



Emma B: What end-of-life support is available in a global pandemic?

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Emma: Hello. I'm Emma B, and welcome to Macmillan's coronavirus series of *Talking Cancer*. You might have already listened to our previous episodes in the series, in which case, welcome back. If it's your first time joining us, this is a podcast from Macmillan and Boots, where I talk to experts to get answers to the questions Macmillan is hearing the most. Today, for our final episode in the series, I'm talking cancer with Adrienne Betteley, who is the strategic advisor for end-of-life care at Macmillan.

Adrienne Betteley: If somebody is approaching end of their life, they are entitled to benefit. There's the DS1500, which is a benefit for people who have got palliative care needs.

Emma: We're going to talk about coming to the end of your life and what support is out there now that coronavirus is in the picture. I do just want to let that this episode contains content which might be upsetting for some listeners. For anyone in need of some support, please do contact the Macmillan support line. It's open seven days a week, 8:00 AM till 8:00 PM, and you can reach them on 0808 808 00 00.

We'll also hear some words of advice from the lovely Dany Bell and you might recognize her from previous episodes in the series. She's Macmillan's strategic advisor for treatment and medicines and she's going to be offering some practical suggestions for those coming to the end of their life during the pandemic.

Dany Bell: If you haven't already started conversations with your family or people that are really important to you about what your wishes are, then I would really encourage you to do that.

Emma: We're Macmillan and we're talking cancer. Adrienne, lovely to have you with us. Thanks so much for joining us on the podcast. Great to have you with us today. As we've done throughout the series, I'm going to timestamp this, and I don't know how you feel, but to me, the information and guidance seems to be changing daily. We're recording this over Zoom on the 20th of November, 2020, and everything we discuss is correct at the time of recording.

Now, we're discussing a really difficult topic today, end of life, and I've got no doubt that the pandemic has massively exacerbated thoughts around this. I know it's a really emotional time for people at the best of times. Adrienne, tell us what has the pandemic meant for those who are coming to the end of their lives? Are a **[unintelligible 00:02:27]** able to visit them at home? Can they get the hospice day care support, for example? So many questions, where do we start?

Adrienne: Okay. I guess, Emma, it's really worth acknowledging that irrespective of a pandemic, it's so difficult for somebody that is approaching end of their lives and for their families, their loved ones around them. That's been made a million times worse for people, obviously, because of all, as you said, the government guidelines,
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changes in them. It's really difficult to understand what you can and can't access from a support perspective and that's been really hard for people.

The other thing I just wanted to talk a little bit about as well is what do we mean by end of life care? Because I think sometimes people think it's just those last days, minutes of life, but actually, when health professionals talk about end-of-life care, and particularly for somebody with cancer, it's more about somebody who's got, for instance, an incurable cancer, but they may well have quite a long period of time to live. It may be a year, months weeks, days, hours of life. It can be any of those things, really, and it's important that people do get the support as early as possible to then have that continuity to be able to develop relationships with the professionals.

What impact has the pandemic had? It's obviously made it more difficult for people. I think particularly early on in the pandemic, it was really hard because people thought they couldn't go to hospital, thought they couldn't access services, were really frightened, which didn't particularly help people in accessing the support that they need, but I do want to reassure people they can get that support, they can district nurses coming into their homes, they can still go to a hospice.

You mentioned hospice day care, so there have been some services that have had to have to be adapted, for instance. Some hospices have had to use their day care and adapt it and change it into inpatient provision, particularly when there were more beds needed, particularly early on in the pandemic, but some of the services are still being delivered more as an outpatient.

I guess the other thing is to acknowledge that actually health and care professionals visiting people at home particularly, they really are trying to reduce contact. They don't want to spread the virus, so they're being really cautious. There may be situations where people are still accessing the services, but it may be in a virtual way. It may be by telephone, it may be a video call, and they may have less face-to-face contact, which is obviously hard for people because they want to see a real person in the flesh, so to speak, but they are still able to access all of those services.

Emma: Just expanding a little bit on the palliative care that people can expect at home. I think that's been a particular concern that we've been hearing at Macmillan. Can you just maybe dig a little deeper into what people can expect and who they might talk to, those pathways of communication, in order to get the best out of that palliative care they can expect at the moment?

Adrienne: Yes. Particularly at home, there are various different aspects of palliative care that they can access. There is palliative care that they can get through their GP, through their district nurses, community nurses coming into their homes. It could be physio, it could be occupational therapist, and or it could be, for instance, Macmillan's specialist palliative care team, which may be a specialist palliative care nurse when things are more complex.

I guess if people are really struggling, there are lots of other means of support as well. There are local hospices in some areas, although not all areas, there is our



Macmillan support line, which is available seven days a week, 8:00 AM to 8:00 PM, that can offer guidance and support. We've got an amazing website. You can get all sorts of information on there.

There's also Boots pharmacies, which are able to support people with urgent supply and delivery of medication, which is absolutely vital for people, because obviously, the more your condition deteriorates, the more likely you're going to need more complex medication. You can also get virtual appointment with Boots Macmillan Information Pharmacist who can give you and your loved ones and carers information about medication and any potential side effects, as well as guiding people to more specialist information support. You can book a virtual appointment with Boots @boots.com/macmillan.

Emma: One of the things that's creating the most anxiety amongst people, patients, relatives, carers is consistency. Adrienne, would it be fair enough to say, I think with the changing landscape, as frequently as it is, and various areas of the country dealing with this pandemic in their own way, to a degree area to area, that is still really important to check with your healthcare professionals because what might be okay in one place isn't okay in another, for example?

Adrienne: Yes, absolutely fair to say. There is different provision across the UK, and even the fact that we've got four nations who have different guidance. It's really important even within your own country, within your own local area, if you are being provided support by a healthcare provider, for instance, they may have different rules and regulations. Each hospital will have their own policies about visiting, things like that.

The community teams will work slightly differently, again, to fit in with the local needs and the local services, so you absolutely do need to check in with whoever your point of contact is, whether it's a specialist palliative care nurse, whether it's your Macmillan nurse that's at the hospital, whichever the provider is, it might be an acute oncology nurse, for instance, but do speak to them about what you can access.

Emma: We're in the middle of a pandemic and I guess one of the biggest worries, seems so obvious really, is that what happens if somebody is coming to the end of their life and they catch coronavirus, what happens then? It's hard to believe that, but, of course, it is what might happen. What should they do if they're getting symptoms?

Adrienne: Obviously, somebody who potentially might be having still palliative chemotherapy who's approaching the end of their lives is going to be, for instance, more susceptible, but that would be the case if we weren't in the midst of a pandemic and they could be more susceptible to things like a chest infection. Don't feel too alarmed. Lots of people manage to cope with coronavirus, don't always have extreme symptoms. Sometimes people just have loss of taste or they might have a bit of a persistent cough or whatever, but it's really important that you notify your healthcare provider and try and get tested as quickly as possible and follow all the government guidelines as you would in any situation.



It's about reducing any contact, about trying to stay in isolation. I do want to reassure people they can still get the support that they need, even if they were to get coronavirus and they were terminally out, for instance.

Emma: I don't think it's news at all that, of course, the pressures on the NHS and the pressures on healthcare services are immense during this time, and how everybody is dealing with this is definitely affecting people's care for all sorts of different conditions. What if people are being discharged to go home but feel that they haven't been sent home with the right support or the right care package, what happens if you are a relative or a carer and you are concerned that people have been sent back and you're not really that everything has been done that could be?

Adrienne: That can sometimes happen even when we're not in a pandemic. It's really important to get in touch with your local GP surgery, who can put you then in touch with the community nursing team, so you can expect to be able to have a visit from a community staff nurse or a district nurse who come out and do a holistic assessment. They'll look at all of your needs in your home.

They'll think about, do you need a bed downstairs, for instance? Have you got access to a toilet? All of the really practical things, as well as you need to also think about, are you getting the right benefits? That's really important, particularly in the current climate when people are really struggling financially. If somebody is approaching the end of their life, they are entitled to benefit. There's the DS1500, which is a benefit for people who have got palliative care needs. That can be fast-tracked if you are approaching end of your life and your GP can sort that out or your Macmillan nurse.

Again, if you are not sure, then please do get in touch with Macmillan support and they can point you in the right direction. Particularly on the support line around the finances, we do have a benefits checker, which is fantastic. You can do it online, check if you're getting the right benefits or if your loved one's getting the right benefits. I would really urge people to make sure they do get the right support, but it is out there and they can get it.

Emma: One of the effects of the pandemic, as you've clearly explained, is that there is pressure on resources and face-to-face contact is reduced, which means that sometimes there may be family, relatives, friends who find themselves in the caring role that would normally be given by a healthcare professional, which is quite a scary, overwhelming experience for a lot of people. How can they best support their loved ones at the end of their lives and what does the guidance so far allow for?

Adrienne: Again, even when we're not in a pandemic, often people do get involved in the care and support of their loved ones at home because there isn't usually the 24/7 support that you would hope to be able to get. If you are looking after somebody, you may get involved in doing some of their personal care, things like that, you may be involved in support in giving them medication, for instance, but they can still access the support from their community team who can talk them through all

of this, whether it's virtual, whether it's coming along and show them how to do things. They won't be own. I really want to reassure people they're not alone.

Also, we need to make sure the carers themselves are supported. They're entitled to a carer's assessment. There may be other sorts of support that they can get. Again, they may be entitled to benefits themselves. Again, it's really worth phoning up our Macmillan support line to see what they're entitled to and what they can get.

Emma: Practical, basic questions. For example, if a relative needs to move in with somebody that they are then going to look after, is that allowed at the moment?

Adrienne: People are still allowed to provide that care for somebody at the end of life. They do have to follow the guidance, but the best thing that they can do, particularly, is to ask their healthcare provider. Speak to their specialist palliative care nurse, for instance, the Macmillan nurse, speak to their GP or district nurse and just ask what is feasible. Nobody would stop somebody being with their loved one at home if they were caring for them. Obviously, people are using their own sensible, pragmatic judgment about supporting a loved one because it's so important to be with somebody, isn't it? It's absolutely crucial.

Emma: Just to be clear, Adrienne, if you are finding yourself in the caring role at the moment during the pandemic, you are not expected to take on that role as the healthcare professional, are you?

Adrienne: Oh, absolutely not. You may end up doing some practical things supporting your loved one at home, but that wouldn't mean you'd be doing really complex things like administering high doses of medication or dealing with really complex care. Anything like that that would be delivered by a healthcare professional will still be delivered by a healthcare professional.

Emma: Just briefly, as well you mentioned, obviously, we need to make sure that our carers are looked after. In terms of support out there for carers, is there someone on the end of the line if this is all too much on occasion and you need to offload and really find some support that way?

Adrienne: Yes. Usually, the community teams who are providing that support are also there for the carer and not just the individual themselves. There are lots of other sources of support. Again, our Macmillan support line is there for people. Please do phone up, get that support. There are other sources of support. There's booklets around caring for somebody at the end of life. There's a guide about that. There's also a Boots Macmillan Information Pharmacist, who we mentioned earlier, who can also support carers and loved ones. Do make an appointment virtually or speak to him in-store. There are some fantastic organizations as well, like Carers UK, who will offer support and advice.

Emma: Adrienne, please don't go anywhere, stay with me. We'll talk more in just a minute.

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Advertisement Emma: 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

Emma: Adrienne, we've been talking a lot about what Macmillan's support line is hearing from our callers. What can people do to feel more in control at a time when everything feels uncertain?

Adrienne: Even when we're not in a pandemic, there is so much uncertainty about end-of-life care. Often when people living with cancer that is treatable but not curable, they are living with uncertainty and trying to maintain hope. One thing that people find really beneficial is having a really good conversation with your health or care professional. It's really important to have open honest discussions that the professional will tell you about your prognosis, about what you can expect, what treatments, what choices there are.

One of the best ways to do this is to have what we call an advanced care planning conversation. It's also known in Scotland as anticipatory care planning. That's really about a nurse or a doctor talking to you and saying, "What matters to you? What's important to you?" Then being able to write down your preferences and wishes, and think about things like if you were to lose capacity, who would you want to make decisions on your behalf, and actually naming that person. Things like would you want to refuse specific treatments at the end of life?

When people have those conversations, they're really, really hard conversations to have, but actually people feel quite empowered and it does almost instill a sense of hope because people feel this sense of, "Okay, I've done that, I've sorted out, I've got my affairs in order. I'm able to have also written my will, I've talked about my funeral, all of those things. It then enables them to think about the here and now and the quality of life and trying to get the most out of life. That is a really empowering thing to do. I really would implore people to have those really good conversations and talk to their loved ones about what matters to them as well.

Emma: It seems like that would be one of the most difficult things in the world to do, but I instinctively understand the kind of space to breathe that it gives you once that's done.

Adrienne: I have to say, with my own mom, when she was dying, she had esophageal cancer, and she went upstairs with her Macmillan nurse and had a private conversation. I felt a bit left out at the time, but we talked about it afterwards. When she came back downstairs, she said, "Oh, Adrienne," she said, "I feel so relieved. I didn't realize I could die at home. I've planned which bed I'm going to die in. I don't want to be in the same bed as your dad. I know what support I can get." It's such a sense of relief to have it out in the open, to talk about it, and to know what to expect. That's hugely powerful for people.



Emma: I guess, as well, Adrienne, never forgetting family members. There's always somebody on the end of the line, we know that, at Macmillan if you are struggling.

Adrienne: Absolutely. I really would urge people to do that, and particularly for those who are bereaved as well. Bereavement support is a bit variable across the country. Sometimes people have to wait to access it, but the Macmillan support line is a really great source for people to actually phone up and just have a listening ear at the other end. Sometimes that's all people need, just somebody to talk to about how they're feeling, because particularly for grief and loss, it's a normal part of living and dying, isn't it? We all experience it.

Emma: Of course. Adrienne, amazing to talk to you, especially with such a sensitive and difficult topic at such a bizarre time that we're having at the moment. Thanks so much. You take care.

Adrienne: Thank you.

Emma: Now we talk to Dany, who is back to give us some practical advice for people coming to the end of their life in a pandemic.

Dany: Hi, everyone. I'm Dany. You might recognize me from previous podcasts. I'm a strategic advisor and I work at Macmillan. Just a few tips for people around end-of-life care. My first tip and probably the most important is, if you haven't already started conversations with your family or people that are really important to you about what your wishes are around where you want to be cared for, things you want to do, et cetera, then I would really encourage you to do that.

We have some really good tools that can help you do that. At Macmillan, we have an advanced care plan planning booklet and it gives you general information on how to talk about your preferences and your wishes with your family, any legal issues, so if you need to give power of attorney to anyone.

I guess, the second tip would be that it would be really nice for you to involve people that you care about in the practicalities so that you don't do things alone. If you haven't got a will, it's really nice to involve your family in that so that they know and also can think about the support services that you want to draw on or that would help your family. I guess finances is often a thing that people worry about, and we do have a guide for end-of-life care that, again, has sections in it around getting financial help and also some information in there for your relatives.

I guess, lastly, it's really important to maintain contact with people and maintain activity. It's hard at the moment with restrictions, but there are ways to do things safely to still enjoy that human contact and get fresh air and undertake other activity. Whilst it's a really difficult time probably for you and your family, I would absolutely stress that those sorts of things are really important.

Emma: Thank you so much for that, Dany, some really useful advice there. For more information about the topics Adrienne and I have talked about in this episode, head to our website, macmillan.org.uk/talkingcancer. There are lots of really helpful

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resources on there as well as details about where you can reach advice and support. Please use them. It's also where you can find out more about donating to Macmillan.

Now, that takes us to the end of this series, and the last six episodes have gone so quickly. It's been so fantastic talking to so many different experts at Macmillan and Boots to answer your questions. Remember, you can still reach Macmillan on their support line, seven days a week, 8:00 AM till 8:00 PM on 0808 808 00 00, or reach out to Boots Macmillan Information Pharmacist, and you can do that in-store or online.

If you've enjoyed this series, please give us a rating or review, and it helps others to find the podcast more easily. Thanks so much for listening. I'm Emma B. *Talking Cancer* is a Macmillan Cancer Support podcast.

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