

Nir:

Hi. Welcome to Home From Home: A Journey Into Elderly Care. My name's Nir. Over the pandemic, I've been having conversations with people whose parents have gone into residential care. I wanted to have these conversations, because I too have been experiencing what it's like to watch my grandparents go from being independent and adamant that they would never go into a care home, to being in supported living.

Nir:

I wanted to find out more about the people in the care system, and to see how other people with elderly relatives feel about it, because so much of that world happens behind closed doors. I needed to know more. What you are about to hear is the third of a series of three podcasts made from those conversations. We've chosen three very different stories, but you can imagine them like acts of the same play, or songs that are part of the same service.

Nir:

If you like, you can scroll through our Zine, an illustrated booklet inspired by some of the things that people have said. It isn't the program, but it is something that you can look at digitally, or if you want you can print it out, so you can hold it in your hands, once you listen to the people's stories. One of the people I talked to was Paul. Heya.

Paul:

Hey Nir, how are you?

Nir:

All right. How are you?

Nir:

I met him on a video call during lockdown. We talked about how unfamiliar it feels to start supporting family members who need intense forms of care. It's complex for everyone to manage and it makes me feel how unprepared we are as a society for this.

Paul:

Yeah, it's something I hadn't thought about until suddenly I had to think about it a lot and that was the real shock for me. I just thought, "Oh, some sort of process kicks in and then something happens," but nothing happens at all. I've got two brothers. We all took up different parts of the fight because it did feel like a fight for a while, but I couldn't help think about those people who don't have any kind of real support network or just someone who doesn't necessarily have the sheer energy to persist in terms of getting the care that someone might need.

Nir:

Here from Ad Infinitum is episode three: A Lease of Life.

Paul:

The experience I have is through my dad and he is still alive. He's 76, now and he's been in a care home for just about four years, but before that he was diagnosed with Parkinson's for 14 years, I think and he was getting increasingly worse at home. He lived with my mum until four years ago in a fairly unhappy scenario for both of them. He was adamant. He was absolutely always adamant that he never, ever wanted to go into a care home. He was very, very persistent about this. As the time went on, right about five years ago, my mum was having to care for him in quite a severe way because of everything the Parkinson's brings with it. It's this awful thing that every single person experiences it in a different way. There's no cure, there's no assured way of slowing it down or anything. Basically, he has uncontrollable shaking, which then eventually leads to freezing because obviously then, it just totally wears away the muscles. It destroys the muscles because it's just nonstop and what also comes along with it are hallucinations and dementia.

Paul:

He had been in the hospital numerous times with various things in connection to it and my mum was having to look after him a lot. It was difficult for her to leave the house and it was very, very full on. Actually, the worry was it was going to kill my mum before it killed him because she was so exhausted. I remember waking up one night and it was when my mum was away and I was looking after dad. I woke up and I was like, "What is that noise? What is that noise I'm hearing?" It sounded like a dog that had its leg broken and it was just like, "Ah," like this. I was like, "What?" It was three in the morning. I was like, "What is that noise?" It was my dad. He was just making this noise and he was just crying and saying, "Jesus, no, no. Why Jesus? Why Jesus?" Things like this. "I'm sorry. I'm sorry." All this sort of stuff. Oh, my God. This is really a head fuck for me to hear this, but it happened regularly, that that was going on.

Paul:

It was in November of 2016 when my dad got taken into the hospital. What had happened was that he'd got up and he had started walking. His walk was a shuffle by this point and he had frozen and he couldn't move or bend anything. My mum couldn't get him to sit down. She just couldn't do anything. She's of a similar age and just doesn't have the strength to start maneuvering someone around. He got taken into the hospital and he ended up staying in a hospital bed 10 weeks. It had been a recurring theme throughout anytime I had spent with my dad in the years leading up to that, that we were never to put him into a care home and that he would sort of threaten us about what he would do if we tried to put him into a care home. He was absolutely adamant that he always wanted to have his independence and felt that bad things happened to people in care homes.

Paul:

He'd say things like, "I will never forgive you, if you do this." We're an Irish-Catholic family and his mum had been ill for a while, but he made sure she didn't go into a home. The idea was that, that was now our task, to make sure he didn't go into a home, but after these 10 weeks in hospital, it was really clear that there was just no way he could go back to living with my mum and none of the three of us, the three sons, there was just no way that we could be there either. We wouldn't be able to work or do anything if we were there. It was impossible. Taking all of the advice from everyone, really was just we need to find a care home for him to be in. We were put in touch with the council's liaison person for putting people into care homes and we were assigned three different care homes to choose from.

Paul:

The very first one we went to was just unreal. Within a minute of being there, there was a mass brawl in the living room of people full on punching each other and kicking each other. All this going on. The floor was uneven and stuff. My dad with his shuffling walk, that's not going to work. We went past a room where they were doing some training and it just happened I just heard the person who was leading the training going, "Oh, my God. It's just impossible to get anything done in here. You don't have any of the right equipment." We were going "ok right...". Things weren't clean. Mum and I just turned and said there is just no way he is going here. The next thing I heard, I got a call from my mum. She had just got a call from the organization saying that my dad had been assigned to that first care home even though we had said this is totally unacceptable.

Paul:

They were picking him up within an hour and a half from hospital. I just couldn't believe it. First of all, I then called my uncle, who's my dad's brother. I said, "Mick, get to the hospital now and make sure that no one takes him. Just go there and just stop them." My uncle Mick is a big enough guy. No one was being aggressive, but I'm saying just stop them because we've said that we don't want him to go there. Then, I called up the person who had assigned my dad to there. I was just trying to get into what is the process behind how this has happened exactly? The cheapest bid won and they got the cheapest bid because they said my dad didn't need 24 hour care and we were saying, "Well, he does need 24 hour care is our opinion."

Paul:

Anyway, eventually we came to an agreement that he wasn't going to go there, that he was going to go to this other one that was quite nice, but that wasn't suggesting that he needed 24 hour care. Reluctantly we said okay, given what our options are here right now. We'll take it. We were all there when he was moved into the care home and I think that was probably the most upsetting time, I think because he was furious that he was being put into a care home. Without going into too much depth about our relationship, we've always had a quite difficult relationship. All of my brothers with my dad and what's weird, now of course, is he's this frail old man. For a long time I thought there are certain things there's no point of me bringing up because he's not the same person that he was then. He's not always with it anyway, but he still has the ability to absolutely scare the shit out of me and my two brothers. There was a lot of that going on during this time when we were with him when he was being transported.

Paul:

It was just pretty awful seeing him, he's just become all skin and bones. He used to be kind of a quite big guy and he's just skin and bones now and being hoisted up from his hospital bed on a stretcher, basically onto somewhere else and hoisted off there. He's just dangling there, this little old man. He went to this care home where they got the cheaper bid because they weren't 24 hour and unfortunately within three days, he was back in hospital because overnight he'd fallen out of his bed and he'd smashed up his face, which is what we told them would happen. The matron on the ward in the hospital, she's saying to us, "What happened? What happened?" I said, "Well, he didn't have 24 hour care, so this happened overnight." She said, "What? It's obvious he needs 24 hour care," but it turns out that no one consulted any nurse. None of the care homes asked any of the nurses who had been caring for him for 10 weeks by that point about what maybe he needed. In the end, after all that, he ended up going to the place that we'd originally, when we were asked to view the three places, had said this is the place we'd like him to go to.

Paul:

Again, we had to go through the process of getting him there and trying to get him to settle in. It's very challenging when you see that suddenly here is this person in a little room and you have to, then sign the forms that he doesn't have the right just to say, "I want to leave," and then he leaves. As a place, it's one that he's remained in, now for maybe four years. It's been pretty good all in all. There are always things that you want to have different for your parents, but with the awareness that there's 90 people there, I feel like they do a pretty good job and it's all clean. The lifts work. There seemed to be enough staff around. The food looks vaguely edible and everything seems to be as it would be.

Paul:

He went in, in early 2017 into a care home, then I became a dad and spent the last part of that year preparing to become a dad and also was thinking I'm probably going to lose my dad as well. Those two thoughts just in my head. He's going to outlive us all. He's just going to carry on and on and on. To be honest, we've sort of been expecting him to die anytime because he goes through patches of being phenomenally unwell and he's in almost constant pain and it doesn't really feel like there's much to live for, really. My dad's a very, has been in his life anyway, a very devout Catholic. He's a good Irish boy. Unfortunately for him now, he derides no comfort from it. I'll say to him, what about JC? If this is the guy that we've been hanging out hat on for so long and saying it's okay because there's life beyond, but the impression that I get is he carries a lot of regret about various things and I suspect the thought of purgatory or hell is keeping him up, which is a shame.

Nir:

It sounds a bit like he's in hell already in some aspects.

Paul:

Well, it sometimes it feels like it couldn't get a whole lot worse, but is there no comfort in your later years to think that actually, you'll go on to something better? I don't believe that, but if that's what you're selling me, then where is the comfort? Every now and again, a local priest comes to visit him. At what point, then do you actually say, "If I believe this, then surely there's comfort in it," but are we just, as Catholics do, are we just repeating it because it's just reflex. It really annoys me that we've all had to go through so much because we had to be brought up Catholic and I did not enjoy it as an experience. We went through all of that, but now as he's reaching the last years of his life, it seems to be providing absolutely fuck all comfort. What's the point? Where's the payoff on this? This is so annoying. We've put in so much. We have to go to mass. We have to feel bad about ourselves. We have to go to confession. I have to feel awful about whatever I'm feeling. For what?

Paul:

What's difficult is obviously the sheer sense of guilt about leaving someone in such a small place. My dad's done many things in his life. He started off as a farmhand and then he's always grown his own vegetables. He likes being outside, doing things with his hands, working like that. He has none of that at all. That's quite challenging because then, also it's difficult to know what to talk to him about because you want to report from the outside world, but at the same time, you feel like you've denied him access to the outside world. You're dangling, "Isn't this place that you can't go to, great?" I'm bringing news from this magical place, the outdoors and that you can't ever experience again. As his Parkinson's has gotten progressively worse, his hallucinations are getting more and more full on. He'll tell you a lot of

things that have happened to him in the care home that you can just only assume are not happening because of all the other things he says that very definitely aren't happening.

Paul:

He's telling you there are people with guns firing in through the window. Stuff like that. That's not happening. He keeps thinking that he's floated up to the corner of the room. That's one of his recurring things. He gets very stressed because he's lying in his bed and he just keeps thinking that he's floated up to the far right hand corner of his room. He just keeps thinking he's up there. You just say to him, "Dad, you're not. You are lying there on the bed. The bed is on the ground. That's it." He will, then also tell you that he's being abused by the staff and that there's things that happen to him at night, which you have to listen to. I don't want to just say "Dad it's not happening" because sometimes it feels like that's not what he needs to hear. I just try to listen. I just make it up as I go along really, but just trying to, in some way, reassure that everything's okay, try to put in there the idea that maybe this isn't happening because there are some other things that he describes that aren't happening and it's challenging because ultimately you'll hear the same story the next time or similar because he's stuck on a bit of a loop. His life is just that over and over and over again.

Paul:

I remember, then he was particularly ill when my first daughter was born and I was really worried that he was never going to meet her because he just happened to be very, very ill. I had spent the whole period of when we were expecting the baby thinking, "Dad's not going to meet her." When she was three days old, I whisked her in the car, right - we're going to go see my dad because I just want him to meet her in some form or other. It's a very difficult place to take a child as well, a care home, because she's two and a half now. Obviously, we've not been for the most recent period anyway, but even up until the last time we went, which was the beginning of this year, she's got no interest in sitting around. She just wants to run off into all sorts of different places. It gets to lunchtime and I tend not to stick around for lunch because it's a fairly torturous affair and if I've got her with me, I'm just going to leave you to it.

Paul:

He then gets sat at a table with other people who probably aren't that much worse than he is, but some of them are much further progressed down the line of being ill and are nowhere near on the same planet and they're holding dollies and I find that image very difficult to take because it just feels like, it feels like, everytime you're abandoning someone, leaving them on the scrap heap. What conversation can he possibly have? What can he possibly get out of any day? There are a lot of recurring cycles of guilt. Then, in the last six months, none of us have been able to go and visit him because of COVID, so instead we've been skyping with him, which is a new kind of communication hell in that he can't really speak very clearly. You can't really hear him. He can't really hear us. There's a lot of talking across each other and confusion. He's relatively fortunate in that my mum has been to visit him quite a lot while he's been there. My uncle Mick, I've been whenever I can. Both my brothers, now go whenever they can. He gets the occasional people he used to play futbol with.

Paul:

He has a peculiarly large number of people visiting him and it's been great for my mum that he's no longer at home. She feels a sense of relief that he's gone, but obviously then feels guilty about feeling relieved that he's gone. They have never got on. It's that generational thing of they never got on, but

they stayed married because that's just what you did. It has given my mum a new lease of life. I really want that for her. If she wants to go on a trip with a mate, she should be able to do it. If she wants to go and meet up with a friend for a coffee, she can now do that.

Nir:

Home From Home: Journeys into Elderly Care was produced and composed with an original acapella score by Jennifer Bell, with me, Nir Paldi and generous contributors Cathy, Paul and Lizzi and was an Ad Infinitum production with support from Arts Council England.