suffer all on your own, there are people around to help.

Emma: Rosie, I'm imagining you're going to echo that.

Rosie: I'm going to echo that and I'm going to be really sneaky. I know you said you were going to try and pin us down, Emma, but can I go for two.

Emma: Go on then, yes.

Rosie: Actually, to be fair, it's because they're not really mine, they're both from a patient who spoke to me this week about her lockdown experience. As we know, it's so hard also for family and friends when a loved one is diagnosed with cancer. Often it's such a struggle for those people to understand how best to help and support, and at the moment, that's, again, even more difficult because there are so many fewer options.

What she said was that, actually, she found it really helpful to just directly ask family and friends and ask for specific help. She said things like, "Can we have a telephone call and a cuppa or an online cuppa?" or "Could you get to the shops and get me this?" Maybe if it was a treatment day, "Could you cook an extra couple of portions of food and just leave them on the doorstep." Not wishing to encourage any infection risk, obviously. Really practical things.

The other thing she said, which was obviously music to our ears and great because that's what Macmillan's here for, but she said the other thing she found really useful was what she described as Macmillan's clear and understandable information, and just to know that Macmillan was there and her needs at its heart. I suppose what I'd be saying is, please, do use all the information of support that Macmillan and Boots have had. Be that Macmillan's online community for peer support, or the support line, and obviously, all the Boots services that Marc has talked about and all this information you'll find on the website.

Emma: It's absolutely brilliant and I'm just encouraging everybody to pass this podcast around so that we can just get as many people to know about all the fantastic stuff that is out there in this incredibly difficult time. Marc, Rosie, thank you very much. As always, a pleasure speaking to you.

[music]

Emma: For more information on the topics Rosie, Marc, and I have talked about in this episode, head to our website 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'll be talking about money worries that people with cancer may have during the pandemic. Subscribe if you'd like to hear that and every new episode whenever it's ready. If you enjoy this series, please give us a rating or a review. It helps others to find the podcast more easily. I'm Emma B. *Talking Cancer* is a Macmillan Cancer Support podcast.

[music]

[00:27:07] [END OF AUDIO]

File name: macmillan series 2 episode 4.mp3