

Cllr Jim Millard: Hello and welcome back to Talk Richmond. Did you know that more than three in five of us will become unpaid carers at some point in our lives. An unpaid carer is someone who looks after a loved one who due to illness, disability, a mental health problem, or an addiction, could not cope without their support. Apparently over 18,000 people in Richmond upon Thames provide unpaid care and today's episode will discuss this role played by so many people who often don't even realise that what they are doing for their loved ones is caring and that they could be receiving support. Joining me today for this important discussion is Sara Challice. Sara lives in the borough and cared for her husband for 13 years after he became severely disabled from a brain tumour. Sara is the author of *Who Cares*, a bestselling book, which empowers carers to look after their health and wellbeing. Sara joins us to talk about her experience and to share her advice on looking after yourself whilst caring for someone. Hello Sara, thank you so much for joining us.

Sara Challice: Lovely to meet you. Thank you for having me today.

Cllr Millard: Thank you so much for joining us and I've already mentioned you're an author. And obviously I know your story is very personal, but I wondered if you could tell us about what happened to you and your husband and what journey led to you writing the book.

Sara: Yeah, thank you, so we're going back to 2002, my boyfriend - I'd only been seeing him for six weeks - fell ill with a brain tumour, and he'd been so fit and well up to that point, we had no idea and I just said to Neal, you know, get better, I'm here for you, not realising the impact it would have on my life and through those years that would happen. So, for 13 years moving forward, I ended up caring for Neal as he slowly became more and more in decline. More disabled, ended up having a stroke, bedbound in our living room and being hoisted every day, and when it comes to caring, you're in that zone of caring for them trying to keep them going. Offering that support mentally, emotionally and physically and at the end of the day your life is on the back burner and that's what happened to me as it does for many of us caring. And with that I ended up falling ill myself from the stress – that constant looking after him. Neal was unable to speak, so we couldn't have that same relationship that we did before. I was more like his mother or his nurse, and even friends and family didn't really understand what I was going through. And sometimes they were judging because I always had a smile on my face looking like I'm coping. A lot of us as carers do that where we want to look like we can, you know, it's our loved one who's ill, not us but the trouble is if you're not looking after yourself, not taking care of yourself, the cracks finally start to show, and that's what happened to me. Neal ended up in a nursing home. I had to be rescued and cared for, in essence, because I wasn't looking after myself. And with that I went on a silent retreat of all things. I managed to shut up for five days, and during that time I thought, oh my God, I've got to make changes because I'm not going to be able to survive caring for him and he'll die in a nursing home. So, with that, that's what I did and bringing Neal back home - not only was I caring for him, I was caring for myself and in the last year of Neal's life I started to write the book because I found that I was actually enjoying life again. I was making sure I was seeing friends or in contact with them, which I hadn't been so much before, and I'd managed to regain my health. And that's the message that I want to share with anybody out there, caring for a loved one: life is not about abstaining and enduring. It is still about enjoying your life because these days, weeks, months, years, they won't come back again. So, it's important that you look after you.

Cllr Millard: What were some of the biggest challenges you experienced through the years of caring for Neal would you say?

Sara: Well for me you know my world became a lot smaller. I felt more isolated. I gave up my job, so that's the trouble for many of us. You cut out what you were doing before and your life is on hold in

essence, whilst you're looking after them. My life was almost tethered to his hospital bed really, even if I did get out and I was seeing friends, my thoughts were always with Neal. I kind of solely made myself responsible for his life, which is a tall order when somebody is very close to going at any particular time. I did have to revive him at one time. And I suppressed my emotions. That's a big one and I would say that about all carers - I was suppressing my emotions, ignoring how I felt emotionally and physically. I didn't want to look at that to be honest with you, I didn't have time to deal with that, but we do need to and I'll be honest with you, I distracted myself with prosecco. I kind of joke about it, but you know, we all have distractions in our lives and for me it was having a bit of a drink and if I got out of an evening I could drink my body weight in fizz, I'll be honest with you. But that's what I did to let my hair down. But if you saw me on Facebook, as I say, well I always had a smile on my face and a drink in my hand. I wanted to look like I was coping when I wasn't, but I call it Fakebook really, because you're not really showing the real me. So, I kind of joked with a friend, said if I took a snapshot every day, say 4:00 PM, you know what I was doing each day for Neal, it ain't me with a drink in my hands, you know, I'm probably changing his nappy. I'm cleaning his feeding tube. I'm hoisting him. I'm probably crying. But not letting others know so it's so important that we do let others know. And if I did get out, I felt guilty and I think that's another big one for many of us caring you kind of feel guilty having fun and enjoying yourself. You know your loved ones ill - you should be caring for them. So, it was a whole load of things that were going on for me at that time, which is very challenging.

Cllr Millard: And you say you know that you weren't listening to your emotions. What do you think the long-term effects of that is?

Sara: I'm going to be really honest with you. I've got some friends who are carers that I know are now long-term sick and I would say that's alarm bells for anybody listening to this. You know you have to take care of yourself. So, for example, a good friend of mine, she'd been caring for her husband who had a brain tumour, and she was going downhill, and we could see it. The impact of the stress, that continuous burden of caring, her walking was deteriorating slightly and he was noticing it when she got more stressed and when he finally passed only eight weeks after she was diagnosed with MS and she is already in a wheelchair. And that's also why I wrote the book. I thought, come on, you know it's crazy to give everything, including your health, because you're ruining your life as well. It sounds a bit dramatic, I know, but that's what I was noticing with me. I was going downhill, and it is so important that you're just gonna have to take a step back and look after your own health.

Cllr Millard: When you look it from the outside, and when you advocate for it like this, it makes total sense, but it's absolutely understandable that people need to hear that message when they're there, in that moment, because it's not what you're thinking about. And I wanted to ask when you were caring for Neal, did you have any support?

Sara: I had support. Well, unfortunately our families live miles away, so I had paid carers coming in at first, we were paying for that, and it was very costly. We did get continuing care eventually. You have to be, dare I say 1 foot in the grave, but it's very difficult to get continuing care. You know the government can't pay for everybody's care. You know it's just not going to happen. So that was very stressful. But we did finally receive that and then it was charities so INS or mentioned before Richmond Care Centre were amazing as well. Really supportive. So, I'd say to anybody out there if you're not supported by charities in your local area, please do ring them up. They offer all sorts of advice. All sorts of support. And then Brain Tumour charity was great as well. I'm still in touch with them and offering support for them because the national charities also do great work, and services in the in the borough as well. So, it was like a befriending scheme would come and sit with Neal and

you know he'd had a carer with him while I took a break. And lastly, I had respite care once in a while, so Neal would go into the Hospice for a week whilst I had a break and oh my God, that was a lifesaver. I know a lot of carers will turn down respite care. They feel awkward at putting their loved one into a Hospice or into a home. But you need that break. Carers need regular breaks.

Looking at carers when you first start caring, we go into response mode very quickly, so you're busy focusing all your love, your time and attention on a loved one, to then start to put the attention back onto yourself can feel quite awkward. You can feel selfish, but self-care is not selfish, it is vital. And with the clarity, you know for me after I'd fallen ill, I ended up meeting up with my friend from next door, Nadia, she's also a carer and would meet with me every week on a Sunday evening and have a cup of tea and go: How was this week? How are you feeling? Because too many of us as I was end up on the slide, you think you're coping but you're actually not your kind of slowly in increments, getting worse, you're deteriorating. But you think you're OK because dare I say you feel uncomfortably comfortable so you're constantly feeling uncomfortable. But you're used to it. You're so used to being in that response mode that fight or flight mode. So yes, checking in with yourself regularly, that's a big one that I did, and I ask carers to do. And obviously if you can't meet face to face because of, you know you may be shielding a vulnerable loved one, do it by Zoom or Skype or just calling them and maybe a fellow carer or somebody who understands what you're going through.

Cllr Millard: You know it sounds like very good advice actually for everyone, for life itself, perhaps everyone should read your book and you also have a fantastic website as well.

Sara: Thank you. Yes, so it is www.whocares4carers.com.

Cllr Millard: Who cares for carers, brilliant.

Recent research suggests an additional 4.5 million people in the UK have become unpaid carers since the pandemic began. I wondered if you had any thoughts on acknowledging unpaid carers and huge amount of work that unpaid carers do?

Sara: Yes, well you know looking at, it's estimated that carers save the economy at least £132 billion a year. That's the cost of a second NHS, which is colossal and when it comes to the carers allowance: it's meagre at best. You know you've got to be caring for over 35 hours. It's £67.25 a week. That's £1.92 an hour and I think a lot of us are caring for much longer than that. When I think back to myself, caring it was 24/7. £1.92 an hour just doesn't really cut it, so I think upping that carers allowance is really important. And also, the perception of care and carers - we need to value care. We need to value our carers and carers need to value what they do. I mean when I was asked you know what do you do? Oh, I'm just a carer. I might have well as said I'm a just a dogsbody, but caring is so much more. Not only do I believe that it kept Neal alive for years longer, but it gives them a better quality of life. Also keeps them out of hospital as well, it saves in so many ways. You know, it really does. So, it extends the lives of others.

Cllr Millard: So, this has been such a fascinating conversation. What are your top tips to anyone who's new to caring? I think we've touched on them already, but let's just sort of ask this as a specific question for anyone who's new to caring, or even anyone who might be neglecting to look after themselves who realises listening to this, that they were already caring for a loved one and they want to do more self-care. What are your top tips?

Sara: OK, so top tip number one is checking in with yourself regularly so you're not on that slide. Do it once a week. Do journaling. It's something that I do and other carers do as well, just fancy name

for a pad and pen, jotting down your thoughts, your feelings, what do you ask yourself? What do I need to do more of? What do I need to do less of? Really powerful. And then connecting again, particularly because we're all isolated at the moment. I know that we're going to start to come out, but you might be still shielding a vulnerable loved one, so do pick up that phone. Do connect with friends and family, even if they're not connecting with you as much as you would like, I know that can be very frustrating. So do connect. Put it out there and connect with charities as well and any other services that you're thinking of. Put those feelers out. Regular breaks, you know short breaks throughout the day and longer if you can and sign up to my Carer's Master Class for things like that or read the book, lots of tips in there. And finally drop the mask. That's another one that's coming to mind. Stop looking like you're coping, trying to be perfect. No man is an island. You know you've got to be there for yourself. Ask for that help. Be honest with friends and family if they ask how you are.

Another thing that's useful for any carer is to have a carer's assessment so they assess your needs, what's going on with your loved one and for you. And what is available for you. It's important that you have that carers assessment. You'll have a one to one with somebody. Get in touch with your local carers centre, like Richmond Carers Centre, or with other charities. They will guide you or you can go online, but make sure you have that carers assessment really important so they can guide you through and give you any support that is needed.

Cllr Millard: Those are fantastic, like everything you said. Thank you so much for coming in to speak with us Sara.

Sara: My pleasure. Thank you for having me.

Cllr Millard: It's been really nice to talk to you. It's been really enlightening and I'm sure this episode will help a lot of other people. So, I noticed a quote on your website that I wanted to leave with listeners. It reads life is not about abstaining and enduring it is still about enjoying, especially if you are a carer. Wise words indeed. Please check the show notes for useful links regarding the local support available, the carer's assessment form and Richmond Carers Centre. If you have any feedback, do email us on talk@richmond.gov.uk. I'm really enjoying reading the emails that lots of listeners are sending in about the topics we've been talking about, do keep it coming. I'm Jim Millard, thanks for listening.