

8th Episode

Landscapes of grief and loss

Welcome to Doorstep Revolution, a project emerging out of the heart of South Riverside in Cardiff and run by gentle/radical, an arts organisation based in the neighbourhood, and interested in connecting up culture, community, politics, spirituality, and healing justice.

Supported by a grant from the National Lottery Community Fund, this sound archive was born out of the pandemic of 2020 and 2021.

We spent time knocking on doors, hearing people's stories and finding out how our thinking about the future might have changed under COVID.

From homeschooling to weddings under lockdown, from acute isolation, to finding new forms of togetherness, these conversations with neighbours reveal questions and profound reflections on recent times and how we might wish them to be different.

.....

Many people have died in this pandemic, including people in our local area. We were privileged to listen to Riverside residents who told us about their experiences with loved ones dying of COVID, and from other causes. They also described the difficulties of funerals under COVID restrictions, and the challenge of isolation while grieving. These are powerful stories of grief, and gratitude. And we want to especially thank these participants for sharing them with us. In this episode, we'll first hear from James and Andy reflecting on different types of grief and then we'll hear from Jackie and Priti who both speaking about losing loved ones in this time.

James

So everyone's having to grieve separately for different things, and that's just not the way that things usually happen. You either share your grief with your friends and they help you to get through stuff because you could converse or you hug each other, if it's your family or close friends, and you go through all of that.

And then a very, very good friend of ours, a girl in Barry, then was diagnosed with cancer in October and she was Stage 4. Lost all her hair and all the rest of it, and she had to have 30 shots of chemo' and radio' which is the highest amount you can have in a short period and luckily now it's all abated and she's getting much better which is... they think she's a walking miracle because they don't know how this has happened! But she's still back and forth to Velindre, like she said to Andy yesterday she had her vaccine jab yesterday. (turns to Andy) Well you had yours yesterday...

Andy

No, Saturday I had mine...

James

Well, sorry yeah, Saturday but yes... Socially it has taken a massive toll on me. And you know, being really introspective, overthinking things and you just do, it's just a natural thing if you are on your own.

Andy

Yeah you said you have been sat here for hours and hours and you overthink things anyway half the time (laughs).

James

No I don't.

Andy

You do.

James

What do you mean? (both laughing)

Jackie

Well, first of all, I lost my aunty in Portsmouth and there was nothing I could do to go down to the funeral and I was very close to her. That was awful. And then you're sort of trying to make yourself think "well what about all the other people" you know? So it helps a bit so it helps you...

Then in May my niece died at home. She was a well-known character in Canton, Alicia. She was knocked over on Ninian Park Road, nearly 34 years ago and she was on a ventilated wheelchair, which was quite a large wheelchair and she had to go around Canton with her nurses, so she was quite well known. She used to go into the Bingo Hall. She passed away, she passed away with kidney failure. Nothing to do with the COVID but because she was at home, we could sit with her and stay with her. But then a week later, her sister went into hospital, she was there for four months, and we couldn't visit her. She was diagnosed three or four days before she died, she had cancer and it had gone... travelled quite a far way into her body. She was on dialysis, a ventilator, and we couldn't visit her and that was the real hard part for us, not being able to see her until the day she died. And they allowed us to go in then. That was heart-breaking, two sisters gone in four months.

And you want to be with your family and you can't. My sister needed help (their mother) and I couldn't go round there. In the end, I just had to, I had to break the rules and go around there and see her because she was grieving so badly. So it was an awful, awful time for us. Of course, you just can't think straight. I got scared then because I didn't want to go out and do shopping and I had to have somebody do my shopping for me. I couldn't walk my

dog, I couldn't. I was just so terrified of going out. That's how it affected me. And then in January, we lost my brother with COVID.

He was in hospital for three weeks. And once again, we couldn't visit him. So it has been an awful time... awful. If it hadn't been for COVID we could have been there for them, you know. If it hadn't had been for COVID, I wouldn't have lost my brother. And he was quite an outgoing person. He did lots of camping and he just bought himself a new motorbike to go to America. He wanted to do, I think it's called Route 66. He was really a strong, strong man... then the COVID got him, you know?

And he was actually in isolation for a few days because he wanted to go and see his grandson. So, we don't really know what happened there. Because he had isolated. It was, well it was awful. If it hadn't been for his daughter going into his house, we wouldn't have known anything because he was so ill, he couldn't phone anybody. He was delirious and never recognised his daughter when she went in and then they took him to hospital then. When I actually rang, I spoke to the ambulance drivers, they said they were taking him to hospital, he was in a pretty bad way. I don't know if he'd picked up COVID from wherever he'd been, but something must have gone on. I just don't know. I'm actually going to see his daughter on Friday to see if I can get some more information.

And then only a few of us could go to his funeral. Same as my two nieces. My one niece who couldn't go from church and she was a Catholic. But the second, she went from the church, St. Mary's in Kings Road, so they had beautiful send offs, with beautiful white horses and a carriage. The sadness of it all is still with us. Because we couldn't be there with the one niece, and we couldn't be there for my brother. So yes, it has been terrible and lockdown has been terrible.

I am under the Mental Health Team to help me to cope. My niece's children, the youngest boy, is under the Mental Health Team. The two older ones have coped with their grief.

Because now they're living with their grandmother. So, my sister inherited three children overnight. She promised her daughter that she would look after the children.

But we did have some good news, we've got my brother's daughter is actually having a baby. And she was going to tell her dad but she never got to do that, but she's due to have a baby in about nine weeks. So that's good to have some good news.

Priti

So March was the month that we had the first instance of major lockdown, which was national for the whole month. And it was during that month that other significant changes took place in my personal life or in my family life.

My mother was diagnosed with cancer 25th of March in the midst of that lockdown and so that was quite significant around the same period. So, for me, perhaps that mindset where others may become more sort of concerned about what lay ahead with life and the lockdown and what this meant for us. My thoughts and my feelings and emotions were totally sort of, you know, meandered off path with my mother becoming so ill, so quickly and being diagnosed with such a serious illness, you know, with her cancer. So, I think that sort of was where I was at with it all obviously, with lockdown, and with certainly not being able to go anywhere, being isolated and stuff like that, but there's two sides of it, you know,

whereas I got a lot more time with my mum. And it was quite a profound period for my mother and I, during that time, from day one. The other side of it was, of course, that we weren't able to visit family or friends or they us, as we would normally while my mother was ill, which would have been quite nice for her. And for us, we were able to have more quality time together.

During the periods I cared for my mother, at the time she was diagnosed there, on until she passed away in December and also through, you know, a lot of stuff I've watched about cancer, this is the first... I should emphasise as well that in our family network and you know, Asians as you may have gathered or not, or people may be aware, we have a lot of extended family that can often live in close proximity of each other and be in each other's lives, almost like an extended support mechanism. And within our significant members of family, we have quite a big family network within Cardiff and this area. My mother is the first of all the relatives, all the sisters, all the siblings, all the children, the cousins, there are a lot of us going into the hundreds, maybe up to a thousand! And she's the first person in the entire network of our family unit, extended family unit to have cancer. So the shock, absolutely! So the shock of that diagnosis and the shock of my mother having a disease and then I have to say my mother's case, it was astoundingly supportive. And you know, the doctor, we have had a family doctor in the community, not living far from here in the Riverside Health Centre, since I was a child and since you know, my father passed away the year before, he's known my parents and family unit very, very well. He's been our family doctor, over many, many years. So, the GP came over to the house after some test results to tell us my mother had cancer. From that moment onwards, we were given the referrals, you know, we had the palliative and the nurses coming out within a matter of weeks.

My mother was in Llandough Hospital within days having further tests and biopsies taken, we had treatment for her, which was arranged and facilitated reasonably fast, I would say, considering what was happening with lockdown with hospital appointments, with not being able to go into a hospital. Just all the massive changes that took place after March lockdown for, not just cancer patients but across the board for all patients, for all referrals. I know many friends and many family members who had their appointments for things like X-rays, MRI scans, cancel, cancel, cancelled, for months upon end, you know? I know there is an aftermath to that even now where many, I've read in the press and you hear it on the news and through word of mouth, cancer diagnoses have been missed.

But in my mother's case I should add this: the reason my mother's cancer was detected swiftly is not because she got a quick route, not because she didn't get a referral to the hospital for further tests because she had back pain, which wasn't suspected as cancer. But because I actually took my mother to Bupa and we paid for a private MRI.

My mother was 76 years old; she was still driving 10 miles each way to work, two months before this diagnosis. She had never had a night in hospital. She'd never had an illness in her life and suddenly a little twinge in her back from the January of last year, when she kept saying she's got a little bit of a twinge, it was worrying her. An X-ray in February showed that she just had a minor tear in her back. The cancer didn't show up as cancer. My mother intuitively felt that she needed something more to be checked. She didn't feel right, she said the pain's carrying on. So when she went back to the doctor, who is amazing, our GP, he said

he would refer her immediately for an MRI scan. He did it straightaway. We then fell into full lockdown in March, those appointments that were referred via the GPs, they were put on hold and cancelled twice. So when the cancellation letters came in for the MRIs at the Heath Hospital, my mother said, "Well, it still hurts". And I said, Well, we don't want to be hanging around, it might be just a bit of arthritis or something, don't worry, mum. So I said we'll get you into Bupa. I rang up Bupa with some very, very polite persistence they agreed. Initially they weren't prepared to do it because they said she was over 70 and she had no pre-existing health conditions. But with some polite persistence, I said, "Well, my mother is generally a very well woman. But you know, she, we really would appreciate this MRI because it's really causing us some trouble at least she could have some treatment." And they eventually facilitated that, thankfully. I took my mum to Bupa in Pentwyn, and I had to wait outside. She went in had an MRI on March 24 at four o'clock and by nine o'clock the following morning, the doctor was at her house in full PPE equipment telling us this twinge in her back turned out to be spots of cancer all over her spine.

When my father passed away on the 1st of June 2019, I was very, very close to my father as well. My mother and I both cared for him towards the latter stages of his life. And, you know, I was with my father in the hospital when he passed away. And I consider that a total blessing because I miss my father every single day. And I always will for the rest of my life as I do my mother. And I just cherish the moments I had with them and count my blessings I had that time. And I know many friends who have lost parents and loved ones. So you just don't realise how lucky we are to have a time with them. And I appreciate that with such gratitude every day and count my blessings.

I had conversations I recorded with my parents, I'd take videos with them. And these are things that were suggested by very close friends of mine, and it's the best thing I could have ever done. I would encourage anybody and everybody... while they still have their parents and loved ones around them, cherish every single moment with them, count your blessings and make wonderful memories with them. Whether they're little things, big things, it doesn't matter. A cup of tea is a precious moment with your mother or father. That's how precious it is. You know, having a video call with them. When sometimes we get caught up in life when we're so, so busy and we think mum, dad I'll speak to you later, I've been there myself or you know, I'll catch you later, if it's a really good friend of yours. You know, people are like precious diamonds, our loved ones, they're so precious in life. And humanity is precious. And it's when we lose that... I've lost friends, I've lost family members through the last year, you know, not just my mother and father...

The moral of my story is that, really make the most and really appreciate those people around us and really make nice memories and make time to talk and all the things we sometimes think we're too busy to do. Because I made a conscious effort to make memories with my mother, as many as she was able. We used to go for walks by the river, you know and I have the videos, the pictures, the voice and you know the camera conversations I think it's so, so important.

Jackie

He was quite into everything, my little brother. He enjoyed life, he really enjoyed his life. It was a terrible thing. Terrible not to be with your loved ones when they're dying. And my niece as well, she was 36 years old... with three children. And I think the youngest boy got to see her three days before she died. He went up there with his grandmother. And all the rest of the time it was all on this FaceTime (is it called?). And that's the only time we had any... could see her and talk to her and tell her how much we loved her.

It's like a punishment isn't? You know? The COVID is punishment enough without you not being able to be with your loved ones when they're dying, and you know they're dying, you know, you can see them decreasing, going on a ventilator, going on dialysis, and you think like, maybe this is going to help her.

But then with all the other things that they start saying, you know they're going to die. And yet, they can't let you in to see them. But the day she died, the night she died, they said we could go up there. Just seems cruel doesn't it? Just to see them before... before they leave this world. And then we couldn't even go visit at the funeral parlour because of the COVID they wouldn't let you go and visit.

And once Alicia had left her house that was the last time we've seen her because the funeral parlours won't allow you to go and visit because of the COVID. So and that's another painful thing as well, because everybody does that, don't they? Everyone goes and visits people that have passed away, especially their family. Just to have your last couple of minutes with them or just to talk to them and even though they've gone, just to express your feelings and hold them and give them a kiss goodbye. We weren't allowed to do any of that.

It's got a lot to answer for COVID, a lot, especially in my family's time over the last 18 months. It's been awful, absolutely awful. Then, you know, you want your family and friends, you want to be with them, talk with them. And you can't, you're not allowed, you weren't allowed to. I mean, my best friend said she worked in Tesco's through the whole of the lockdown and yet she couldn't come and see me because it wasn't allowed. It just didn't make sense, didn't make sense to her.

I spent a lot of time on the phone obviously talking to my friends and my family... just trying to get over the pain of losing them.

Priti

Well, I would just like to say, thank you for giving me the opportunity to share my experience over the last year and also during the pandemic, you know, as we try to slowly emerge on the other side of it. And all I really can say to anybody out there is that whatever is going on in your life, wherever you're at in your life, or whatever experience you've had during the pandemic.. always remember that, you know, there are always people out there who are less fortunate than us. And gratitude is everything. And, you know, being mindful and being present and really being so, so grateful. Whether it's that glass of water on the table or whether it's being in the warm. I think gratitude is everything and if there's any lesson that I've taken from the pandemic to share is that I've certainly become eternally far more

grateful, not only for the time of the people around me during the pandemic, not just my mum, but also moving forward, all the things that we have, many of us take for granted, for I will never take for granted again.

.....

We hope you enjoyed hearing from some of the voices in our community. Doorstep Revolution is an ongoing project. So if you're a Riverside resident and want to get involved, do get in touch with us at gentleradical.org. In the coming months and years, we'll be continuing to build a resource of stories, perspectives and dialogues, exploring the realities, as well as the dreams of people living on our doorstep.