

In Search of the Invisible Army – The Caregivers' Story  
Episode 1: Finding Guidance

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.

I'm at QMC Hospital in Nottingham, to meet Iris

**Paul:** How long have you been in the hospital for, Iris?

**Iris:** I think it's just over a week this one. [*Little noise*]

**Paul:** And how are you feeling today?

**Iris:** [*Weakly*] I want to go home

*Hospital noise*

**Iris:** I don't know what it is that I've got. And the doctors don't know what I've got either.

Iris has multiple myeloma. She's nearly 90, and as you can hear, she's very frail. The last few months she's needed a lot of help from her husband Ivan.

**Paul:** What kind of things do you have to do to help care for Iris?

**Ivan:** Well, meals. And all sorts, and everything. You have to get her up. Bathroom. A lot of things. Yeah.

Ivan's 89. And it's not been easy for him. He tells me later that Iris has been struggling to get to the bathroom, she's been sick a lot. He's been having to deal with this, to get her dressed, to help her around, and do the cooking. And it's not all stuff he's familiar or comfortable with doing.

**Ivan:** Well...

**Iris:** He's doing so much.

**Ivan:** No, I don't know whether I can do it all. I can do, I mean I can manage breakfast, can't I? And, er, something else, but it's the-- night meals, it's the cooking you see. I have been doing it but it's a, struggle anyway, I mean I'm not as good as I was. Because I had a fall and banged my head you see and that's why. This and everything started after that, seemed to start after that, with, with Iris. See mine cleared up but, Iris's didn't. See. Hmm.

Iris and Ivan don't have any kids and whilst Iris's nephew has been helping out where he can, it's clear that if Ivan's going to keep looking after Iris, and keep her at home, he's going to need a bit of extra help.

While Ivan is tending to his wife, I speak to Iris's doctor about their situation. Tahir/Dr Masud is a Consultant Geriatrician at QMC and President Elect of the British Geriatric Society

**Dr Tahir Masud:** Ivan himself, he's got some health issues which need to be dealt with and in order to allow him to maintain his quality of life, I think he would really benefit from extra social services providing some extra help for him, in order to look-- for him to continue looking after his wife.

I can tell from talking to Iris, that that's what she wants – for her husband to carry on looking after her, and for her to stay at home with him.

**Paul:** And Iris, could I just ask you, I don't want to disturb you too much, sorry, could, could I just ask you a couple, couple more questions? Is, um, is Ivan good at taking care of you?

**Iris:** We've been married over 50 years. We've never had a cross word.

**Ivan:** we was dancing three days a week up 'til March, 'til I fell, in the bungalow.

**Paul:** And, who's the better dancer?

**Ivan:** Well I've got medals and she hasn't. That's how we were, not really now, but I'd say we're both about the same aren't we?

**Iris:** I would say who remembers the steps.

**Ivan:** Ah. She remembers the steps, I follow. [*Chuckles*].

Situations like Iris and Ivan's are only becoming more common. The problems of an aging global population are well-documented but to put some figures to it – The percentage of the world's population aged 65 and over is expected to almost double by 2050<sup>i</sup>, with those over 80 the fastest growing subset of this group<sup>1</sup>. But what will this mean for carers? Here's Dr Mahiben Maruthappu, former Senior Fellow to the CEO of the NHS, and co-founder of the tech-enabled home care provider Cera.

**Dr Mahiben Maruthappu:** These conditions are getting more complex, not less complex. People are requiring more and more help at home. I think we will only need more carers. And I think even AgeUK recently said that there are a million people who require care but are not getting it. So if anything there is a shortage at the moment.

Current trends would agree with Mahiben. The number of carers of Ivan's age has more than doubled in the last decade.

It's important to understand upfront what we mean by the term carer. I'm talking about those often referred to as family or informal carers, who spend their days and nights looking after wives, brothers, mums, granddads, friends and neighbours. Some carers live with the people they care for, others travel to care, and some do it at great distance.

It's not just the demand for older carers like Ivan that's set to increase. The number of carers in the UK is expected to rise by 40% in the next twenty years from 6.5 to 9 million. Looking further afield, the World Health Organisation anticipates that in some developing nations, needs will soar by over 400% over coming decades.

As compelling as the figures are, talking in numbers can perhaps mask what is a pretty straightforward fact: this really affects all of us. There's five of us in my immediate family,

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and three of us have filled what people would describe as a caring role. That's not unusual, Carers UK say three in five of us will be carers in our lifetime.

**Anil Patil:** One or the other day all of us either we will be a carer or somebody will be providing the care, I don't know when that will happen but during our lifetime, sure, we will play one of those roles.

That was Anil Patil, CEO and Founder of Carers Worldwide, a charity that operates in low and middle income countries.

In this three-part podcast series we're going to take a closer look at the lives of carers and the huge role they play in supporting our healthcare systems. We'll hear from carers from lots of different places, as well as leading experts from healthcare and major carer charities.

We'll look at whether carers get enough support

**Sue:** I felt I had to fight and I still am fighting for every single thing

At how caring affects peoples' relationships

**Lina:** She feels that she's more Michele's mother than Michele's wife

And what it does to their wellbeing and sense of self-worth.

**Shazia:** And I think that made me stronger, I kind of just realised that I'm part of this army of people out there and it's something which we should be proud of... and people should recognise the work that people do.

We'll see the challenges carers face,

**Anthony:** they were talking about potential amputation if he didn't make the progress he needed to

The great knowledge they gain through their experiences,

**Emily:** sometimes the carer is the person that knows more than the professional sitting in front of them.

And the tremendous force for good they can be for others.

**Floris:** I get a lot of energy of helping people.

A lot of the research behind this series has come out of an industry white paper Havas Lynx produced earlier in the year. Just a quick note – Havas Lynx is a global healthcare communications company. Alongside everything you'll hear on the podcasts there's a fair amount of studies, statistics and other supporting evidence in the white paper – more than I can cover here – so if that takes your interest head to [invisible.dasharmy.com](http://invisible.dasharmy.com). On the website you'll also find interesting blogs and a series of films – featuring interviews with some of the experts we spoke to as well as some keynote talks.

In this first podcast we're going to look at the recognition and support carers receive, but first I'd like to focus briefly on their importance to healthcare:

**Dr Mahiben Maruthappu:** So, I think carers are invaluable. They are a key component to making the health and care system function. And it is the regular, daily, compassionate care that people receive that allows them hopefully to stay out of hospitals and where possible not even need to see their gps. If we didn't have family carers looking after people in their homes or in other contexts, it would probably cause a lot of the system to collapse, speaking frankly.

Mahiben called carers invaluable.

Actually the value of their contribution has been measured – in the UK it's estimated to be worth 132 billion pounds a year. That's roughly the same as the entire NHS budget.

Of course it's not just about the money. Carers have a huge impact on the lives of the people they take care of, as Dr Sarah Jarvis told me. Sarah's a GP and the Clinical Director of Patient.co.uk.

**Dr Sarah Jarvis:** I've spent 27 years as a GP and I don't think a day goes by without me being in the awe of the carers who look after my patients. To have

a carer around who cares for you, loves you, is your companion, but also provides for your physical needs can make all the difference in the world.

Sarah's right, it really *can* make a difference. Healthcare professionals might spend years honing their expertise in medicine, but some carers spend just as much time honing their expertise in one person; administering medications, observing symptoms and behaviours, helping a person get in and out of bed, feeding, washing and emotionally supporting them. Here's Anil from Carers Worldwide again:

**Anil Patil:** Quite often professionals don't recognize, carers know what is best for their loved one. Quite often we look at carers as a labour force, not as a knowledge force. We as the professionals, we hardly spent time with them, we ask so many questions and then at the end what information we provide, our skills, our knowledge, our training, it is the caregivers that are implementing that knowledge. Whatever changes we are seeing in the person being cared for is that because of the carers.

Studies show that the help of a family carer can improve adherence to meds and healthy living habits – one in particular showed that relapse rates amongst people with schizophrenia can be reduced by 20% if carers are included in treatment.

So carers are not only a huge help to patients, to doctors, and to healthcare systems. The impact they have on therapy outcomes also means that they're an asset to pharmaceutical companies and treatment providers. Here's Elizabeth Egan, Executive Director of Strategy & Innovation at AstraZeneca Global:

**Elizabeth Egan:** Carers are huge contributors to successful outcomes for patients. They become experts when it comes to things like symptom tracking, monitoring what patients are eating, monitoring how patients are sleeping, ensuring that patients take their medication at the right time in the right quantity, and monitoring things like how stressed is the patient. Basically they are an absolute lifeline for that patient and a rich source of information for us as a Pharma industry.

But do we recognise the value of carers contribution to healthcare? Sarah Jarvis doesn't think so:

**Sarah Jarvis:** I suspect as a nation we completely fail to recognise what a crucial role carers play, and how not only our National Health Service but our social care system would crumble without them. It is very difficult to keep that in the front of your mind at times, because perhaps they've always been there.

And neither does Anil Patil:

**Anil Patil:** Carers are invisible, they are hidden behind the curtain, they're among us, but we don't have eyes to see them. And maybe that it is because of that invisibility. There is not much recognition.

I would like to say one more, that in my opinion carers are wounded healers – they have wounds within them but nobody has the eyes to see that wound, to heal that wound.

Anil describes quite beautifully a sentiment that ran throughout our research.

That word, invisible, came up time and time again in our conversations. The first time I heard it, was when I spoke to Shazia.

**Shazia:** I think carers are sort of almost invisible in society. Because we all sort of think of it as, oh, yeah you're just looking after your Mum or your brother or your sister because that's just what you do, it's sort of one of the main family values that everyone has. That we are taking people for granted. Carers are taken for granted.

Shazia's 22. She balances caring for her mum, who has Parkinson's, around working full-time.

**Shazia:** So because it's a progressive illness I've had to take on more challenges with her condition as times gone on. It started off where she was quite independent still. Whereas now she needs support with almost all aspects of life so it's everything from emotional support to helping give her tablets and stuff like personal care as well. I think caring itself is a positive thing. I think, now looking back I think I couldn't imagine my life in a different

way.

Shazia has some help from professional carers, but other than that it's just her and her mum – It's been that way for a long time – Shazia's an only child and her parents separated when she was young. Before we hear more from Shazia, think back for a just a sec to how you pictured your parents when you were really small. You relied on them to be strong, to shield you from the difficulties and threats of the world, to pick you up when you fell down, to dust you off and set you going again. For most of us this image fades as we grow to adulthood and gradually take on more responsibility for our own lives. For Shazia, that image shattered before she was even ten.

**Shazia:** So I was eight or nine at the time. And it was just so hard. Just being told that she's got this incurable illness. We don't know. All we know is that is going to get worse with time. We don't know what sort of scale or how quickly it'll worsen. (/) And it was like when I used to see my friends parents picking them up from school and they were perfectly fine. And then my mom's like her side started shaking. And it was horrible. It was just was one day she was fine and it was almost like overnight that the illness was just came out of nowhere.

In an instant, Shazia's world had been turned upside down by a disease she'd never even heard of. She says she was in no way prepared. At nine years old how could she be. But it's not just young carers like Shazia that feel this way. A Carers UK survey of 2,100 carers found that 75% felt just as unready as Shazia. The route to caring doesn't necessarily allow for you to 'get set'.

Some face an event that changes their life in an instant – an accident, a sudden deterioration in health, or, like Shazia, an unexpected diagnosis. Suddenly, the new carer is thrust into a new world of medical terminology and difficult decisions, as Emily Holzhausen, Director of Policy and Public Affairs at Carers UK, explains:

**Emily Holzhausen:** It is extraordinary really that we ask nurses to go through really important and valuable training and yet we sometimes ask families to do exactly the same tasks with no back up or information.

Other new carers experience what Janet Dunnnett describes in her book *The Dwindling* as 'need creep'; gradually and almost unknowingly taking on more and more responsibilities in

the face of a decline that progresses at imperceptible increments. As Becky, another young carer, told us:

**Becky:** Being a carer, you don't get told, you're gonna be a carer now. It's literally you just start taking on that role. So my sister came, I helped out with the nappies, the cleaning, feeding her and bits like that so you just naturally help out and then it's only until when you're doing it every day, the same thing, you start to realise, oh right I am a carer and that's what you do really.

That said, some of the carers we spoke to did actually feel that they'd had a bit of a heads up about what was coming. Aparna, a carer I spoke to from India, found out during pregnancy that her daughter Saanvi would be born with paralysis down one side of her body. So Aparna did a lot of reading before Saanvi was born, consuming as many books and articles as she could get her hands on. Another carer Karen, who also shared her story with us, knew all about her partner Yvette's health issues before they got together. Did it make a difference? Nope. Both Karen and Aparna said that when it came to it, there were aspects of caring they were in no way ready for.

But let's go back to Shazia

**Shazia:** I think at the start I found it really difficult to talk about it to anyone because I thought why is it my Mum? Sorry I'm getting upset. I think it was really hard because we didn't know much about Parkinson's. And it's not really one of those illnesses that is sort of well recognised and even now.

Shazia's struggle to accept what had happened to her mum, and her ensuing and consuming feelings of uncertainty were common amongst the carers we spoke to. Floris, a carer from the Netherlands, who looks after his wife who has MS, described his wife's diagnosis as a punch in the face.

**Shazia:** The uncertainty was horrible because one minute we'd been told it's incurable but she's still living with it was just... You were just thinking how can it worsen? You know will she ended up being completely paralysed or... How how can her symptoms because I'd never seen it in any other relation like a grandparent or anything I've not seen a friend or anyone even on television. So I think it was uncertainty that was probably making us the most anxious.

Especially given her young age, it's easy to see why Shazia would find it so difficult to come to terms with the fact her life had been completely altered by events beyond her control or understanding. It's at times like this when everything is turbulent and awash with uncertainty, when people feel at their most powerless and vulnerable, that carers like Shazia are most in need of support.

But sadly, they don't always get it.

**Paul:** So do you think they recognised your needs as a carer?

**Shazia:** No I don't think. Not in those early stages. Well I don't think they do in general. I don't think there's anywhere near enough support out there for carers. I think you have to, sort of, go out of your way or look yourself to find it.

Emily Holzhausen from Carers UK says the first step for carers getting support, is identification – that is, for the carer to identify with their role, and for the people around them to recognise this.

**Emily Holzhausen:** Well it's hugely important to be recognised and identified. Recent research showed that people take too long to recognise and identify themselves as a carer. If they do that, if they do that early, and they get the information and advice. It can help them to stay in work for longer. It can improve their health and wellbeing, it can improve the care that they feel they are providing. Overall it improves everybody's quality of life, so it's hugely important.

**Emily Holzhausen:** There are a lot of what people call hidden carers so they are people that don't necessarily identify themselves, they are not known to services. And there are certain groups that remain more hidden if you like. And they include, for example, children who are caring for a parent or a sibling. They are people that are older and people don't necessarily notice that a 92 year old might be lifting a man out of bed every morning. And it's very important that people think about caring and identify carers and put them in touch with support.

There are a number of reasons why carers remain 'hidden'. One of them is actually the label itself: carer. To some, it's hugely important to have something that describes their role. But not everybody likes it. As I said earlier, these people are daughters, husbands, mothers, friends – and it can feel like taking on the title 'carer' diminishes this relationship. Emily said that, whatever their feeling towards the term was, what was important was to get people to acknowledge that they were taking on extra responsibilities.

We'll return to the difficulties and importance of this term in our second podcast. Labels aside, there are many layers to the issue of identifying carers. And the first goes back to where we started: and carers being invisible, and out of sight.

A lot of the carers we spoke to felt that other people simply didn't get what they were going through. Public awareness and understanding of what it is to be a carer varies from country to country. Anil of Carers Worldwide works across developing nations like India, Nepal, and Bangladesh. He says the lack of public awareness in these countries, and thus the lack of policies or services that support carers, is reflected in the absence of any effort to track/record carers.

**Anil Patil:** Of course there are statistics out there about various issues, the number of people suffering from mental health issues, or with a disability, or people with dementia. All these issues need a caregiver, but absolutely nothing. In a country like India or Nepal, we do census every year and there is no question asked around the caregiver – do you, does the family have a caregiver who is looking after somebody with that care. Absolutely nothing. And sometimes we also count how many animals we have in the families, but not the role played by the caregivers.

Anil said culture plays a massive role, citing the huge stigmas that surround many health conditions in some developing countries. Indeed, Aparna the carer from India I mentioned earlier, told me how she'd seen other parents of children with disabilities hide their child away. If a carer feels ashamed of their situation, then they're unlikely to reach out for support or talk to people about what they're going through. Traditions of family are important too.

**Anil Patil:** Partly in developing countries everyone expected that there is a concept of joint family or extended family so there is a lot of support system is there and also culture it is expected that you look after your parents or

relatives who is sick or disabled. Unfortunately in the last 10 to 15 years that concept of joint family or extended family is eroding faster than one could imagine. Now more and more nucleus families. So erm and the caring, the role of caring is falling on this illusion

The UK's actually quite well-regarded globally in terms of carer awareness; we have well-established national charities like Carers Trust and Carers UK and high-profile awareness events like Carers Week and Carers Rights Day. But support workers told us there's still a lot more that needs to be done; that, for example, support and understanding for carers in the workplace lags well behind what's afforded to those with parenting and childcare responsibilities. The presence of stigmas around healthcare conditions is still felt, and the concept of family is of course global – Shazia mentioned it in that first clip I played.

**Emily Holzhausen:** I still think that caring is not fully understood and until it's fully understood it cannot be fully appreciated. So we do need to raise more awareness so that people understand and appreciate what people do but appreciation should also go hand in hand with concrete support.

For carers to access that concrete support that Emily mentions, there need to be gateway mechanisms that open the door to it. And given what we've heard from Shazia and Becky about how they came to the caring roles, and the barriers they found in getting support, it might take someone else to help a carer to come forward and point them in the right direction. Healthcare professionals are extremely well-placed to do this effectively, but the responsibility falls far wider:

**Emily Holzhausen:** We have a number of different programs of work where we look at best practice about how people are identifying carers and there are huge number of places that this can happen. So we have supportive employers who are looking at employees that are carers and identifying them that way. Pharmacies locally have had different carer identification programmes. GP practices can do it. Certainly hospitals where people come to visit, and look at people coming through the door. Banks and financial institutions can look at third party agreements. So there's a number of different ways that people can identify carers to make sure that they get the advice and information that they need.

Whilst I was interviewing carers in Leeds I came across the yellow card identification scheme. Very simple – a yellow card, with a referral form on it. It's available at GP Practices across the city – anyone in a practice can fill it in with a carers details and send it on to Carers Leeds support services who then follow-up. The scheme generates about 500 referrals a year this way. It's really effective because, in prompting staff to ask the question 'are you a carer', it not only drives carer identification but it also encourages practices to consider what support they're offering – whether they could be doing more?

Another really great by-product of the scheme is that It's opened doors to practices and carer support services working more closely, in a range of ways. Off the back of the scheme, Carers Leeds have delivered training to practice staff, they've used surgeries to run carer clinics, one-to-one sessions, and awareness events as well. It was first introduced about ten years ago, and since then the yellow card has been adopted by all GP practices in Leeds, and it recently won a Health Service Journal award. Not bad for what really is just a brightly coloured bit of card.

It's worth noting that one referral doesn't fix everything for a carer like Shazia. Most of us have experienced how notoriously disjointed healthcare systems can be – doctors and departments don't always talk to each other, and people drop through the cracks. In the UK we have annual carers assessments, but supporting carers is about much more than formal evaluation. There needs to be continued communication and check-ins throughout a person's time caring, at every appointment or visit, to check that they're coping and connect them with any additional help they may need.

Now although Shazia was a 'young carer' when her mum first became ill – and therefore in one of the groups that often remains hidden – she was identified as a carer. But that alone is not enough. For it to mean anything, for it to help Shazia in any way, she'd need advice and information:

**Paul:** And in the early days especially, do you feel like you were given enough information?

**Shazia:** No, not at all. I think if I hadn't sort of gone out of my way to look for the information. I don't think I would have come across it or I don't think like the doctors or any one really thought about the effect that it would have on me and even to give my Mum more information really. And I think that's something they really to change.

Beyond being told her mum's condition was incurable, Shazia didn't get anything so much as a leaflet, and she told me she was the sort of person always on the lookout for leaflets and information when she was at appointments and things.

In a study involving carers of cancer patients over 70% said they felt they needed more information to adequately provide care. Now it's fairly obvious of me to suggest that simply telling a young girl her mother has a degenerative condition and not much else is woefully inadequate. But what information to supply and how to deliver it is quite dependent on the individual – not every carer wants to know it all. What's important to understand perhaps is the depth and breadth of what carers might need to know. Shazia had never heard of Parkinson's when her mum was diagnosed. Certainly at this point gaining an understanding of her mum's condition was really important to her. But that was just the start of it.

Shazia's been going to scans and blood tests with her mum since she was nine. One of the first questions I asked her when we met, was to describe her mum's condition

**Shazia:** So it's sort of mainly fluctuates between dyskinesias which are involuntary movements and a main side effect of the dopamine tablets that she's on. And then other times she's quite stiff. So she might need a lot of help just moving out of the chair to the bed door or just helping up and down stairs or to the loo or kitchen or whatever. And she also sometimes can feel quite emotional and overwhelmed and quite depressed just general low mood. That's probably just due to the illnesses. She feels frustrated that she can't do more for herself. She has experienced some periods of insomnia as well which obviously is a nuisance because it means that she can't do as much during the day as she'd like to.

Her depth of understanding of her mum's symptoms, her medication and its side effects, was instantly apparent, and it bears testament to the huge amount of medical knowledge, care skills, and emotional intelligence that Shazia has had to acquire, largely under her own direction.

According to a 2015 report on the state of caring in the US of the 57% of carers that assist with medical tasks, only 14% report receiving any training.

**Shazia:** I think the first few years were probably the hardest. Now I've I've sort of come to accept it. I've sort of come to take on the aim to make sure no 11 or 12 year old is in the same position that I was.

On top of medical and care duties, carers have to learn to navigate healthcare systems, liaise with specialists and other practitioners, coordinate care professionals, and manage prescriptions. And then there's everything else that carers take on; the running of a home, the managing of affairs; Shazia had been shopping, cooking, driving, cleaning, paying bills, and budgeting, since she was in her teens.

Shazia's ability to thrive in spite of a lack of support, and her defiantly positive attitude in the face of her experiences shouldn't give the wrong impression. Neither should the fact that we live in an information rich era, in which technology puts boundless sources of information at fingertips act as any sort of illusion.

Guidance is crucial to carers. The demands put upon them are varied and changing, as their situation fluctuates according to the condition of the person they support and various other factors around them. And remember all that uncertainty Shazia talked about? That doesn't necessarily fade – lots of carers we spoke to described it as a constant presence – they found that caring could be highly unpredictable. Carer's don't know what's just around the corner and so often have no idea what help or information they might need, let alone where to find it. Here's Emily one last time:

**Emily Holzhausen:** Advice and support is the first step and without that it's very hard to move on to anything else. Most people when they start caring don't really know how things will unfold and they quite often are learning on their journey and you don't know what you don't know.

### *Outro*

This podcast was brought to you by Havas Lynx. For more information about the things you've heard, or to read the white paper, go to [invisible dash army dot com](https://invisible-dash.com).

In the next episode, we'll talk about relationships.

**Shazia:** because it's sort of a bit of a role reverse it can get a little difficult at times. And it's a bit weird for me telling her what to do. But it sort of has a bit of comedy

factor as well.

I'd like to thank you for listening and I'd like to thank all of our contributors for their participation and time, especially Becky, Shazia and the other carers and support workers we interviewed throughout our research.

This podcast was written and narrated by me Paul Eccles, with editorial support from Caroline Crampton, and production and editing by Dan lord in the Studio 6 team at Havas Lynx. Thanks also go to Marc Duffy and SOAP Studio for their support.

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