

CABS podcast

What does home mean when you can no longer live there?

Dr. Verina Waights, Dr Manik Gopinath, Professor Mary Larkin and Dr Ann Mitchell:

DR VERINA WAIGHTS: When asked, most people want to live in their own home. Yet for some people, this becomes no longer possible. So what does the evidence tell us about what home means when you can no longer live there?

I'm Dr. Verina Waights, and you are listening to the Open University Center for Ageing and Biographical Studies-- that's CABS for short-- research group podcast. I'm joined by three colleagues from CABS, and together, our research expertise covers a wide range of fields and subjects.

Hello, everyone. Thank you for joining us today. Let's start by introducing ourselves briefly and the specific focus of our research. Monique, would you like to go first?

DR MANIK GOPINATH: Thank you, Verina. Hi, everyone. I am Manik Gopinath, senior lecturer in ageing. My research focuses on the environments of ageing, ranging from people's own domestic homes to care homes. Within that, I look at how where people live matters for as well as affects their well-being.

DR VERINA WAIGHTS: Thanks. Mary?

MARY LARKIN: Thanks, Verina. I'm emeritus professor Mary Larkin, and my title is professor of care, carers, and caring. Most of my academic life has been looking into care at home and the importance of the home environment. But my more recent work has been into care in residential establishments, particularly care homes, and looking at the role of relational care in improving the quality of care and the well-being of all those who live and work within those establishments.

DR VERINA WAIGHTS: Thanks, Mary. And Ann?

DR ANN MITCHELL: Thank you, Verina. My name is Dr. Ann Mitchell. I'm an honorary associate at the Open University. I also work as a consultant researcher. And at the moment, I'm involved in a number of projects, including looking at ethnic minority nurses working within practice and the Windrush generation health and social care needs. Thank you.

DR VERINA WAIGHTS: And I'm co-chair of CABS. And my research focuses on older people's and family carers' well-being, including the impact of hospice at home services that provide palliative and end-of-life care for people living at home. So what does our research tell us? In the UK, the majority of people aged over 65 live in their own home, with some 2.5% of older adults living in sheltered accommodation or in a care home. Manik, what does home mean to older people when they can no longer live there?

DR MANIK GOPINATH: Right. That is a more complex question than it sounds because not everyone who has lost home has physically left. A research that I and my colleagues do with older people tells us that home is almost never the physical dwelling alone. It is more about what a place enables, such as the routines that flow without effort, the possessions arranged in the way you like them, the relationships within and beyond your door.

And here is something that always stays with me. So a home can be cramped, not really fit for someone's needs anymore, and that person still feels deeply at home there. They'll tell you, I love being at my son's, my daughter's. I'm very comfortable there. But it's not the same. It's nothing like my own home.

And now when people do move into sheltered housing or into a care home, something interesting happens. We find that those who are involved in choosing the setting they're going into, who are able to bring what is meaningful to them, and who are supported to form new connections, they make home again, not the same as before, not without some loss, but genuinely.

And then there is this, which I find perhaps the most striking finding of all. There are people who have lived in the same house for decades and no longer feel at home there, not because the house has changed, but because it can no longer hold the relationships, the routines, their sense of self that once made it home. And so home, it turns out, is not a place you live in. It is more a place that holds you.

MARY LARKIN: And as Manik alluded to, moving into a care home is often difficult for people because they're in unfamiliar surroundings, their routines have changed or become completely different, and they've lost their family and community relationships, or they're considerably diminished. And there's a loss of their self-autonomy and sense of worth as well. And this can lead to their poorer physical and mental well-being.

Our recent research into what is known as relational care has shown the value of focusing on the interdependence in relationships in care homes and moving away from seeing individuals as just a collection of needs to be met by others towards mutuality and reciprocity in caring relationships, whereby no one is solely a giver or a receiver. And central to the practice of relational care are the emotional, physical, social, and spiritual aspects of the care home environment because these can make residents feel a sense of belonging and sufficiently at home to enjoy freedom of expression and find meaning in their lives, building relationships with each other, with members of staff, and extending their relationships outside of the care setting to the family and the wider community.

So just for example, the physical environment can nurture relationships and autonomy by, for instance, having a mix of private and communal spaces, encouraging residents to bring their own personal possessions, and encouraging them to pursue their pre-existing and new interests and hobbies. So, for example, we found one lady loved knitting, and she was encouraged to set up a knitting club in her care home. And that helped her build relationships with other members of staff and strengthened her relationships with the care staff as well.

DR VERINA WAIGHTS: That's fascinating, Mary. We also know that some older people need help to remain in their own homes and others moving with a relative, with over 3 million adults aged 40 to 60 in the UK caring for or supporting older parents. But my research highlights conflicting and nuanced views. Some older people enjoy their carer's company, but others say having carers make them feel that their home is no longer theirs. They feel supervised with a loss of autonomy and privacy, that they reluctantly accept it so that they could stay at home in their neighborhood with their family and friends.

Carers tell us of the joy and privilege of caring for a relative or giving back to their parents, but they can also feel torn between the needs of their relative and those of their children or cultural pressure to provide such care. Many carers experience poor health and well-being. And sadly, some feel their relationship with spouse or child becomes lost.

Caring can be overwhelming and relentless, and taking breaks are difficult due to lack of respite care. Also, new challenges emerge if their relative's health deteriorates. Those reducing hours or exiting work often experience financial hardship. The most devastating is the emotional distress, sense of failure, and guilt of realizing you can no longer cope, and your relative must go into a care home, possibly against their wishes.

But really positively, for some older people with a terminal illness, the hospice at home service enables them to die at home with dignity, even though they may now be living in what was a dining room with a hospital bed and hospice staff popping in regularly. It still feels like home. However, not everyone leaves home due to care needs. Sometimes people have to leave home because they are experiencing domestic violence. Ann, can you tell us what home means when people and their children have to seek safety in the refuge?

DR ANN MITCHELL: Thank you, Verina. Domestic violence is normally mainly aimed at women. But we should not forget that men too can face domestic violence and that it seriously impacts individuals' lives. The persistent abuse can include cursing, screaming, constant criticism, and threats to cause harm, remove children, or kill the partner or oneself.

So it's a very serious situation when this occurs. But women have found a lot of courage to take their children and leave their home and the rest of their family. Women in my research study that took place in Guyana said the refuge was a safe home where they started their healing process with support from staff and counselors. Home was also the feeling of togetherness, with other women experiencing similar issues, enabling them to have a voice and live new lives on leaving the refuge.

Here are some extracts on some of the women that I talked to in the study. Ganet resolved that the shattered early life would not stop her from getting on with her life and left to work as a landscape gardener. Similarly, Ina found her faith, helps her to get rid of hatred, forgive, and makes her feel she's worth something. She trained to become a qualified nurse.

And Janet felt mentally and physically strong to cope with any adversity that she may face after spending her time in the refuge. She left with her children and is now managing her own photographic studio.

DR VERINA WAIGHTS: That's very encouraging, Ann. There is much to reflect on here, but time today is short. So finally, and in one sentence, please, can you each say what assumption about what home means you most wish to challenge and what needs to change to make that possible? Ann, would you like to come in here?

DR ANN MITCHELL: Yes, certainly. Thank you. When you no longer feel you have that place of safety, where there's comfort, warmth, and able to relax, somewhere you feel you can call home, this can have a serious impact on all aspects of your life.

So what is needed? Policies that develop support systems and can mobilize resources to enable women-- and, of course, I did earlier said men too-- who are survivors of domestic violence to feel that they can have time away to heal and recover and spend some happier times with their children and other family members. Thank you.

DR VERINA WAIGHTS: Thanks, Ann. And also, having family or carers coming into your house every day or relatives moving in can make you feel that your home has been invaded and is no longer your own. Policymakers need to understand the relentless financial, emotional, and well-being toll on carers and do more to support them to cope, especially with respite care that lets life feel more normal for just a little while. And now, Mary, would you like to come in now?

MARY LARKIN: Yeah, I like to put forward the challenge of assuming that you're just doing care to older people in a care home. And in doing that, you need to attend to the needs of the staff and their relationships as well. For example, our research has shown that this is required for the reciprocity and mutuality central to relational care and for relational care practice to take place. Feeling at home for staff only take place when this is done, and it's been found to improve staff well-being and increase their satisfaction, creativity, motivation, and retention.

DR VERINA WAIGHTS: And Manik?

DR MANIK GOPINATH: Yes. So, for me, it is do not conflate staying in one's long-term residence with feeling at home. And, therefore, the question we need to ask is not how we keep people in their residence, but how do we sustain what makes it home. Older people often know when their current residence does not work for them, but many cannot do anything about it. And that is where I think the change needs to happen.

DR VERINA WAIGHTS: As you can hear, what home means when you can no longer live there is complicated, conflicting, and nuanced. And we would love you, our listeners, to join in our conversation. What does home mean to you? What does home mean when you are caring for

a relative or a friend or if you're a care worker supporting residents to feel at home or making daily visits to those living in their own home? Please leave us your thoughts in the comments. If you are interested in contemporary issues and debates on ageing, please join in the CABS public seminar series and the Open University free OpenLearn courses. Just follow the links in the discussion box. Thank you to Ann Mitchell, Mary Larkin, and Manik Gopinath for joining us today. I am Verina Waight, and you are listening to the "What does home mean when you can no longer live there?" CABS podcast. Do join us next time.