

Keziah:

Hi. Welcome to the second series of Home from Home: Journeys into Elderly Care, brought to you by Ad Infinitum. My name's Keziah. I've been having conversations with people who make up a fragment of the sprawling social fabric of the elderly care system. This three-part series will take a closer look into care from perspectives that are underrepresented and intersections that require more compassion led, people focused support, than traditional forms of care are currently providing.

Keziah:

The music you are hearing is centered around the South African group Chant. The thinking here is that just as it takes a community of people to raise a child, it also takes a community of people to care for our elders, or at least it should.

Keziah:

Healthcare studies in the UK show that Black and Asian people with dementia are not receiving the same quality of care as their white peers, and they're less likely to opt to go into care homes. People who reported a lifetime of racial discrimination had poorer mental wellbeing, and the health of white people age 61 to 70 is equivalent to that of Caribbean people in their late 40s and early 50s.

Keziah:

In this episode, we'll be providing space for the experiences of people of Caribbean heritage seeking to understand how different cultural practices of care and endured racism is affecting our elders entering the healthcare system today. Anndeloris Chacon is a registered nurse and CEO of Bristol Black Carers, a charity committed to culturally appropriate and holistic support for carers and their families. I spoke with her to find out why services like this were so important.

Anndeloris:

The importance of Bristol Black Carers is that it gives people a place that is comfortable, trustworthy, and make them feel valued. Because I have heard many people say that they go to different organizations. They don't see people that look like them. The language when they're speaking, somebody looks at them funny because they said a word that's funny. And we often get labeled as being aggressive when we're trying to express ourselves. And most Caribbean people tend to use their hands and tone of voice to describe what it is they want to see. And in the British culture, that doesn't seem to be acceptable. So they were not feeling welcomed.

Anndeloris:

Some of the things that I've come across is people say, "Well, if you don't like it, go back to your own country." But some of these people were born here. Yes, their skin black, but they were born in England. They belong to the British colony as such. So, what country are you talking about? As well as for the Asians who were born here. We make people uncomfortable then where do they fit? As an elder, to be told that you don't belong here when you have contributed your working life to building this country is an insult.

Anndeloris:

The other thing is food. There isn't a Caribbean option in terms of food for people who go into the care homes. I'm not saying that they have to cook it every day, but there should be an option sometimes. The

other thing is that we like to oil our skin, cream it, rub it down. And we know that it keeps our skin supple. But that is not a practice that is being carried out. And that is something that a lot of families have talked about that, "My mum's skin is so dry and it hasn't been creamed for the day."

Anndeloris:

Those are little nuances that make people feel uncomfortable. Because if you can't take care of my skin that you can see, then how are you taking care of me? If you can't provide the meal that I eat, then how do I fit into this room? If you think about us coming from the Caribbean, there aren't many nursing homes for the elderly as such. It wasn't part of the culture because you grew up with your grandparents until they died. So you didn't think of it.

Anndeloris:

But now because we are in a different culture and the work environment is so different, we need to be supported to have the appropriate homes for elders to go into. But because there are a few of them that experience negative aspects, word of mouth travels like the rain and people have built that distrust. And I don't think the communication again between the authorities or the institutions with our communities has been clear.

Keziah:

To stoop to low levels of telling anyone to go back to their country is problematic for obvious reasons. But to say it to an elder just provides more illumination of Britain's ugly colonial past, and a lasting reluctance for institutions to accommodate the myriad of ethnicities that reside in modern Britain. Speaking on his approach to understanding a person's lived experience is Ramses Underhill-Smith, managing director and founder of Alternative Care Services, the first LGBTQ+ focused domiciliary care service in the country.

Ramses:

In terms of our mental health with the black community, we talk about how trauma from racism impacts mental health, how it impacts your daily life. And those are the things you can't necessarily explore in an environment where someone doesn't understand you or where someone's going to decide that, "Actually, it's not that bad here." Those kinds of things is not what you want to hear. You want to be able to have a space where you can explore those issues.

Ramses:

And actually, yeah, it may have been the reason that I got sectioned, or the feeling of hopelessness. Or we connect in those ways where culturally what's affecting you is not looking at who you are as a whole person. And there's nothing wrong. We are here. We're European. But we also come with other elements that go unexplored and unsupported. And when you start to unpack those things, often you can get to the crux of the problem and the issues easier.

Ramses:

And I've heard people say the reason someone's got mental health issues is because they're transgender. I've been into an establishment and I've heard that people say that. Or, I've heard people say the reason someone's got mental health issue is because they need to see a witch doctor. It's just, the amount of nonsense! So for me, I think it's really important to understand the whole of a person.

You can explore that. And we're not going to turn around and say actually it doesn't exist or you're crazy, or ... Whatever the issues are, we'll work with you to unpack those things.

Keziah:

This type of attention to understanding the nuanced history of a person will not only better inform their care, but encourages mental grounding that can prolong deterioration of the minds. Life story work is a practice that is becoming more valued by care providers, especially those caring for people with dementia. It involves focusing on a person's past and bringing their history to life and into the present. In the context of racial nuances, this type of holistic approach with people who understand and look like you can make all the difference. Holding space with us now is Antonette Clarke-Akalanne, a poet and self-titled active elder who reflected on an incident whilst working in the healthcare system and opened up about her general thoughts and feelings towards the prospect of going into a care home.

Antonette:

When I first came to England, you know in Barbados, Barbados is a very British little island. In fact, at one stage we were called Little England. We had the first statue of Nelson in Trafalgar Square in Barbados, Bridgetown, Barbados before the one was built here in Britain. You won't believe that. All my education was English literature, English geography, Kings and Queens. I could relate all the poetry and everything, everything English. So I was, even snow, which we talked about.

Antonette:

So when I came to England, I thought that people would know me. Not me personally, but Barbadians. They didn't even know where Barbados was. I was asked if it's part of Jamaica. Some people say, "Is it part of Africa?" Nobody knew, which was quite surprising because I knew so much about Britain. Anyway, this day on the ward ... I mean, I was only 18 at the time.

Antonette:

And this day on the ward, this woman said to me, I was offering her a bedpan. And she said to me, "Nurse Clarke, is it true that you people live in trees?" And oh, suddenly I said, "Oh yes. When Princess Margaret came to Barbados, she lived in the biggest tree." But that didn't go down well with the woman at all. And she reported to me to the sister that I insulted royalty. And the sister reported me to the matron. And I had to do my punishment for insulting royalty was to do a long shift. It wasn't that I was offended or upset. The matron didn't look at the fact that that was very insulting towards me. But it was that I had insulted the royalty.

Antonette:

I come from a culture where people tend to look after their relatives, their elderly relatives, if they need care. A lot of elderly people are quite competent and look after themselves anyway. But those who are in need of care, families tend to look after them. We don't have a sort of care system in Barbados. I also lived in Africa where there's a wonderful extended family system whereby an elderly person, especially in the village, is looked after by their elderly relatives if they need care.

Antonette:

But there are a lot of elderly people who are active both mentally and physically and look after other people, look after the youngsters, the children when their parents go to work. So for me personally, I

don't welcome a care system for myself at all, because I find that would take away my independence and my autonomy. You're cared for by absolute strangers that you've never ever met in your life. People who haven't even got empathy with you. The staff change around so much so that you can even have a continuous relationship.

Antonnette:

The environment is strange. You don't even know where your things are. There's nothing around the place that actually reminds you of home. And even those things that you brought in that remind you of what is in a strange room. So it's very different. It's very different. Whereas if you're at home, and relatives and friends look after you, at least you know those relatives and friends. You have that confidence. Provided you're not a danger to yourself. So at least you've got some familiarity.

Antonnette:

So I presume having this unfamiliarity, strange environment even adds to your dementia, make people even worse. So hopefully, I will have enough money to at least pay for a carer to come in once or twice a day because going into care is something that I don't ... I would prefer to die first.

Keziah:

As dire as that may sound, it's a sentiment that is commonly shared. 97% of people surveyed express they don't want to go into a care home. And 71% would prefer to reach the end of their life in their own home. Home care is known to improve the lives of those living with dementia, maintains a person's independence, and can be more cost-effective for the family involved. The challenge is often in the struggle to find the right carer.

Keziah:

So in many cases, family or friends will fulfill that role. Often described as an invisible workforce. These carers provide support, not as a profession, but as a loving obligation, juggling the responsibility with 9:00 to 5:00 work. As of 2020, there are over 30 million people in the UK caring through the pandemic, saving the economy £132 billion per year. Whilst in conversation with Anndeloris from Bristol Black Carers, I asked about the vital role informal carers provides, but was quickly pulled up for my terminology and rightly so.

Anndeloris:

I have seen the terminology of unpaid carer, unofficial carer and different descriptions before the word carer. And I do not like it because it sort of degrade the carer. And the carer is a person who voluntarily supports someone who is ill, whether physical, mental, emotional, whatever illness it is. They have done that. And in some instances, it's not voluntarily. It was entrusted on them because it suddenly happened to someone in their family.

Anndeloris:

Anyone else who gets involved is a paid professional in some form or fashion. Because the word carer for me is very, very dear because no one in this world could ever pay anyone who takes on the role as a carer, because there is no monetary equivalent for what a carer does. And work tends to be 24/7.

Anndeloris:

Everyone who is able to care for their loved one at home, with additional support, because remember the nurses are trained how to turn patients. The healthcare assistants are also taught manual handling. They are taught how to feed and all these different things. As a carer in a home, nobody teaches you those things. So you need that support and that education should be given to them to help them manage better. Because we have carers being stressed out and pulling their hair out, and losing their confidence, losing their mental capacity before the government or someone steps in to give support.

Anndeloris:

We have felt this greatly through COVID and people don't realize how much money this government has saved during this COVID period with all the carers taking care of their loved ones at home without being asked, without having a break, without being supported. And what friends and relatives need to realize that they do not to only check on the person who is ill. They need to give some time to the carer as well. Because what I've noticed is that when that person dies, everybody forgets about the carer. And that carer still needs support because they have been isolated. They have given up so much to do what they love in caring for their loved one. And some of them are lost because their whole world was around that person. And we need to help them rebuild their world by keeping them connected to us as friends and family.

Keziah:

Even with carers relieving some of the financial and resource related pressures, only 12% agree they get enough support from the social care system. It's here I turned to my family. My aunt, Mavis Wenham, is currently the sole carer for her mother, my grandmother, Margaret Wenham. Years ago, after retiring in the UK, my grandparents decided to return to Dominica. Over a period of time, signs of deterioration started to arise. But it wasn't until hurricane Maria devastated Dominica in 2017 causing my grandmother to have a stroke that they were moved back to the UK.

Keziah:

March 2020: in came the pandemic and the day center my grandmother was staying in closed and gave little to no further support. Given circumstances that surrounded the passing of her father, Mavis decided that relying on care services wasn't an option. With a stoic composure, she shared some of what her experience has been like.

Mavis:

The most challenging moments I suppose in those early months, although I worked very part-time and I have worked very part-time, I suppose because I was working from home I was doing an awful lot more than I would have done before as we all are. And therefore, having meetings and trying to care for mum. And in the early days, because of her Alzheimer's, I suppose, it was just her understanding the change where she was, the environment and needing to go toilet. Anything it was quite disruptive for my work. So that was really difficult.

Mavis:

And I think the second challenge was to realize how much support she needed. Just the level of confusion for her in those earlier days was really difficult for me. And also I'm a person that travels quite a lot. So not being able to go abroad. Not to really be able to travel and having to think about mum in relation to anything simple that I want to do. So I've literally been inside this house since last year March. I've been out four times.

Mavis:

I'm a meditator. And I've been meditating for about 30 years, 25, 30 years. So I can be very calm within the chaos. So because of that, I think I didn't have a breakdown. I probably would have been completely broken down a long time ago. Even now, I mean, I've worked it so that once she's washing, I'm meditating. When she's eating breakfast, I'm meditating. So throughout the day and in the evenings, it's all around meditation and just bringing myself back to balance. That's what's kept me functioning. If I had to operate outside of that, we'd have had serious problems long time ago.

Mavis:

I think I'd have had a complete breakdown and gone absolutely bezerk, probably beat up my brothers and sister for lack of involvement. Because, I mean, I could understand that it changed so that people couldn't come in the houses. But I was thinking, I keep saying to them, get onto the phone on the video, let her see you, have conversations, get involved and question her.

Mavis:

I mean, she's in a very different place. This woman is completely independent now. She's going up four flights of stairs at least once a day. She's doing all sorts of things that she just didn't do. So I realized that she had become institutionalized by these care people. So I just thought dropping by a meal at the door, things like that. So I'm very disappointed with my siblings. They haven't done a lot more in the context of what can be done. Containing the anger and annoyance and disappointment has been the biggest thing for me.

Mavis:

But I think I was quite surprised because actually if anybody knows anything about me and my mum is that we didn't get on at all. We didn't even talk for years. And I would be the absolute last person on earth she would choose to have to stay with. And she does remember this very well. So that's why it's really been odd that we've ended up in this situation.

Mavis:

She's smiling. She's talkative. She's communicative. Her level of independence. My mum has a real mouth on her. So she will say, "No, I'm not doing that. I'm doing this." Although I'm like, "Aargh, that is my mum." Actually, I say I've got my mum back. She found her groove. Stella got her groove back. I don't think it's necessarily institutional. It is institutional but it's not intentional.

Mavis:

But what happens is people, obviously the carers in the day center try to assist people and do the job as quickly as possible because they've got others to deal with. But the impact is that they strip people from all type of independence. My biggest concern is when she goes back home and goes back to day center, how quickly that can be undone. And so therefore, what do I do? Do I just carry on or do I say, actually, well, it is what it is? We all have to share in that responsibility because where she is now is what she was before social care became involved.

Keziah:

As I alluded to earlier, the distrust towards care services was caused by the circumstances that surrounded the passing of my grandad's. Although the family organized themselves around my

grandparents' care when they came back from Dominica, my granddad's, Henderson Wenham, was diagnosed with dementia in 2019. And after receiving poor treatment in a rehab facility, passed away in January 2020. Mavis, although still dealing with a bereavement and looking after her mother, is now in the arduous process of filing complaints.

Mavis:

For my dad, they've upheld everything about the poor quality of care, and awful experience of a care home that didn't seem to have a plan. So for instance, we just knew that he was really in a lot of pain in the bed. And once they checked it out, they realized that he had all sorts of bedsores. They weren't even moving him from side to side. He kept wanting to go toilet. They were saying, "No, no, you've had a severe stroke, you don't know what you're doing. You don't need to go toilet." So they would say, "No, do it on yourself and then we'll clean it up." They were giving him pads.

Mavis:

Go in there more than one day seeing the same clothes. Literally, he only had a vest or T-shirt and a pad and that's it. And they argue, "Well, he's in bed." We'd say, "But dad even if he was ever ill would never be in bed like that. He'd be fully dressed." And then find they were giving him ... Going there I think it was Christmas Day. We brought him his meal, which we brought at lunchtime. But in the evening they're like, "Oh, here's your dinner, your Christmas dinner." And it was beans and mashed potato. And that was Christmas Day. Thank God we had brought him food.

Mavis:

The fact that he was a Caribbean man and it just ... And for my dad, that would have been what would have just really distressed him to end up being in that situation. The man had never been ill. He had always been very independent. The thing is, I mean, we could see it happening. I was aware of it, but I think that time we were all both shocked and exhausted and working and moving around my parents' care. Obviously, we got children or whatever. So we were trying to be at home and there. We saw it. But at the same time, it became difficult to respond.

Mavis:

So I did get in all the private people in. I brought in a male Caribbean carer, young man that I knew, paid carer to do one-to-one just reminiscing. And just really getting him thinking about the Caribbean and stuff like that. We started to bring him foods because as I said, we saw the food a number of times and I thought my dad wouldn't eat that. And they kept mashing his food saying he could only have liquids. And we were like, "This is nonsense."

Mavis:

I don't think people still get it. People don't get it. They think food is food. People are people. But actually, it is important. Especially when you do start to become confused, you do start to revert to what you know and the longer-term memory. And having a severe stroke means that his dementia was probably quadrupled. It really had advanced. I went abroad and it was literally I came back I think about a week or so before and I was horrified when I came back at how things had deteriorated. And so things just slipped and, yeah, he passed away.

Mavis:

Social care's more or less said yes, yes, yes, yes, yes. But actually, we did what we could, or something like that. So I'll be taking that up with the ombudsman. And the health service for some things they've said, "Yeah, absolutely we are really sorry." Other things they've said, "well, the hospital consultant put on the record that they'd had a discussion with me and my sister and we had agreed to do not resuscitate", which was not true. They do have the right to make that decision, but they certainly would consult with a family and have to go through a process. They didn't. But he wrote that that had happened.

Mavis:

So when the ambulance was called when my dad wasn't feeling well. The ambulance was taking him to the hospital. Then they saw the record and took him back and put him in his room and left him because it said, "Do not resuscitate." And that's what happened. I was due there that day. In fact, I was due that morning at the time it happened. But then the physio wanted ... It was a first day back after New Year, the 2nd. So the physio wanted to go straight back in and do the work. And so I switched it to the afternoon.

Mavis:

Then they started to call me and say ... After I now know that he was already gone, they called me at midday saying, "Oh, you're due to be here. Can you come soon?" I said, "Yeah, yeah, I'm going to come but I switched it because of this." They said, "Oh well, come as soon as you can." And then later we found out he had passed away at midday. It all started about 10:30. So this woman was ringing me telling me, "Oh, are you going to come? Are you going to come?" When my dad had already been put back into the room and had passed away. So the whole of it was absolute crap.

Mavis:

And so therefore, the idea of my mum having to rely on those, or even myself, I'm just thinking, "My God." I say to my kids, "Just take me to some island somewhere and just let me go." Because if this is the quality now, as we privatize and do all the other things and God knows where are we going to end up in 20 years, really?

Mavis:

People work hard. My parents worked hard in the UK. They both got into really good positions as managers, City of London and the GPO, which is now the Royal Mail. Did really well. Paid their dues. And therefore, should have ended their lives with dignity. So I think for everybody, whether they work or not, I respect young people because they're my future, and older people because they're who brought me along. So I think we really need to show some respect for older people. Not to see them as finished. Recognize what they could still give and support them in their end of life.

Keziah:

And keeping with that same energy, I'm grateful to include words from my grandmother. This is special as it's the first time of her reflecting on her first arrival to the UK and reminiscing her late husband, Henderson Wenham.

Margaret:



Well, the time I came, everybody was leaving Dominica and going to London. Oh, I was very pleased to say, "Well, I'm leaving Dominica. I'm going to London."

Keziah:

And what did you first think of England?

Margaret:

I started crying saying, "Oh, I'm shocked. I should not come up here at all." Oh yes, it was cold. The people was, some, some was very nice. Some didn't want to talk to me. I did not like it at all. I didn't like some of the people. Sometime the look they give you and the things they tell you. There's places you couldn't go, especially when I said, "Well, I'm going to London." They didn't want to know. They didn't want to know why I shouldn't come to London. What are you doing here? Sometimes I don't answer them at all.

Keziah:

And how did that make you feel at the time?

Margaret:

Terrible. I was feeling terrible at that time.

Keziah:

How do you feel about care homes?

Margaret:

It's not your own home. You cannot do what you want. I would like to go back to the West Indies, Dominica with my daughter.

Mavis:

Who? With me? Oh God. I'm surprised.

Margaret:

I would like to live with you, Mavis.

Mavis:

Oh, wow. This is a first I have to say.

Margaret:

She's very nice.

Mavis:

Oh boy, I didn't even pay you, mum.

Margaret:

And understanding. I love Mavis very much.

Mavis:

My mama has never, ever said that in her life.

Margaret:

I miss him. I miss him terrible. His jokes. He used to give a lot of jokes, things that make you laugh. He was a very good man, very good man. Call his name every day because I miss him very much. He had a good life.

Antonnette:

Your elders may have lots to share, so tap into them now. Because when they're gone, they're gone. They can tell you firsthand how things used to be, and share secrets locked in their memory. They may give insight in how their lives looked, which may not be recorded in the history book. You may discover bloodlines that you never knew existed, or understand the values of relics you overlooked or missed.

Antonnette:

Elders could share words of wisdom, or shine light on things long forgotten. Do not discard your elders. They're your living ancestors. Ask them what, when, why and how. Don't delay. Ask them now. They may tell you things that happened a long time ago, or may share customs and traditions that you do not know. Do not leave it long to talk to your gran because when they're gone, for good they're gone. All is not recorded in a history book. And what is written may be someone's subjective view.

Keziah:

You've been listening to episode one in series two of Home from Home: Journeys into Elderly Care, featuring words from Anndeloris Chacon from Bristol Black Carers, Ramses Underhill-Smith from Alternative Care Services. The poem was by Antonette Clarke-Akalanne. And sharing her experience of the care system was Mavis Wenham, featuring words from her mother, Margaret Wenham. The podcast is narrated produced, edited, and music arrangement was by Keziah Wenham-Kenyon. Commissioned by Ad Infinitum with support from the North Wall.

Keziah:

Join us next week where we'll explore how organizations are taking a different approach to caring for LGBT+ elders, and plans for the first LGBTQ+ retirement community in London.