Age And Stage Episode 10

Daisy McAndrew 00:03
Hello and a very warm welcome to Age & Stage. This is the podcast for everyone caring for or supporting elderly relatives, parents, friends or neighbours.

Annabel James 00:13
This time, it's a difficult topic as we mark Dying Matters week.

Liz Pryor 00:17
Do you mind what happens to you as you come towards the end of your life? Would you like to decide what care you have where you die? Would you like to decide who looks after you and who doesn't look after you? It's important to talk about that. If you feel very strongly about it.

Annabel James 00:32
That's Liz Pryor from the Anne Robson Trust. And yes, I know it's a subject that we try to avoid talking about, but it's such an important one, and Liz has so much valuable information and advice for those of us caring for older relatives and friends, it's well worth taking a listen.

Daisy McAndrew 00:49
My name is Daisy McAndrew.

Annabel James 00:51
I'm Annabel James, and this is Age & Stage. Just before we start our conversation with Liz, I wanted to thank everyone for subscribing, downloading, sharing, and also for some of the lovely reviews we've already received for the podcast. Thank you so much.

Daisy McAndrew 01:08
It is very, very nice to think that we are helping. And we've had this conversation so many times with our friends and our sort of wider friends and WhatsApp groups, which is really where this whole idea came from, because the sandwich generation that we are, it's something we talk about a lot. So now, talking about it more publicly, and getting that conversation going with people we don't personally know is really lovely. And yes, reviews saying, You know what a lovely, upbeat conversation can be hard. You know, these times can be hard. That's the other thing. It's very lonely, sometimes looking after elderly relatives and so on. So you know, if we can help with that loneliness, that will be very, very good.

Annabel James 01:48
There isn't much subject matter, there isn't much similar out there at the moment. So hopefully more people will find us over the coming weeks and months. And actually, as our episode list grows, there'll be more information on more subjects for more people, which is really exciting.

Daisy McAndrew 02:06
Exactly that. Just looking at a review here, saying loving the honesty. I'm wondering whether we're going to get to a stage where we're being too honest. Forget we're not just talking to each other when we give a bit too much information. TMI, but we'll keep each other in check.

Annabel James 02:25
Well, speaking of honesty, it's time for a frank conversation about a difficult subject, as we mark Dying Matters Week with Liz Pryor.

Daisy McAndrew 02:33
Liz, thank you so much for joining us today. And obviously, the subject matter we're going to be covering is something that we all spend a lot of time thinking about, isn't it? Can you just explain a little bit what the Anne Robson trust is and what it does.

Liz Pryor 02:47
The Anne Robson Trust is a charity that I set up nearly seven years ago I think. I set it up in memory of my mum. I set up the charity to help people be supported as they die, to have as good a death as they can have. We do a number of things, a whole spectrum of things. We have three avenues of work. We have our resources on our website, bit like yours, not nearly as extensive as yours, Annabel, but similar, but much more specialised. So it's around death and dying, and how to plan for it, what to plan for, how to record the things that you want to record, why it's important all the way through to how to support someone when they're dying. We also run simple wisdom workshops, which are very simple. They're more like conversations than workshops, really bringing those resources to life and having a conversation about them. And then the main crux of our work, and how we started off is working with healthcare organisations, so acute NHS hospitals, so big general hospitals and hospital trusts, community NHS Trusts, and care homes and hospices. And very recently, we started working with a primary care network, so looking at having volunteers supporting people in their homes in the community, we help them set up specialist teams of volunteers who will sit with people who are dying, give their time to them, be there for them, so that these people aren't lying in bed in a hospital or wherever they are, whether they're in the hospital or hospice at home, in a care home. They're not on their own in those days, weeks, hours before they die.

Daisy McAndrew 04:25
When should we start thinking and talking about death? Because I think a lot of people will think if you start actively planning it, you're almost willing it to happen, and clearly not willing it to happen.

Liz Pryor 04:37
Well, I'm testament to the fact that that does not happen. I've been talking about this for quite a long time, and talking about death and dying doesn't mean you're going to die. Actually, I had somebody in a workshop who said something very funny, and she said, You know, I suppose you're right. Talking about death doesn't mean you're going to die. I mean, it's a bit like saying talking about having a baby makes you pregnant, isn't it? I suppose it is. To answer your question, Daisy, I think now, yesterday, a year ago, start talking about it. Don't talk about it all the time. You know, it's not something we all need

to be droning on about. What we need to do is have those conversations, in my opinion, before you're staring it in the face, before it hits you before you're in the eye of the storm.

Daisy McAndrew 05:22
And what are the questions and conversations we should be having?

Liz Pryor 05:25
Everybody's different. Do you mind what happens to you as you come towards the end of your life? Would you like to decide what care you have, where you die? Would you like to decide who looks after you and who doesn't look after you know, some people have situations where they don't want certain members of their family coming to help. It's important to talk about that. If you feel very strongly about it, some people don't feel strongly at all, and they just go, do you know what? You decide, I'm not bothered by it, which, again, is another complication, because then, you know, I've been listening to some of your other previous podcasts. You mentioned complications with siblings around all of these sorts of things and disagreements. And you know, it can be really, really hard if there are lots of people with an opinion, and the person who's dying hasn't written anything down, they're all guessing.

Annabel James 06:13
Do you think we should have the conversations and actually then write this stuff down and do the advanced care plans and the DNRs and all the different bits of paperwork that one could do.

Liz Pryor 06:26
There's a bit of work to do way before the advanced care plans and the DNRs, which is about right from when you begin to sort of collect things in your life, it's a good idea to have a will. We have something on our website called "my wishes" checklist, which is free to download from the Anne Robson Trust website. It's a crib sheet, essentially, of things that might be useful to jot down. No one wants to think about it but anyone, we might go under a bus tomorrow. You know, how annoying would it be if your family didn't know the Netflix password? Also insurance, car insurance, you know, all the housekeeping, boring bits of life. It's a good idea to jot down. You can fill in my wishes digitally so you don't need to print it off if you don't want to. But I would always recommend you store it somewhere really secure, you know, a password protected area on your laptop, or something like that.

Daisy McAndrew 07:18
And Liz, I suppose here we're talking about, there's sort of two elements, there's the run up to the death, there's the death, and there's after the death. So when you're talking about my wishes and stuff you're talking about after the death, and in some ways, I find talking about that with my family, so you know, like, what sort of funeral would you like. That doesn't seem so bad, but talking about the actual death does seem like a very difficult conversation.

Liz Pryor 07:46
It's very, very final, but I think the more we talk about it Daisy, the more it's not so frightening. It could be not so frightening. And that's why during in our simple wisdom workshops, we talk about, what are those parts of that process that you can recognise. You know, I didn't know until I started learning about this sort of subject, that during the stages of somebody actively dying and actively dying, my husband

laughed at me, I did a radio interview, and he said, You can't, what's that? You can't say that - it doesn't work. And I said, No, no, that's what the clinicians will talk about. So it's important that people understand these phrases. And we have lots of resources on our website that go through all these different technical terms that people use when when they're having conversations with families and families so often a) don't hear it because they're like, I'm in this awful situation, and b) don't understand it, even if they do hear it. You know, when somebody's actively dying, they go through stages of physical changes to their body. Your breathing might change. You know, there are lots of different physical things that happen to you that I think if you can understand a bit about that, you can feel a little bit more confident in how you're sitting with someone and how you're supporting them as they go through that themselves. And you know, I always feel if the people sitting around the bed look absolutely terrified, how frightening must that be for the person in the bed?

Annabel James 09:16
You're listening to Age & Stage. Are there any questions you have or topics you'd like us to discuss on future episodes? Do please email ageandstage@agespace.org or follow the links in the show notes to this podcast. Now back to the show.

Daisy McAndrew 09:33
People often say that they want to die at home, and families often jump through lots of hoops to make that happen. My father died in a hospice, and actually, I think he had a fantastic death, and he was surrounded by people who knew what they were doing, and we as the family found it so reassuring for them to explain to us that he was going from Phase A to Phase B to phase C, that his breath was changing. And if you're on your own at home, I just worry that you don't have any of that expertise around you.

Annabel James 10:03
I don't think you even need to be at home.

Liz Pryor 10:05
That's why it's important to do these workshops to come and learn about it in a time when you're not in that awful crisis moment. We had a lovely email from a lady recently who said, both my parents died within the space of four months, and if I hadn't been to one of your workshops, I would not have been able to support them in the way that I was able to support them, and I would have been much more traumatised than I am. So I know they work, and I know having that little bit of education around what's going to happen, or probably will happen you know, there are always other things that can happen, but what's normal and what can easily happen, it's important that people learn about it and don't just sort of shy away from it and put it in the corner that we're going trying to hide.

Daisy McAndrew 10:53
And Liz, can you give us a mini workshop now of what sort of things our listeners can expect?

Liz Pryor 11:00
It needs context, and it needs a lot of discussion. I don't think we've got long enough for me to give you a really good example of what it looks like. But most deaths - not all, because it's really important that

we say that not all deaths are easy and dignified, and some nasty things can happen when someone's dying - but usually somebody gets sleepier, they're probably unconscious, which is different to being asleep. You can't wake somebody up if they're unconscious, so then they come in and out of it, they might rally a few hours or days before they actually die, and may even go so far as to wait for their son, who's coming from Australia, and spend some time with him, and then die. They may have family sitting with them, but they may not want to die with their family next to them. So they may wait for that family to go out for coffee, and then they die when they're on their own. So these things happen. It goes they get sleepier. Then as it gets closer, their breathing will change. So you, I don't know if you've come across the word Cheyne-Stokes breathing. Cheyne-Stokes breathing is when someone's breaths get shallower then it might get a bit irregular, and then they might stop breathing for a bit, and then they'll go <gasps in air> and then everyone in the room does it as well. And it's the weirdest experience. The other things that might happen is their extremities might get cold because all the blood is going to their centre core to keep them warm and to try and keep their organs going. But these things are all very, very natural and very normal. We hear something called terminal agitation, which is when people get very suddenly, get very anxious, they might feel very sick. All these things can be managed with medication. I don't know if you've come across something called "just in case" medications, or drugs that you can have if you're discharged from hospital to die and the palliative care team, they will send you home with a pack of drugs that are called just in case meds, or just in case drugs that the community nurses or palliative care team can administer, should it become necessary, medications for all these different symptoms of end of life will be in those just in case meds.

Annabel James 13:16
And presumably there really isn't a time frame for all of the signs that you've just spoken about that could be days or weeks?

Liz Pryor 13:24
Just like somebody who might be in labour for three days, or they might have a baby on the kitchen floor. It's about as simple as that. It just totally depends on the person. You know. I know, my dad stayed alive longer than the doctor thought he would, because he was absolutely determined he didn't want to die.

Annabel James 13:41
When you and I first met, I was still really confused about my own mother's death, and what we realised, I think, in speaking with you, is that we never had the conversation with the medics. We actually didn't know she was dying. We thought this was a blip and she was going to recover and she was going to go home. And it was all such a shock. It was so bizarre. And I think we had expected the medics to have the conversation with us. So from a family perspective, how do you sort of navigate your way through talking to the medic? If you haven't got an Anne Robson volunteer sitting by your side, what's your advice to family members who feel they might be getting to this stage but are not necessarily getting a huge amount of communication from medical staff?

Liz Pryor 14:25
My advice would be to ask the question, if you feel you can ask the question very directly, do you expect my mother to die in the next week? That's the question I would ask. You know, would you be

surprised if my mum died in the next 12 months. So some people don't like saying dead or died or dying. Some people would prefer passed away or moved on. My advice would always be to say the D word once, so that people really do hear it.

Daisy McAndrew 14:56
And what do you think the mistakes that people make, other than not communicating directly, not asking the difficult question, either to the medical community or to the family member, what are the other mistakes that people commonly make?

Liz Pryor 15:09
I think not having had the conversation much earlier on, you sit in the garden with a glass of wine and have a chat about what music you might want at your funeral. You know you can all talk about it, whereas, if you're actually planning your mother's funeral and she's dying and you want to talk to her about what she actually might want. It's much harder for everybody. It's important to have those conversations. I think that's a mistake people make. I really do. And then you go on to DNA, CPRs, and all the clinical paperwork that you can have in place that are really, really important as well

Daisy McAndrew 15:41
Talk us through those. So there's a do not resuscitate. But what are the other ones that people should be aware of?

Liz Pryor 15:46
Well, there's an advanced care plan, or it could be called a living will, or it's called loads and loads of different things. And there's some amazing information on Age Space's website and on our Anne Robson Trust website too. It's a plan about what you want to happen to you as you die. You know, there's something called a respect form, which, again, is this very simple tool. And lots of clinicians use respect forms now, and hospitals use them. It's really key to write down what you'd like, because if you've got it written down, they will endeavour to make that happen,

Daisy McAndrew 16:18
I suppose as well as the D word being uncomfortable for a lot of people, the word hospice is also uncomfortable for a lot of people, because it denotes the end to you know, if you say Dad, I think the time has come to go to the hospice. It's like you're saying Dad, you're about to die, to a lot of people's ears. And yet, my own experience showed me that it was a brilliant place to be. But it's scary, because you think once you go in, you're not coming out, which we all know, you can go in for respite and you can come out. But how do you go about finding a hospice how? Because my understanding is there's so many different types, and there's sort of postcode lottery. And how does it work, I guess, is the question I'm asking. How do hospices work?

Liz Pryor 16:59
Do you want to pick it up Annabel?

Annabel James 17:03

I suspect it comes more down to the resources of the hospice as to whether or not the local one to you has a bed. I think what's brilliant about the hospice movement is that they do so much more in the community these days. So actually, dying in a hospice isn't necessarily what everybody has, if you see what I mean, you can die at home with the support of the hospice, which I think is brilliant, because in a way, dare I say it's such a really difficult time that must be the least worst option for many people,

Daisy McAndrew 17:37
You've got the expertise, but you've got the comforts of home, and your family can be there

Liz Pryor 17:40
I mean, I think hospices are incredible organisations. I think about a third of their funding is NHS, but that's being reduced. They tend to have between sort of eight and 15 beds, inpatient beds, but their day services and hospice at home services are usually quite extensive. Some hospices only have hospice at home. They don't have any inpatient beds. I would say to your question Daisy about how to access it, Google it, but also talk to your GP, push in, get an appointment, get in front of them and talk to them about it, because they should always be the first port of call, but you can ring your hospice directly as well.

Daisy McAndrew 17:41
Other things that family members can do to prepare? I keep reading at the moment about these services that will go and interview your parents and put down their memories and so on into some sort of talking book, or a literal book, or something like that, which it seems, you know, a very, very, very sweet idea, but I wonder what more practical issues the things we should be thinking about?

Liz Pryor 18:45
Take in a little bit of something that they might like a taste of. You know, people when they're dying, one thing I didn't pick up earlier on, people when they're dying, they don't want to eat and drink anymore. It's not because they're being starved or any of these things. It's because their body can't digest nutrition or fluids, but they might quite like to have a bit of a taste in their mouth, a little tiny bit of ice cream, for example, or, I don't know, but not great big spoonfuls of it, because they don't., people don't need that. The thing we haven't talked about is lasting power of attorney, which I think is very, very important if you're in a position where you can't make decisions for yourself. Do you want clinicians to make the decision? Or would you prefer your closest loved ones to be able to do that? If the latter is the case, then you must get a lasting power of attorney in place, and it's really, really important.

Annabel James 19:36
You're listening to Age & Stage from Age Space, if you'd like to find out more about how we can help, Age Space is a one stop online resource for anyone caring for or supporting elderly parents and relatives. It's packed with information on funding, on care, on legal matters, then do just please head straight to agespace.org Now back to the conversation.

Daisy McAndrew 20:01
Just going back to the pregnancy analogy, obviously, there are birth doulas and there are death doulas. What are death doulas?

Liz Pryor 20:10
So death doulas are a movement of people. They could be called Death Doulas or Soul Midwives sometimes they're known as and they're people who literally are a midwife for the end of life rather than the beginning of life. I've worked with lots of soul midwives and death doulas, but not in their capacity in that role. So often they'll come forward to be volunteers to do the work that we're doing with healthcare organisations. What we do is slightly different. Theirs is rather more spiritual. They'll sort of support someone on their journey for the last 12 months of their life, is usually what they do, I think, and then support the family a bit afterwards, after the death as well. Some of them you pay, and some of them don't. I think most of them you pay. But as I said, we are about to start a project working with our local primary care network, which will be putting engaging volunteers to support people in their homes as they die. It won't be the same as being a death doula, but it will be very much there for the last three months of someone's life. I think,

Annabel James 21:14
Is that the kind of grand plan for the Anne Robson Trust?

Liz Pryor 21:18
Yes because everything in the NHS at the moment, well, not everything, but the focus is very much moving it back into the community, rather away from acute hospitals. What they're trying to do is reduce emergency admissions admissions reduce emergency call outs for ambulance paramedics to come out and try and allow people to die at their preferred place of death if they can. So the focus is very much on the community at the moment, and whilst we're obviously carrying on working with acute hospitals and hospices, our new project is looking at how we can provide support in the community.

Daisy McAndrew 21:54
Liz that's fascinating, and it just makes me think about all our expertise. Once somebody, you know myself or Annabel or you have been through this once you've actually learned the hard way, a lot of knowledge, and that knowledge, you know, yes, you'll be using it again sadly, when your other parent or your in laws will ever die. But actually, you know you could offer your services as a volunteer once you've been through it yourself. I mean, there might be an army of people listening right now!

Liz Pryor 22:23
Well, I hope so. That would be amazing, wouldn't it?

Annabel James 22:25
Well, we'll certainly put something on the links. If somebody has recovered from their own experience to the point where they think they'd like to use that experience to help other families, that would be a lovely thing.

Liz Pryor 22:36
Thank you. That would be great.

Daisy McAndrew 22:38

Well, Liz, best of luck with the Anne Robson Trust, something obviously you've set up in in your mother's memory. I'm sure she'd be incredibly proud of you.

Liz Pryor 22:47
Thank you. That's very kind. Thank you for having me.

Daisy McAndrew 22:53
Well, Annabel, that was a fascinating chat, a difficult conversation for many of us. We don't like talking about the D word, as Liz was saying, but gosh, she had a lot of really valuable advice, the obvious ones, but I thought the my wishes checklist on her website sounded very, very useful, and

Annabel James 23:11
then we didn't get into the stages of death, but I think very helpful, hopefully, to some of the things to look out for that people might want to see if you know, feel that their parent or relative is in that final stages. Because I think it's a really without having any information about it, I think it's, you know, it's even more frightening, isn't it?

Daisy McAndrew 23:29
Yeah, I thought the workshop sounded really interesting, she was talking about her four hour workshops where she really gets into giving somebody all that advice. "Just in case" drugs. I'm not sure I knew about "just in case" drugs being sent home. I mean, that's reassuring.

Annabel James 23:44
And I love the fact that the Anne Robson trusts are working not just in hospitals, but in hospices and care homes, so really helping to sort of spread that information and advice, you know. And obviously, if you don't have access to one, the fact that they've got loads of good stuff on their website.

Daisy McAndrew 23:59
Yeah I mean, I have to say we did plan my father's funeral around his death bed. And actually it was quite jolly. I mean, you remember him, Annabel, he was a very, very funny man, and he was coming out with all these, you know, saying, I don't want any of you to wear black. I want you to wear bright clothes. I want you to sing Que Sera Sera came up with that. And, again, it was all because we were surrounded by people who were giving us the space to talk about things that, you know, he wanted to. We love to see that he still was cracking jokes. It was very reassuring for us and and I was so upset to hear about Liz's mum, Anne, but her experience and my experience was so different, and it was because we had, we were surrounded by the right people, and you can prepare for that.

Annabel James 24:47
Yeah, my dad left us his entire funeral service in triplicate that we were unable to deviate from, even if we wished, which was absolutely fine, and got it out, you know, two days before he actually died. So that it was on the desk and ready to go, which was extraordinary. Yeah, I think, you know, my mum had a very different experience, and I wish we'd known then, you know what we heard today, actually, I must say, so really, really helpful and incredibly useful. And so thank you, Liz,

Daisy McAndrew 25:17
Thank you. Liz, so much.

Annabel James 25:25
Thank you so much for listening to this episode of Age & Stage.

Daisy McAndrew 25:29
If you found this show useful, and we do hope you have we bring you a new episode every week with the latest advice and knowledge from experts in all aspects of later life. So click follow or subscribe in your podcast app to make sure you don't miss any editions.

Annabel James 25:44
Next time, we talk to geriatrician and Author, Dr Lucy Pollock.

Lucy Pollock 25:49
People in primary care, in general practice, they have got an enormous workload. And also, quite often, these medicines are added by a specialist. You know, GPs do not like to stop a tablet that a cardiologist started. And also, to be honest, there is so much medication now that quite often the GP won't know what that tablet is.

Daisy McAndrew 26:07
Thank you so much if you have rated or reviewed our show, it's been great to see the value that so many have gained from Age & Stage already. But if you haven't, leaving a review, can recommend new listeners to the show, and we would really appreciate you taking a moment to write a few words, and please do tell a friend who you think would benefit from hearing Age & Stage. Thank you so much, and we'll see you next time.