

In Search of the Invisible Army – The Caregivers' Story

Episode 2: Finding Friends

This is In Search of the Invisible Army: The Caregivers' Story. A podcast mini-series brought to you by Havas Lynx.

I'm Paul Eccles

In our interviews for these podcasts, we asked carers about everything from whether they got enough sleep to their ambitions for the future. Naturally, it got pretty personal at times, and there was one question in particular that raised a few smiles.

Paul: Do you feel loved Shazia?

Shazia: Yeah. By my Mum, definitely. And I think that's the most important thing. I must admit, I've never been asked that before!

That was Shazia. We heard from her in our last podcast, and you'll hear more from her a little later. Interestingly, all the carers we asked that question too said that they felt loved. But that didn't mean they didn't feel lonely. Here's Leanne, another carer we spoke to:

Leanne: It's really hurtful. Is this horrible. I feel really lonely. My mom's there. But she's not there.

In this podcast we're going to look at the relationships around a carer – with the people they look after, the doctors, nurses and other professionals that they deal with, and also the wider network of family and friends around them.

The research in this podcast has come out of an industry white paper I worked on with Havas Lynx earlier in the year – for more information on that go to invisible dash army dot com.

Let's go back to Leanne:

Leanne: At the moment, I'm caring for my mother who is 70 years old this year end of this year. She's suffer from schizophrenia and she suffered from roughly 25/26 years now. Yeah. And it's ongoing and the whole situation is up and down. You know not even talking about days you know one minute she's okay and the next minute she's not so depend on her moods and depression which is unpredictable. And I'm with her every day for seven days a week. Yeah

Leanne's a single mum in her 40s, and she lives with her three daughters (all in their teens), a few minutes away from her mum.

Leanne: Yeah I turn up at eight o'clock. And sometimes she's settled then I can go home 2/3 in the afternoon or if not then I got to stay all the way until, you know to late night it all depends. But very full on every day.

Leanne's also cared for her dad, who died of lung cancer a few years ago, and for her grandma a bit too. Over a third of carers in the UK are sandwich carers like Leanne; caring for parents whilst trying to raise children. According to Carers UK, only 12% feel that they're juggling everything well.

You might notice some car noises in the background of my conversation with Leanne. When we met, Leanne didn't want to be interviewed at home – she didn't want her daughters to hear us talking – so we sat and chatted in the back of her car.

Leanne and her mum moved to the UK from Vietnam when Leanne was 11. They came to join her dad, although her parents separated about a year after they arrived. And then, when Leanne was 16, her mum suddenly became unwell.

Leanne: Oh gosh. It was horrible. I-from beginning. So every time I bring my friend or the neighbour, she will start swearing at them or spitting at them.

And I remember one time we live in the maisonette and it is upstairs and

downstairs is a sort of corner shop. And hear her voice saying that can you throw all the shop stuff downstairs which is knives and scissors and you name it. And luckily I don't know why a lot of people passed by but it doesn't hit anyone, well the police turned up and arrested her and then they found out she's not well.

Things like that night and she opened the door. You know and disappear with no shoes on or you know in this weather though not enough you know clothes on.

Leanne's mum was sectioned for five months, and then later discharged. A few years later her brother was also diagnosed with schizophrenia – a serious episode led him to hear voices telling him to walk into the River Thames. He got so deep the waters were up to his chest before people calling from the bank brought him to his senses. Leanne's brother lives with their mum. She says he manages to look after himself, although he's struggled with alcohol and gambling addictions and has hassled her for money in the past.

Leanne's cared for her mum ever since she first became ill – she went to college and worked for a short time as a hairdresser, but gave that up as her mum needed more attention. and her brother wasn't able to help with this.

Leanne: To be honest I lost my mom 25 years now. She's like a little child. I had three daughters. But she's the fourth one. To be honest she's worse than that. She's like a zombie because of medication.

Paul: Okay. And how was that for you?

Leanne: It's really hurtful. Is this horrible. I feel really lonely. My mom's there. But she's not there. Like we were going out every single day to get fresh air. But I can't get one sentence out of her mouth. And I end up snapping at her all the time you know. Because we went out for so many hours I want to be bonding.

[Leanne sighs]

Leanne: Sometime I'm like ma'am wake up, you know, can you be my mom instead of me being your mum. But for a change, I need to talk to you I need to, you know, I need someone to talk to. I am tortured between you know like when I'm with her, I don't want to be with her, when I'm home I feel guilty by leaving her with my brother you know

It was really sad to hear Leanne's feelings of bereavement at the decline in her relationship with her mum, particularly when combined with her sense of duty to her. As she says she seemed very conflicted – getting frustrated at her mum for not being able to *be* a mum and support her at a time when Leanne needed her most, and then beating herself up for feeling this way.

Shifting relationship dynamics are common in care relationships.

Here's Emily Holzhausen, Director of Policy and Public Affairs at Carers UK:

Emily Holzhausen: Most people say that the relationship changes. Some people find that the relationship strengthens, deepens and gets a lot better. Other people find that you need to renegotiate the roles that you have with the person that you're caring for. And for some, I'm afraid, relationships break down as a result of the changes that people have in their lives.

Sadly, Leanne's relationship with her mother probably falls into that third category. But Floris, a carer from the Netherlands whose wife has MS, told me caring has strengthened their relationship.

Floris: She is my wife, there is nobody else I love more than my wife.[27:15] It's amazing how our love is, we are always one mind. It made our relationships stronger. Sometimes she says I love you more than I did because you are taking so much care of me.

Floris has a real energy and enthusiasm for caring, and we'll hear more from him later. The renegotiating of roles that Emily mentioned comes very sharply into focus amongst those caring for their parents – we've heard Leanne describe her mum as an extra daughter. Here's Shazia again, who we heard from in the opening. She cares for her mum, who has Parkinson's:

Shazia: It can be... because it's sort of a bit of a role reverse at times it can get a little difficult at times. And it's a bit weird for me telling her what to do. She hates using her wheelchair, her wheelchair is over there... She won't let me take it anywhere. So she's got a hospital appointment later on today. So I have to always find one in the hospital just lying around because she refuses... she hates being seen in a wheelchair. So its stuff like that it's a bit weird telling your Mum off or just telling her what to do I think. But it sort of has a bit of comedy factor as well.

Paul: Has your relationship with her changed in the period that your Mum's been unwell.

Shazia: Yeah, erm, I think I've had to be more independent and grown up quite quickly. Much quicker than I probably would have wanted to. And yeah, I don't know. It's hard. Yeah it is just something I would never have imagined because being an only child as well. We were very close to begin with... But it's sort of stuff like when she says sometimes I wish I would just die so you would have a life... That sort of stuff like really hurts me. But I don't let her know that – because then I can also see how frustrated she might be. And how horrible it would be for like her to rely on someone because she was so independent before this happened.

You can see the complex tensions that caring has created for Shazia and her mother – the uneasiness of a rearranged hierarchy, the sense of guilt and burden her mother feels.

Looking back at Leanne, the break-down in her relationship with her mum is perhaps as much to do with the barrier she feels her mum's schizophrenia creates between them, as it is to do with their care relationship.

But for Lina and her husband Michele, who has the lung disease COPD, it's the cat and mouse relationship they've adopted. Here's Lina, who lives near Milan in Italy, with her daughter in law acting as translator.

Lina: She used to be his wife and now she feels his mother. She constantly rebukes Michele for not taking his dugs, to get dressed, to get washed, so their relationship is like a mother to a child.

Lina told me the onus is on her to take care of Michele – to help him with his oxygen therapy, personal care, and taking his meds. She says Michele is stubborn and uncooperative – he bats her attentions away, and gets angry, but refuses to wash himself or do anything to control his deteriorating condition himself. It's this tension, rather than Michele's care needs as such, that seemed to be putting the real strain on their relationship and on Lina. In comparison, another carer who shared her story with us, Karen, described working "as a team" with her partner Yvette. Both take active roles in things like remembering medication. Karen said their relationship is as strong as ever, and Yvette's condition is well-managed.

Studies show that more balanced care partnerships like Karen's and Yvette's can lead to better health in the person needing care – one in particular suggests that this is because it encourages the patient to take a more active role in taking care of themselves.

Even the language we use can be important. Think for a minute about the labels 'carer' or 'caregiver' and 'care recipient'. Don't they straight-away imply something that's one way – that one person is doing all the caring, and the other is passive and powerless.

That's what Kate Swaffer thinks. She and her husband Peter don't like any of those terms.

Kate's an acclaimed author, activist and academic amongst many other things. She also has younger-onset dementia.

Kate was diagnosed when she was just 49. She was as active as ever and yet her doctors' approach was to say 'there's nothing we can do'. This was followed by service providers advising her to 'get her end of life affairs in order, to get acquainted with aged care, to give up work and study, and to prepare for death'.

Kate Swaffer: But you know the day I got diagnosed I'd squeezed in a university lecture, taken the kids to school, been to work, gone to my appointment, gone back to work – why was it even logical that the next day I couldn't do anything?!

And I eventually termed that Prescribed Disengagement® and even trademarked the term because that disempowered me further; it took away my hope it took away any sense of a future.

A big part of what Kate describes as her Prescribed Disengagement was that her husband Peter was also told he would soon need to quit his job and care for Kate full-time:

Kate Swaffer: So it actually taught him to just take over which further disempowered my ability to function.

Kate and Peter followed this plan initially, but eventually realised it was an unhealthy approach. It disregarded Kate's fierce independence and they felt it totally went against her best interests. They also felt that calling Peter Kate's carer denigrated all other aspects of their relationship (something I think many people feel). Peter had cared for Kate a long time before she had dementia. He supports her now as he did then, as she also supports him. So Kate came up with an alternative way to frame her relationship with Peter – she calls him her Back Up Brain:

Kate Swaffer: And we kind of liken it to the back-up computer. So you know all young people have grown up with computers, hopefully you back

up the computer regularly in case your computer crashes now that's kind of how my husband supports me – the only time he would step in is if it was dangerous at this stage. He waits for me to ask for support rather than taking over from me. And what we see around the world generally is that most care partners just take over from day one and that's actually really unhelpful.

Kate says that this simple term Back Up Brain (or B-U-B) helped to set guidelines for her and Peter that maintain a healthy balance. It enables him to stand alongside rather than care for Kate, and helps Kate maintain her independence – which is integral to her thriving as she lives with dementia.¹ /

Every relationship is different. Back-up-brain might not work for all. But if you think about the sense of balance that the term 'care partner' rather than 'caregiver' implies, you really get a sense for the power of the language we use in describing caring roles.

Kate is Chair, CEO and co-founder of Dementia Alliance International (DAI). You can read more about the Back Up Brain and Kate's perspective on dementia in her book *What the hell happened to my brain?: Living Beyond Dementia*. For details of this and the many other amazing things Kate does head to KateSwaffer.com

As a carer, you'd think the healthcare professionals you come into contact with through caring would be key in helping you find your way. But when I chatted to Leanne, she didn't have a lot of good things to say about her mum's doctors and psychiatrists. In fact, she referred to appointments as a waste of time. Such disconnects are obviously not ideal, especially as it sounded like Leanne needed more support. Unfortunately, they're common, as was apparent from a conversation with another carer Sue.

Sue's husband Anthony has a form of young-onset dementia called PCA. His symptoms are fairly advanced – he's visually impaired, immobile, and totally reliant on his wife.

With the help of professional carers Sue takes care of everything from personal care to physio. And yet in spite of this, she says she's met a lot of resistance from his healthcare professionals:

Sue: I think they were very difficult from diagnosis getting people to listen to us and know that I had the experience. To begin with I think I was just purely seen as the carer who's maybe making a fuss. So I felt they weren't really taking onboard my experiences. And I felt in some meetings that I had known more than they do. We did get to a crisis point where things were very bad. I felt I had to fight and I still am fighting for every single thing.

Sue: You want to have a good and open relationship with your healthcare workers. You know, we should be looking at the whole person not just the odd bit, um, and I really sort of felt I had lost a lot of confidence in them

Emily Holzhausen, from Carers UK, says that the problem is that professionals are often too patient focussed.

Emily Holzhausen: We've still got a long way to go before we are at a point where carers are feeding back to us that actually yes they are involved

Because if you go to see a health professional they are quite rightly very focused on the person in front of them, the patient. They don't always ask the carer how they are doing or how they are managing. The kind of assume care and support will happen without necessarily including them.

Those we spoke to that had found good relationships with healthcare professionals, said they were worth their weight in gold. Shazia had mixed experiences, but here she is talking about her mum's current neurologist and neuro-psychiatrist:

Shazia: They've been amazing. Like one them rang me up on "A" Levels results day and he was like 'if you've not got the grades then I'll like fight

for you to make sure you get in to your first choice university'. And they've like always really involved me in the care and always asked my mum how she's doing, how I'm finding her, if I've noticed any changes since they last made changes to her medication. And so it's nice to know that they acknowledge my role and actually take on board any feedback. I don't know what we'd do without those two consultants really.

It's not rocket science to suggest that relationships like this one benefit everyone. We talked in the first podcast about the need to identify carers and connect them to information and support. Healthcare professionals are really well-placed to do this- Here's Dr Sarah Jarvis, a GP and Clinical Director of patient.co.uk:

Dr Sarah Jarvis: It's absolutely essential that a GP knows if somebody needs caring for, who is looking after them and whether their needs have been met, because it's only by doing that can we work together as a team to ensure the best outcome for the patient and of course [03:00] to look after the physical and mental wellbeing of the carer.

For healthcare professionals, carers offer a window into the world of a patient. Leanne for instance, is with her mum at least eight hours a day, feeding her, giving her medication, observing her behaviours and symptoms. Emily Holzhausen told me that the time carers spend with the people they look after can make them a huge source of knowledge:

Emily Holzhausen: They describe themselves as becoming experts in care over time. Some people with very rare conditions sometimes the carer is the person that knows more than the professional sitting in front of them. And they learn a lot over time.

One such expert in care is Beth Britton. Beth's a respected campaigner, consultant, and writer, who champions dementia care issues. She cared for her father, who had vascular dementia for the last 19 years of his life:

Beth Britton: I think the position we found ourselves in was having to find practical solutions to the problems that my dad had. And so we spent a lot of time with him, and we tried a lot of different things, and we discovered things that really worked. So, for example, he really struggled with drinks and with thickening drinks - my dad loved a cup of tea, but you try thickening tea, it's a nightmare! But thickening smoothies worked brilliantly, and when a person can't swallow very well and their nutritional intake is declining, that is at least one way of getting some fresh fruit into them.

And the staff had never even thought of that.

So I think there's a lot that carers can contribute and I think that goes back to the point about needing actually involve that carer expertise because it's absolutely invaluable.

As Beth says, bringing onboard this kind of unparalleled insight can only benefit the patient – and there's studies that support this. The presence of a carer can mean that patients are five times more likely to complete a self-management programme that they're less likely to relapse, and more like to take medications and stick to healthy living habits.

Now, clinical settings like hospitals aren't always the most welcoming place for carers. It's somewhere they can end up feeling forgotten or excluded.

And that was the experience of author, journalist and co-founder of John's Campaign, Nicci Gerrard. Like Beth's father, Nicci's dad John had dementia. He lived well with it for ten years – tending his garden and teasing his grandchildren – until leg ulcers resulted in a five week stint in hospital. Here's Nicci, talking at the Royal Society of Medicine earlier this year:

Nicci Gerrard: That hospital had restricted visiting hours and then an outbreak of noro virus. Which led to a virtual lock down so that for days on end he saw none of us, he had no visitors at all.

Courteously and uncomplainingly my father went off a cliff. He went in well, he came out skeletal, incontinent, and utterly immobile. He couldn't put one foot in front of another he couldn't even lift a fork to his mouth.

Hospital we learned is a very hazardous place for those who are frail confused and whose grip on life is precarious one in three beds are occupied by people with dementia, and they need a constant and empathetic presence that nurses and doctors simply cannot provide

We understood too late that he needed people who'd help him eat, drink and move around.[02:00] Without them he very quickly lost his capacity. We needed to talk to him to read to him to, to hold his hands, to look into his eyes, to stroke his hair to tell him that we loved him.

Nicci's father passed away nine months after he left hospital. One third of people with dementia who go into hospital for an unrelated condition never even return home. Nicci saw the senselessness in this, and in her father's decline, and saw a need for change. So with her friend Julia Jones, whose mum also has dementia, Nicci set up John's Campaign.

Nicci Gerrard: The power of the campaign lies in its simplicity. It says that carers of people with dementia should have the same right to accompany them in hospital or any other institution as the carers of sick children [04:05]. Just as it's almost unimaginable now that parents were ever kept away, so we believe that in a few years' time it will be unimaginable that carers are.

Since the campaign began over 1000 institutions have pledged support – from hospitals to social housing organisations. The campaign guides these institutions to introduce a range of practices that actively support carers. Things like unrestricted visiting hours, so carers can be there as much as they wish, and discounts on food and parking. Some have introduced carers charters – a code of conduct that guides staff on how to interact

with carers and lets carers know what they can expect – whilst others even have zedbeds so that carers can stay the night with their loved one.

But what's the effect of all this? Does it actually improve things at all?

Nicci Gerrard: There is robust evidence that where carers are welcome there are fewer falls, less malnutrition and dehydration, that stays in hospital are shorter, that readmission is less likely It's good for doctors, nurses, carers and above all for patients.

Besides the benefits Nicci listed, institutions involved in the campaign have also reported fewer complaints (a sure sign of better communication between staff, patients, and carers), and that patients are more at ease and less agitated, which is key, when you're talking about dementia./

What the impact of John's Campaign really typifies, is the huge benefits that come when professionals and institutions broaden their perspective. From one that focusses on the patient, to one that takes in all the aspects that make up a person's care (including of course, carers). Here's Anil Patil, founder of Carers Worldwide:

Anil Patil: We as the professionals, we never looked at the bigger picture. Always we are looking at the person with disability or the elderly, person with the HIV/AIDS or person with mental health issues – but never from the carers point of view.

If you want to see the change in the person who need the care, to first provide the support and attention to the caregiver. And almost 50 to 60 percent of your issues are resolved.

You can find out more about the difference John's Campaign is making at JohnsCampaign.org.uk – there's a lot of really great information and resources on there, including the reported results of the campaign's impact. A full version of Nicci Gerrard's talk is available on the Royal Society of Medicine's website, rsm.ac.uk. Just search John's Campaign in the site's search function.

We'll return to Leanne now who, like many carers, felt that her caring role cut her off from other people.

Leanne: My mom is my first priority now and, I know my kids supposed to be first. So er...Every time I went back home to my house I feel exhausted even though I don't do any physical stuff. But my brain is so heavy. And I just go in my room and shut the door. And I want to be on my own which is unfair for my children really because they aged like they want to come and get their mom because they has no one, just me only.

Paul: So, do you think that looking after your mom has an effect even for your children?

Leanne: A big impact for my children. My kids turn up you know come up to me and ask for something I give very simple advice or I shut them away. You know I didn't provide for them at all. I used to have so many friends they keep calling you you know would you like to go out and then I say no sorry, maybe next time. So I'm on my own now, they drift apart now. So there's no social of life at all.

According to Carers UK, 8 in 10 carers have felt lonely or isolated as a result of their caring role. That notion of Leanne closing the door to her children is striking, and particularly telling of her difficulties in balancing her roles as a parent and a carer – at times she seemed to feel guilty that she wasn't able to fulfil either properly. Over half of sandwich carers like Leanne worry about the effect caring has on their children. Leanne's comment also illustrates the way that caring can lock carers away – not just physically but mentally.

Leanne: I find it not just me but all the carers. We find it very lonely. We short of people to talk to. I can't talk to my girls. Of course they know that I'm caring for their grandma and their uncle.

I can't share with them because I do on no more burden, you know it's not fair for them to know too much about it.

There was a sense amongst Leanne and other carers we spoke to that it was not just the intensity of their duties that isolated them. They felt the uniqueness of their experience stood them apart.

Leanne: One time like I invite with my my my friend who is ex-carer. And he's he's a writer, and he's got a lot of friend you know doctor, lawyer and he invites me to come for his birthday party. Oh my God. I turned up and I feel so embarrassed. You know they're all lawyers' doctors then you name me and then suddenly me. So I sat there all night. Feel so uncomfortable.

Leanne's feeling of shame around her caring role ties in with the themes of the first podcast, about the lack of recognition for carers. Other carers we spoke to were worried about stigma and judgement too.

These kinds of fears were often bound up in a more general feeling that other people just didn't understand what carers were going through. That sharing stuff would only serve to unfairly burden people. Or that people didn't make the effort to reach out because they didn't appreciate the strains that carers were under.

A desire to feel understood is perhaps a basic part of the human condition. And whereas Leanne felt unable to reach out due to a lack of understanding, Floris, had the opposite experience. Floris you may remember we heard from much earlier in the podcast – he cares for his wife who has MS. He and his wife had a great network of people around them, all lending their hands to help lighten the load. And what Floris said was integral to this network, was a feeling that everyone understood he and his wife's situation

Floris: They all really mean a lot to me, but the most important thing is they mean a lot to me in a different way.

the relationship with the healthcare professionals of my wife is really good. I can email them, I can call them, they are always helpful to me so,

My family is my family and we talk with each other like families do, My father was a healthcare professional, so he understands what MS means for us as a family. And I talk with my online community; And my boss, or HR Department, they understand what my wife's going through and they are trying to help me in a way that I can still do my job and be able to care for my wife and for my family. So,-group helps me in his own way.

Floris talked of the support he received from other carers, and that's something he and Leanne had in common. Leanne goes to a support group at her local Buddhist centre, and one run by Rethink, the mental health charity.

Leanne: Yeah I attend once a week Buddhist centre. They're running once a week, for carer to relax to turn up to meditate and relaxation you know and then we had chance to sit around and talk to each other. As a carer you know sharing our experience what I've been through during the week and we had, I'm lucky to have met a good bunch of people and they help support me you know mentally and you know I can share with them everything. I don't have to hide.

When I talk to them I feel like they understand me completely because they care as well. They are same situation as me. So they understand every single word that I've been saying to them.

So those places like Rethink and Buddhist centre. You know I'm saving my life you know. So I keep turning up for last 10 years now.

For some of the carers we spoke to, joining a support group had been a real turning point – they positively lit up at the mention of it. It was here that they felt truly

understood. This seemed to be universal amongst carers in fact, yet people have different needs and expectations of support. Some prefer to connect with carers who share an experience of the same condition or disease, partly for emotional support and solidarity, but also because of the possibility of sharing practical advice. Who better to help you solve your problems than someone who's been through it already?

Carers also seek support by age, gender, and, in Leanne's case, faith. Buddhism was a huge part of Leanne's life. Besides going to the Buddhist centre, watching YouTube videos of Buddhist meditations was one of her few coping strategies. It's another indicator of the importance of culture, something that our conversations with carers and support workers indicated isn't always catered for as well as it might be.

And of course, some go online to mix with other carers. Being able to access forums and social media, at a time and in a way that works for them, is a lifeline for those hard-pressed or living in remote locations.

Despite modern communication technologies, access to peer support really varies around the world. The UK has quite a healthy offering, both online and offline, compared to other countries we looked at. Anil Patil of Carers Worldwide says that the provision in the countries he works in – India, Bangladesh, and Nepal – is really poor. But where Carers Worldwide have intervened to introduce support groups, the effects have been just as transformative as anywhere else. Here's Anil, to close out this episode.

Anil Patil: One adult carer, she had three disabled children, muscular dystrophy, husband died three years ago, and it was affecting her health, she was not having proper sleep, not able to take nutritious foods – simple nutritious food, unable to go to work, and she was almost attempted three times to commit suicide.

And our carers group came to know about her situation, one of the carers who went to her house and who talked to her, spent an hour – we know your situation, why can't you give just one hour of time to us, come and meet with carers who are in a similar situation. So with great difficulty, she was able to join the group and attend the meeting. And every carers were able to share the experiences and how, what the situation was, what the

situation is now, and she found very moving, at the end of that meeting she was saying she found a purpose in life. I know there is a great difficulty moving forward but these are my family, these are my friends, if I need I can call upon them and now she became a leader of that group – the one who wanted to commit suicide. Can you put the value on that?

This podcast was brought to your by Havas Lynx. For more information about the things you've heard, or to read the white paper, go to invisible.dasharmy.com.

In the next episode we'll look at how caring affects how carers feel about themselves.

Martha: So it has given me some strength and some non-transient qualities and things that have come up that I would not have known I had. So that one is something that has made me grow.

I'd like to thank you for listening and I'd like to thank all of our contributors for their participation and time, especially Shazia, Leanne, Martha, Floris, Lina, Sue and the other carers and support workers we interviewed throughout our research. An extra note of thanks to the Royal Society of Medicine and Nicci Gerrard from John's Campaign for granting us permission to use extracts from Nicci's talk.

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