

Nir:

Hi, welcome to Home From Home: Journeys 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. 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.

Nir:

What you're about to hear is the first 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. 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 could print it out so you can hold it in your hands whilst you listen to the people's stories. One of the people I talked to was Cathy. I met her on a video call during lockdown.

Cathy:

Hello.

Nir:

Hello, how are you doing?

Cathy:

Not so bad, thank you. And you?

Nir:

Yeah, I'm all right.

Cathy:

Surviving.

Nir:

It was just three months after her mom had died in a care home.

Cathy:

When we had the funeral for mom-

Nir:

She says that because of the pandemic, they had to make her mom's funeral happen remotely for the people who couldn't be there in person. She says she sent out an order of service, the eulogy and videos of her brother reading poems and said, "If you'd like to go somewhere quiet, that would be lovely." So if you would like to go somewhere quiet to listen to Cathy, that would be lovely too. She says, "The broad

lines of people's stories about witnessing parents go into care can be so universal. It would be very easy to construct a made up story because the broad headlines are the same for everybody."

Cathy:

But of course the actual specifics are so very, very different.

Nir:

Here from Ad Infinitum is episode one, In a Class of Her Own.

Cathy:

So, mom and dad lived in the house that they had got married into. So they got married in 1960. And my mom lived there until 2013. Neither of them were terribly good at house maintenance, and they certainly weren't the most... Mom was not the most organized. And I'm looking around this terrible room. Sorry, mom, I'm not either. But she just was not great at cleaning and keeping the place in good order.

Cathy:

So, I guess the first sign was about the five years, or maybe the 10 years of, "Can we help with this, or maybe we could help you sort out X, Y, or Z?" And the two of them resisting that massively. And then gently suggesting when my dad died that that might be a good time to leave this house. It was really crumbling around my mom. And she was adamant that she wouldn't. So she stayed on in that house, in spite of there being really dodgy wiring, and one socket working in the... It was just really appalling. The reason I tell you that is because she moved from a very decrepit, uncomfortable, unheated, everything falling apart, very unhygienic, dirty, awful house, but it was hers, into something that wasn't hers. But it was a sheltered flat, which was...

Cathy:

As an occupational therapist, I couldn't have designed it better. It was perfect. It had everything she needed. It was clean, it was warm, it was safe. It had a wet room. It was just right. And it's a series of flats that you have a tenancy for, it has a warden, but to access some of the flats, you go inside and down a carpeted corridor, and there are some shared areas. So there's a lounge and a sort of sitting dining room where you can entertain or meet, whatever. A little garden, a little hair salon, laundry. It's lovely, really lovely. It's a miracle. No, it wasn't a miracle, it was really hard work getting her in there.

Cathy:

Anyway, she was not well, not physically well, but mentally very able. No cognitive problems. And she lived there quite happily, and it meant that she could make new friends. During the first two years, two, three years that she was actually... She lived six and half years in this sheltered flat. And there were some nice things because it was about a mile and a half, two miles from where this house that she'd always lived in. But for my mom, Oldham to Royton, which is two miles, it's like different worlds.

Cathy:

And there was a woman that she hadn't seen since she'd lived in Oldham. And she knew because... It's a very northern story of this woman who was an apprentice dressmaker to the woman who was a friend of my mom's mom who made a wedding dress. And I felt my mom would really take to her. But instead

my mom was a bit sort of didn't really want to know, because that was her past in Oldham, and she left that past. So it was kind of complicated.

Cathy:

But it was full of weird politics. And it was very fascinating. These places are fabulous because they pull together people who have got lots in common because they have grown up within a particular area, but education and class-wise, it was interesting because it's a housing association. Most people in there are not massively well-educated or particularly wealthy, because if they were, they would be paying for a private, slightly posher place. But having said that, because it was one of the nicer ones, there were people who had... They'd perhaps worked during...

Cathy:

They weren't all women who had lived in Lancashire. I'm trying not to stereotype, but it's really difficult because many of those women did, they worked on... So my mom, she worked in the market, she worked in the kitchen, in a school kitchen. And there were lots of women who had done that, or who had not worked and stayed at home with the kids. But there were also a handful of maybe ex-teachers, a couple of nurses. So, the politics was quite interesting because they did not quite rub along.

Cathy:

So, for example, they would have social events in the communal areas. And I guess in the first year or two, my mom tried to get involved with this, but she was very sniffy about bingo, and they just played bingo. They would throw a party for any excuse, really, which is great. Like St. Patrick's day, or Easter, and somebody's anniversary, or a birthday, or whatever. And mom used to get her hair done and go, "Oh, it was fantastic." But then she would just moan about the fact that the music was all not her kind of music. And they would swear a lot.

Cathy:

Mom never swore. And they would be swearing a lot, and laughing, and getting drunk. And she was really unhappy about this. And my mom was really weird because she was in this social setting where she occupied a very strange space where she placed herself above many of the people there, but the people who were perhaps more educated and had a bit more experience, and had traveled, they didn't quite include her either. So it was not easy for some of the time.

Cathy:

The group that were quite bonded is a quite noisy... I don't want to use the word "vulgar", but I found them quite funny. I quite enjoyed their company, but they were quite vulgar. They didn't really gel with my mom. And like I said, the ex-teachers and so on, they'd been very sniffy. So she occupied this strange middling space. I'm making it out like she was Billy No Mates, but she wasn't. She made two, three, four quite nice, good friends. So it was fine.

Cathy:

But then this other thing happened, which... A couple of the friends that she had, that she judged were nice people, good people, not these common people. Inevitably... I'm looking down because I find this really sad, and they died because that's the nature of the thing. So she'd gone there when she was... So

she lived there for six and a half years, like I said. The first two, three, four years she was quite able to be involved in things, but there'd be people on the latter end of their stay there.

Cathy:

And she happened to make friends with people, and the friendship lasted a year, two year. She really cared about them. And I remember talking to my daughter about this. I said, "It's heartbreaking because there I am encouraging my mom to make friends and be sociable, but with each friend she makes, she risks a bereavement." And they remind her of her own trajectory. And it's really sad because the alternative is to do what she in the end did, probably for other reasons as well, but is to not engage and not make friends.

Cathy:

Because how many new friends can you make, knowing that in two, three, four, five years, they're going to die. Unless you're very grounded in yourself, which she wasn't. At my age I hope... You hope that you will find some way of coping. But I've not been there. And what I could see was mom being repeatedly bereaved of friends that she just made. I had never thought. That never occurred to me, but it was only watching mom in that setting that made me realize what a risk it was each time she made a new friend.

Cathy:

So she became a bit more isolated in the fifth year. And then the sixth year, she didn't really engage very much with the people outside of her flat, only in fits and starts really. But she had a period of delirium a year and a half ago-ish. And it was quite out of the blue. So she'd gone from being pretty sharp. So she'd still ring me and remind me of things that I needed to bring to my next visit or, "Have you spoken to Peter about X, Y, or Z?" And a little bit of slowing, a little bit of word finding difficulty, but mostly grand.

Cathy:

And then this particular Christmas, she had a catastrophic delirium. And by that I mean she was hallucinating. Bizarre hallucinations. Lots of comedy scope there, but it really wasn't funny. It was very... It was weird. Because she wasn't distressed by the hallucinations, mostly. And they just amused her. And, in fact, almost entertained her. But she lost all track of time and she was ill. She went into hospital because she wasn't safe at all.

Cathy:

But in the process of her being in hospital, because they could find no one reason, they wouldn't admit her to a ward. So this is part of the story of the awfulness now, but she was on the discharged ward, which what that means is there's a bay where everybody who's been discharged from one of the wards sits and waits for their ambulance. And then there were a couple of other bays that have some beds where people are just waiting for the doctor to say, "Go home," but they're not going to be treated.

Cathy:

And this particular place, it had very rotating staff, lots of banked staff, the usual kind of story, really. No windows, no clocks. In fact, if you wanted to write how to make you or I completely delirious, this is what you want to do. Not helped to drink, not monitored for food. So everything that could be contributing... It was terrible. So, what I should say before I say anything else about any other part of

this is, the individual staff, with only one or two exceptions, were absolutely kind and as good as they could be.

Cathy:

But, as you would guess I'm going to say, they just didn't have the staff, didn't have the resources, blah, blah. So, what happened was, a social worker was allocated to arrange her going home. There's no way. She still didn't know who she was, where she was. She now couldn't physically manage anything. She couldn't put her shoe on because she couldn't work out which way round a shoe goes, whether it goes on her foot or... She was in a terrible state.

Cathy:

So the social worker said, "Well, we'll get her admitted for respite to a care home." So I said, "But respite from what?" Said, "Two days before she came into hospital, she's a lady who lives on her own." And what I should also say is, at various junctures throughout our conversations, my brother and I, with my mom, it's been, "And I'm not going in a care home." So I knew that it would not be right to agree for her to go to a care home.

Cathy:

Because as an occupational therapist, I also know the very last thing that you do with somebody who's delirious is keep moving them around, put them somewhere which is also unfamiliar and so on. So, eventually I just said, "Right, well, we'll take her home and we'll organize 24 hour care in her home." The health service and social services would not fund any part of it because she wasn't ill. She had no diagnosis. She had about 15 diagnoses of physical ailments. Because she didn't have a dementia diagnosis, mental health services couldn't help.

Cathy:

Because she didn't have a particular thing that was causing this that was being treated, she didn't qualify. And partly because she had savings because she'd sold this wreck of a house. So it's a lot of money. It is a lot of money, let's just put full stop, 70,000 pounds or so is a lot of money. It's not a lot of money when it's all the money that you've got from 50 odd years and a house that you sold. That Peter and I had said that when she gets really, really towards the end, we'll pay for her being in a nice care home, whatever.

Cathy:

However, because she had the 70,000, social services wouldn't engage at all. Tried to organize 24 hour care privately. Most of the conversations went, "Yes, we can do that. Oh, of course, yes, we can do that." And the cost was horrific. But as soon as they found that there wasn't anywhere for carers to sleep over, it wasn't workable. People who pay for their care privately, here's my mom in the middle again, generally are really rich. Or not really rich, they're comfortable.

Cathy:

And maybe they still have their own home or a small home that has two or three bedrooms for the grandkids to come and stay. So, culturally, the companies are used to being able, quite rightly, for their workers to have time to go and have their dinner, to sleep privately away from the person they're caring

for. But my mum was living in a housing association one bedroom flat, so that wasn't available. So there's my mom, again, in the middle.

Cathy:

She had too much money to get something provided through the services, but not enough, and she wasn't in a position enough to be able to fit the middle class provision that most care companies are providing for. And the company that we eventually got this set up with, they had never done anything like this before, so they were really pulling all the stops out. And, in fact, what I did was I researched what the protocols were for delirium and found that there were two or three places in the country that were really top of the game in how you approach delirium.

Cathy:

And it was all about getting people home. It's about reorientation, about time, enforcing sleep, making sure that we use bright lights during day time, all that kind of thing. So we put together this package with the company and I put together the care plan. It took about three days to start getting better. It took about three weeks before we could withdraw the 24 hour and make it... Withdraw the night sitting. And it took probably two months, three months before she was maybe at 70 to 80% of what she'd been before the delirium.

Cathy:

So, tick, job done, great. She even went to a couple of games of bingo downstairs, and she stayed well-ish for a year. So she got another year after her delirium. So mom died in a care home, but I didn't see her at any time while she was in that care home. And so my first time of seeing her... She died on April 19th, and I hadn't seen her since April 1st. She'd been in hospital, and then into the care home.

Cathy:

The care home was very... It must be incredibly hard to work in. It's an old Victorian, rambling, several big, what would have been very posh houses. A bit shabby, thin, narrow corridors and carpets, and just really a very, very difficult space. I so felt for the staff there. But despite that, it was clean, and the staff that I spoke to on the phone all made me feel that it was a very kind and caring place. So it was a kind of weird, sad, warm, but not what you want ending to it all really.

Cathy:

So the first time I saw her was after she'd actually died. I got a phone call during the night, and she died in the previous half an hour, an hour. They weren't sure because they had just gone to check on her, she wasn't expected to die, and so I drove down to see her. And the thing that really was amazing... Seeing her was strange and sad and... Yeah, it was strange and sad. One of the things that happened though, was that one of the...

Cathy:

Well, I think there was only actually one member of staff on. But when she came in, at one point she was talking to me and she had asked me privately before she was taken away, whether I wanted anything from her body like her jewelry and so on. And I said, "Actually, yes, that would be nice." So, when the night sister was removing those and just arranging my mom in the bed, she was talking to her. So, in the same way as you would... I've worked in the NHS for 30 years, and the same way that you

would talk to anybody alive and explain what you're doing and why, and introduce yourself, and all of the things.

Cathy:

She did that with my mom, even though my mom was dead. And I found that a real surprise. Although I had worked in the NHS, I wasn't around the immediacy of death very much, and so I had never seen that. And it wasn't what I expected, but it felt really incredibly tender and kind, and deeply moving. And I was thinking about why it felt so moving. And I suppose what it did, without trying, was it told me that although I haven't been able to be there during the short time she'd been in that care home, she had been met with kindness.

Cathy:

So, in other words, I was witnessing an incredibly kind, tender act that... You couldn't fake that. It was beautiful. And it was both very heartwarming for that moment, but it was also really heartwarming for what then... I didn't realize this, this is only thinking about it afterwards, but why it made me feel so good was that it just conveyed how caring and kind, certainly that individual was. And therefore it was beautiful.

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.