

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. 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 second 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 a 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 spoke to was Lizzie, a psychotherapist.

Nir:

Nice to meet you.

Lizzie:

Yeah, nice to meet you, too.

Nir:

I met her on a video call during lockdown.

Nir:

Thank you so much for doing this. I really appreciate it.

Lizzie:

No problem. It's an absolute pleasure.

Nir:

Lizzie revealed the painful process that started as her mother began to need extra care, and the nature of that care had to be decided by the whole family.

Lizzie:

I never imagined that I would go through what I went through. For many people, it's almost unbelievable that if a daughter wants to look after her mother and her mother wants to be looked after by her daughter, where's the problem?

Nir:

Here, from Ad Infinitum, is episode two, Splits and Glitches.

Lizzie:

I'm the youngest of three, two sisters and myself, and I have always had a really close relationship with my mother. So as she started to, in her late 80s, sort of deteriorate and have more care needs, the whole question around where did she live, what did she do became more and more in sharp focus. So we discussed it at length and I had this ... because I've got a nursing background, I had this idea that I could ... myself and a social worker and a carer and so on, we could provide care, look after her in my own home and help her to have maximum quality of life with people that she's close to. Obviously it's a big thing to leave her own home but she also was very keen on the idea and I discussed it with my sisters. One was absolutely against me looking after her and the other one was okay about it.

Lizzie:

I could see that there was very big differences in ways of facing into her needs between the three of us, and I was very much of the position that I wanted her to maximize her quality of life and do whatever she wanted to do and help her to fulfill her wishes in the last phase of her life. So I was already seeing that there was tense family dynamics going on that were going to be potentially really problematic. This was in a context of a family that had always been very close and together and relatively united. We all spent Christmas together, gave birthday presents, saw each other. There was no obvious sign of dysfunctional family. This is something that happens a great deal with families. When the matriarch or the patriarch starts to deteriorate, underlying splits that are in the siblings can get played out in the most ugliest of ways, which is what happened in my family's case and what has deeply, obviously deeply, disturbed me.

Lizzie:

So what had happened a few years before is that my mother wanted to go to India and she wanted to go and we had a day's meeting about it and I said that I would accompany her. I said I'd look after her the whole time. I had four people, sisters, husbands, totally against me. So she was denied the chance to go to India. It was always on her bucket list and why not, and so what if she dies on route? Or so what if she dies while she's in India? So what? She's living. She's not in some waiting room waiting to die. She's living. This was the fundamental difference between our philosophies, that they were sort of battenning down, 'wait to die, keep safe, but don't live'. I was 'live and if you die on the way, well, you're going to die anyway so you may as well die while you're enjoying yourself'.

Lizzie:

In December, 2014, out of the blue, she had a series of strokes the day that my sister had decided that she had to go for respite in a care home. Interestingly, they were still planning to take her despite she had all these classic stroke symptoms. I was told that she had a funny turn and they kept her in her own home. My sister didn't want her to go to the main hospital because she thought it would be overwhelming for her. She had more strokes, an on-call doctor came and we took her to the main hospital and she spent a month in a neurological unit. This was the start of very serious family dynamics.

Lizzie:

I think what happens in a situation of extreme stress, where there's a complexity of needs because you've got the needs of the elderly person, you've got the children of the elderly person who are in shock and worried and upset about their parent. Then you've got a conflict with one's own needs because in my sister's case, she was exhausted looking after her. She was saturated. She wanted her to

be taken care of elsewhere. She felt at the end of her tether. So you've got this complex play out of needs about whose needs are we actually meeting here?

Lizzie:

So she was there for a month. What happened is that I got a lot of awful emails to me from my sisters saying this was the wrong decision and so on. It was not appropriate, that she will be overwhelmed in this hospital. But I was really clear that this was absolutely the right decision. So this was just before Christmas and I was then excluded from the family Christmas. So then there was a big question around where does my mother go after she's discharged? They had decided, my sisters and their husbands had decided to get her into this local home and they asked me to go to look at it. I went to look at it and I was appalled by it. It was the institutionalization. My mother was always somebody who liked aesthetics and she lived in the countryside and where she lived had beautiful views of fields and sheep cows.

Lizzie:

It was just this horrible, modern, soulless place and everybody, all the old people, just looked deeply unhappy, depressed. I just knew she'd hate it and I knew that she didn't want to do it. She didn't want to go into a nursing home or a care home at that point. I sort of discussed it with the physio therapists saying that this was not in our agreement with my sisters and I, because we'd already discussed it before she had her strokes, what was going to happen. Because the physio said "Well, the family want her to go to a home." And I remember having to say, "I am also family. I am one of her daughters."

Lizzie:

I remember that there was such a pressure from the physios and doctors that they did not want to have to get involved in a family conflict. But I remember really having to kind of reinforce that. "But hang on. We need a meeting to discuss this." Had I known then what I know now, I would have gone to the discharge department and said that, "First of all, my mum needs to have a mental capacity assessment." Because in the mental capacity assessment, if the person is deemed to have mental capacity, they have every right to decide what they want to do, including a decision that other professionals may think is not wise, but they have the right to do that. Rather than a decision without any consultation at all, zero consultation with her. But because the hospitals are so pushed for beds, all they want to do ... nobody looks at the psychological impact of what does it mean to take an old person who's already traumatized, they're already displaced, they've left their home, they're already mentally not functioning because they've had strokes and they're already in a stressful ward, and they're already disorientated, and endless staff.

Lizzie:

So they're already in a state of fear and all they want to do is go home to a safe and secure place. That's all they want. But all the hospital wants is to get the next person on the conveyor belt out the way because they've got all these emergency patients in a state of crisis that have got to take the bed. So the subtleties of best interests, mental capacity, what does the person want? What are the implications of sending an old person to a nursing home or a care home? What are the social and psychological and spiritual implications of doing that? None of that is addressed because it's literally one in, one out.

Lizzie:

We had a meeting on the 27th of December, and it was very clear that everything was a fait accompli. Everything had been decided. Any previous discussions about what her wishes were or what we'd been

working towards her coming to London and her being looked after by two people and myself who she really loves and who love her and who she feels safe with. All of that was whitewashed. Gone.

Nir:

Why were they so against it? I mean, what was the-

Lizzie:

You know what, Nir, I have no idea to this day why. I suspect that ... and again, this is an ongoing theme, which I think is very much part of family crisis and elderly crisis is the unresolved sibling dynamics. In this case, I think it was sibling rivalry. Whether it's true or not, I don't know. Probably it's true, but again, what happens are these really deep unconscious processes that get played out in family units and then because the matriarch or patriarch is collapsing, there's no rudder or no anchor to the family structure anymore and so the children, the grownup children, then start unconsciously ... because their matriarch/patriarch is under threat, significant threat of death, there's a regression. So the rivalry that probably was at play at somehow or other, which happens with many kids, then gets played out. If there are splits and glitches in that structure, in that mechanism unconsciously, then it can ... if the siblings aren't very mature, it can play out in the most ... in my case, in the most ugliest of ways,

Lizzie:

Then the most awful thing happened, which is that I was visiting my mom every day in the hospital, spending every afternoon with her, and one day I went into the hospital and when she woke up, she wouldn't look at me, she wouldn't talk to me. It was like this wall had come between us. We were very close and her whole demeanor had changed. She looked depressed. She had previously been rehabilitating very well. She had been having banter and jokes with the physio, with rehab and so on. At that time she only needed one carer to help her turn and see to her basic needs. Then she told me that she had been told that she was going to go to this care home. So my poor mother was ... I can't bear the pain of it, the bewilderment she must've felt. She wouldn't look at me because she was clearly very angry too, and felt very betrayed by all three of us. From that moment on, she declined. All of the rehabilitation progress went. It was like she'd been given a death sentence, and she had. Basically, she had.

Lizzie:

She was being told, "Society's giving up on you. Don't think about having your own life anymore. You're going to basically be in a waiting room until you die." So I tried to stop her going to the care home and the chief nurse agreed with me and the chief nurse couldn't exercise his sway in this. It was all sewn up. We delayed it by 24 hours and it was non-negotiable. So she went to this care home and prior to this, she'd been trying to mobilize on a Zimmer Frame, doing well before she was told she was going there. She got to the care home and for the next two weeks, she stopped walking completely. I felt like it was a protest on her part. She couldn't protest verbally, but she protested by immobilizing herself. In a way it was a very powerful protest. Like, "I'm not moving. I don't want this. I don't want to be here."

Lizzie:

It was very painful. Very, very painful to see how unhappy she was and ... very, very painful. I would spend three days in London working intensely with seeing patients and then four looking after her. Because I felt like ... well, I was totally against this, but this was the situation we were in and I wanted to maximize my full support for her and help to bring a homely presence to this home. I'd said to my

sisters, "Look, I think we shouldn't rush any decision. I think she should come home to her actual home and we should look at all options available to her, including a nursing home or care home. But all options, and don't make a rash decision." I offered to see all my patients on Skype at the time and stay with her for that whole month so that she can settle, she can recover, she can be at home in a familiar, safe environment and we can take our time to decide what's best for her.

Lizzie:

My mother never went back to her own home. She never got to say goodbye to her home that she loved, that she was so happy in. She never went back there. So she was frightened. She told me she hated it. I've got it on a piece of paper. When I would leave on a Sunday evening, she said in her little handwriting, "I will be brave," because she's bewildered and hated going downstairs, didn't like being part of ... Why should an old person, just because they're of a certain age, why are they all going to suddenly be all friends with each other? She wanted to stay in her room, which had her familiar furniture in, not this pseudo, artificially contrived social situation that just because you've all got disabilities at one form or another, you're going to be best buddies.

Lizzie:

The carers are on a terribly difficult timeframe, impossible amount of care to deliver in a certain period of time, and they have to look after four to six people and get them all up and dressed and so on.

Nir:

So I was just wanting to ask whether you feel that it is wrong putting an elderly person in a care home, as simple as that? Or do you see nuances within it?

Lizzie:

My personal opinion, I think it's absolutely unacceptable and I think that children have a responsibility, just like we look after children or dogs or whatever else, we have a responsibility to look after our elders. At the same time, I understand that a lot of people do not have the capacity to care for an elderly person, or if they've had a complicated relationship with their parent or they hate the parent or the parents abused them or whatever else, then I can understand that it makes care-taking very, very problematic. But what galls me in my situation is that I have a nursing background in general nursing and mental health. I'm also a psychotherapist. So I understand about psychological processes, so I know I have the capacity and the desire to look after my own mother and give back to her what she gave to me.

Lizzie:

It didn't even have to be ... it didn't have to be me. It could be one of my sisters. It wasn't like I had to do it and no one else. No, I don't care which one of us looks after her. Just let her be in a home situation, not an institution. So I personally am totally against institutionalized care. I think it's dehumanizing. I think it promotes dependency. I don't think it enhances people's wellbeing. They get fed a very, very bad diet. And how you look after somebody and facilitate a meaningful end of life phase is so important. I will campaign until my dying day that the system we have at the moment is not acceptable and elderly people need to be integrated into our society, not stuck out on a limb, invisible for the majority of people, that they don't see them.

Lizzie:

I think that we are phobic as a society and as individuals, we're phobic around death and dying. We can't handle it and so we stick our elderly away, unconsciously, because it's too threatening to see our own mortality in them. Then we have a situation where people will stay away from visiting their parents, or they'll do a tokenistic once a month or once every two months visit. Because it's so deeply confronting to see fragility and deterioration and dementia and Alzheimer's and so on. So they give it to the institutionalized parent and basically abdicate responsibility. So I think that the factors are extremely complex and I think it's too easy for us to do this, and I think it's a tragedy. Absolute tragedy.

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 Lizzie, and was an Ad Infinitum production with support from Arts Council England.