

In Search of the Invisible Army

Episode 3: Finding Me

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

Something I'd not really expected when we started interviews for this project was that many of the carers we spoke to felt that caring had been an enriching experience:

Martha: Taking care of her gave me some confidence in life yeah. It did because here we have, you are all alone and you have no-one else to turn to and that one made me so strong and I got some confidence that there is nothing I can't do.

That's Martha. She sounds pretty chipper there but caring for her mum was hard.

Martha: Basically it was the toughest year of my life and very emotionally draining and many times I felt myself crying like I would get to bed and shed a lot of tears.

No matter how tough the hardship and how painful the heartache they'd endured, I'd say pretty much all the carers we spoke to felt that caring had done good things for them – it had taught them things, and shaped their character. Whether they felt valued by the world at large is a different story. And that's what we're going to be looking at now – how caring affects a person's sense of themselves, their sense of who they are and what their worth is.

So, back to Martha. Martha lives in Meru, a town of around 50,000 in central Kenya. She's 50, married and has three almost-grown-up kids. Her mum had diabetes for many years and for a while Martha cared for her at arm's length.

For Martha, her mum's diabetes was manageable. It was when her mum developed cancer, which spread from her cervix, that things became more difficult:

Martha: The problem came when the cancer spread to the lungs. And er now she started experiencing cough and the doctor and the oncologist obviously nothing they could do because of her age. Feeding started becoming a problem. And now because of not feeding well the diabetes now started showing some deterioration.

Martha: She couldn't do anything. She told. It was care totally from feeding and walking, everything.

And when Martha says everything she means everything. It was overwhelming for her, in a lot of different ways:

Martha: You can imagine for me having to get my mother. For me having to dress my mother, having to feed my mother and to car-ry her around the house. At times she didn't even want me to touch her and I had to call like a neighbour to come and change her diapers. It was not nice. It was not good. That, the hygiene was what was so stressful. In our tradition, usually, you don't see your mother naked. And now here I am I have to like change her everything and it was er it was difficult for me, very difficult.

The physical burden of carrying, washing, and changing her mother wore heavy. She was exhausted too from the lack of sleep. This was common amongst all the carers we spoke to, even those who were generally getting on pretty well in their caring role.

For Martha though, as for some others, the strains were emotional and psychological as well.

Martha: So many times if she like refused to eat, I would often not sleep. I would sit at home and look at her and tell her now she's upsetting me. And er at time I would even break and cry in front of her and she would feel so bad. One time she told me, Martha, just take me home, you need a life of your own, just take me home and let me die there, and you will continue having a life. And er for a mother to tell you that in meant that she had given up and she just wanted to let you be.

Martha: Watching my mother deteriorate from a very strong woman to a very weak person. It was not very good for me. So basically health wise I gained a lot of weight I think it was stress. I got to 104 kgs, I got de-pressed and I became careless and with my diet and my exercises. And my whole life was just for her. I took everything... All my thoughts were on her...

All in all, it combines to create a very stressful environment. I'm sure that sounds obvious, but it's worth considering the severity. Here's Emily Holzhausen, Director of Policy and Public Affairs at Carers UK:

Emily Holzhausen: What we see for people that have got quite stressful caring responsibilities for others they are twice as likely to suffer from ill health. Amongst our members we have about 80% of them suffer from a stress related illness as well because of some of the strains of caring

Caring is so closely linked with chronic stress that researchers actually use it as a model for studying the effects of chronic stress on people. And the problem is that carers often find it difficult to get help.

Emily Holzhausen: I have to say when we have done research as well we have found that a number of carers put off vital treatment because they couldn't get the right support and advice and information for the person that they care for.

Martha talked a lot about rushing, and about forgetting herself – I heard this a lot from other carers too; that their health and wellbeing had to come second; that, as we discussed in the last podcast, healthcare professionals were preoccupied only with the health of the person they looked after.

Martha: Because even the time that we took her to hospital nobody ever asked me 'mother how are you coping?' How difficult is this? And help me at least give me tips on how to cope with it so they left me to handle her and handle myself.

Martha just about managed in spite of the strain she was under but in such highly-demanding scenarios people can reach burnout. Becky, another carer we spoke to, seemed to have suffered this in the past. As a young carer, she'd looked after her mum as well as her brother and sister. Carrying this burden single-handedly, the intensity of it all became too much for Becky. And eventually she decided she had to leave home. Dr Sarah Jarvis, told me that in order to avoid situations like Becky's, carers need support and reassurance that it's ok to take time for themselves. Sarah is a GP and Clinical Director of patient.co.uk

Sarah Jarvis: They need to know in their hearts perhaps as well as their heads, that in fact, maybe, leaving their loved one for a few hours, or sometimes in respite for a few days, is the best thing that they could do for that person, because that's the best way of ensuring that they are in the best position to look after them long term.

It's not just the intensity of caring that stopped carers taking breaks. A number of times carers told me that they found it hard to make time for themselves without feeling guilty about doing so. Here's Shazia, who's featured throughout this series. She cares for her mum, who has Parkinson's.

Shazia: Sometimes it does put like a lot of self-doubt in my head. That like, oh I'm not good enough, or you know what more could I be doing for my Mum? Or should I, you know, stop working part time and start spending more time with her and stuff like that. I think, oh my God, like how many more years has she got? You know, is she going to be here to see me have children? Or for me to get married or whatever? And I think, yeah, it sort of makes me feel quite doubtful of myself. And just whether I know whether I am doing enough.

Moreover, planning anything in such an unstable environment can seem unfeasible. Here's Martha:

Martha: You can imagine living with a terminally ill person in the house and er you don't know what's gonna happen any time. So every time you are on flight mode, every time don't know what will happen. And er everybody could see, even friends that came to stay with me, everything was just crashing. Because now, reality dawned on me that

things are getting to the worst and everything is going to come to an end one time and I was not ready for that. So living with that anticipation and fear made everything so unstable for us.

This sense of instability – of not knowing what was coming – was really common amongst the carers we spoke to. And it became apparent that the pervasive lack of control carers felt they had over their lives, contributed to the stress and anxiety that they experienced.

Shazia: So it's always the uncertainty of what if they put her in a home or something. Once she's in hospital or when she is in hospital... when is she going to come home? Because she's been in twice now for about a year. But when she's at home it's still you know it is still trying to remember stuff like have I put the key in the key safe for the carers? Have the tablets been delivered by the pharmacist? What if she's had a fall? Even when I'm out with friends at the cinema, it's still stuff that I worry about. What if there's lots of traffic? It's sort of made me quite anxious because I just don't want to let her down. But I still think there's always that uncertainty of what if she gets an infection and what if she goes back into hospital? That constant fear is always there.

The effects of this lack of control, of the intensity of the caring role, went beyond health – in general the health and wellbeing of the carers we spoke to was symptomatic of their overall care picture.

As the American writer and surgeon Atul Gawande discussed in his 2014 book *Being Mortal*, a sense of autonomy is crucial to maintaining self-esteem and ultimately wellbeing. “All we ask is to be allowed to remain the writers of our own story,” he writes. “That story is ever changing. Over the course of our lives, we may encounter unimaginable difficulties. Our concerns and desires may shift. But whatever happens, we want to retain the freedom to shape our lives in ways consistent with our character.”¹ I think some of the carers we spoke to felt that they were not the writers of their own story. Even amongst those coping well, there was a sense that the unpredictability of peoples' situations had led them to curb their ambitions at least a

little. When I asked carers about their plans for the future there was a real hesitancy to count on too much. Instead the approach was to take each day as it comes, and not to look too far ahead. When your situation is so prone to flux and change, keeping expectations down and planning only for the short term are probably good coping mechanisms.

But some carers can grow to feel restricted to the point of being trapped, as Emily Holzhausen of Carers UK explains:

Emily Holzhausen: Yes some people say that they do get stuck in a cycle... So it can be difficult and challenging, particularly if carers are in a low income they don't have the opportunity necessarily to go out and do things or they don't have access to enough breaks to be able to give them a wide variety of life.

Martha talked about her life being on hold, something I heard a lot from the carers I spoke to.

Martha: *It was not easy because my family noticed that things are getting tight. Everybody kept off. And the fact that you call on family to come and help you and and at least even encourage you, the family are not willing to come in because basically they are scared you are going to tell them to help you with finances so they kept off. So emotionally, financially everything just went down for me.*

Martha's comment about her family is worth a pause for thought. Anil Patil of Carers Worldwide told me that the cultural expectations of family care that are present in some developing countries can actually be the very reason that family members stay away when someone becomes ill – they feel the expectation is so great that they fear getting involved at all.

The real tragedy was that some carers couldn't see a way out, or any possibility of changing their situation, whilst the person they cared for was still alive. This was the case for Leanne, who featured in our second podcast. Leanne's a full-time carer to her mum, who has schizophrenia.

Leanne: I feel like there's a dead end in front of me. There's no way out. And, I really, really don't know. I don't know what to do. I feel lost.

Paul: Do you have any ambitions for the future?

Leanne: Obviously I would love to. Like I'm not going to say that I'm completely cut off from caring role but I would love to go find a part time job, like I'm doing hairdresser which is I enjoy doing try to get my life to try in some kind of normality really. But I don't see that happening. I don't see that.

Paul: Do you feel like your life is fulfilling at the moment?

Leanne: No...No. I feel like a failure.

Paul: Why do you feel like a failure?

Leanne: Because caring is not is not our job is it. I would love to go on find a 9 to 5 job. Earn my own money and live with my head high up

For Leanne, caring had stripped her of access to a job, close personal relationships, and good health – the ‘wide variety of life’ that Emily Holzhausen described; the things that we commonly derive a sense of status and wider purpose from. Other carers we spoke to felt this too, and it was this that seemed pivotal in how carers felt about their role. Some of Leanne’s feelings relate to the lack of value she feels society attaches to what she’s doing – and carers invisibility overall. She talked of feeling intimidated going to parties or her daughters’ parents’ evenings because – other people had jobs and she didn’t, so she felt inferior to them.

It’s tragic that Leanne should feel her life is at an unbreakable standstill. For Martha, her life only started to move again after her mum had died. But starting again was hard.

The intensity of the relationships created by caring can make grief even harder to cope with. Martha said she’d never been closer to her mum than in the final years of

her life. When I spoke to her, it was only eight months since her mum had died. She felt at once relieved and totally lost:

Martha: And when everybody was crying that now she is dead, for me it was like, I thank God like my family is never going to suffer again. I'm going to have a new life now, at least I'll be myself, I'll not see her suffer, the way she suffering.

Martha: I miss her presence in the house regardless of what she was going through. Now I come to the house, she is not there, I want to tell her some things I can't tell her. I want to cook her special meal, I can't do it *[gets upset]*

In his book *Levels of Life*, Julian Barnes describes his hatred of the terms people use to talk about his wife's death – phrases like “she's passed” implied a finality that didn't fit with his experience of grief. He tells of how a friend approached him at a social event he and his wife would normally have attended together and said “there's someone's missing”. This he found much more fitting. For carers like Martha, it's not just a person that's missing – it's a way of life.

Martha: Ok there was a sort of emptiness that I used to occupy myself so much on her now there is no more so there was emptiness I felt some sadness that I will never see her again. And then I felt totally lost. So then what next?

Everything she'd built her daily routine round had gone. And it's not just death that causes these sense of loss. The move to residential care can be just as painful, as Dr Sarah Jarvis, GP and Clinical Director of patient.co.uk told me:

Dr Sarah Jarvis: Very often, carers have completely, effectively given up themselves in order to care for their loved one. They have given everything. And yet sometimes perhaps because of their own failing health, or simply because that task has become so monumental, they have realised that their all is not enough. Now, that often means that the patient has to [11:30] be moved to residential care, and that is not

only a huge bereavement for the carer, but also sometimes a sense that they have failed, that what they tried to do was not enough.

They've suddenly gone from not having two minutes to themselves, to this great, vast, empty canvas, which can seem very, very bleak for them. And at the same time, they will often feel guilty - completely inappropriately guilty, because they've done such a great job - but they'll often feel guilty that they didn't do more.

In the UK 2.6 million people start caring every year. But each year, nearly as many people find that their caring responsibilities come to a close. Emily Holzhausen from Carers UK says that those coming out the other side of this turnstile of care can find themselves abandoned:

Emily Holzhausen: The network oddly that they had before of health professionals are obviously no longer interested in them. And the friends and family that they had a strong network of before have fallen away over time as they've not been able to keep up with them or share experiences with them. It can become extremely lonely and isolated without the contact that they had before and. So it's very important that people are supported there and helped back to find connections into the community and that can be quite difficult.

Amongst the many conflicting emotions that Martha felt, there was also a sense that her life was finally hers again:

Martha: I feel energized, I feel a lot of – things now need to be done. I want to do all the things that I never did. I want to take care of my health. To do the things that were messed up during that time, that's when I'm repairing. so basically I am concentrating on making myself happy, and making me be what I should have been. I want to just concentrate in making myself a better person and my family, at least to concentrate on loving them, making them more comfortable.

As I mentioned at the start, Martha was really positive about her caring experience at times. Her renewed enthusiasm for life included a determination to make use of the things her experience had taught her:

Martha: And after caring for my mum now I noticed a lot of many strong things and strengths that I didn't know I had. I noticed that I can face I can face challenging situations. I noticed that it takes a lot of joy when a sick person gets some love.

So taking care of my mother has made me notice a strength in me that I can also now take care of somebody else apart from now my mother I would want to have an organisation that I get to see sick people who are neglected by their families and help them.

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. It has made me a better person and brought up some humanness from me that I didn't know I had.

Note that Martha said that she'd like to start up her own caring organization – for some of the carers we spoke to caregiving opened up opportunities beyond their role looking after the person they cared for– opportunities that inspired a sense of purpose that they'd not had before. One such carer is Floris.

Floris lives in the Netherlands with his daughter and wife. His wife has MS, and his experiences of looking after her have inspired new ambitions in him

Floris: Yes and I kind of create them right now because of all the energy I get from taking care of my wife and writing about it.

I'm really busy with raising awareness about MS. So I started my own blog but I also have a new site called platform.MS, my ambition is to make that into a company I can run and make a living from.

I get a lot of energy of helping people.

That last remark is worth dwelling on. We'll come on to the many skills and abilities carers gain through their experiences in a minute. But the one acquired quality that

was most universally reported – and maybe this'll sound obvious – was a sense of empathy, and a deeply ingrained caring for others. Even amongst those that never considered themselves particularly caring people. And this seems to be a real motivator in why many carers, like Floris and others we spoke to, seek out advocacy and support roles that allow them to use what they'd learned through their experiences to help others.

And what they'd learned was pretty considerable in a lot of cases. As we discussed in our second podcast, the time carers spend looking after a person can lead them to become experts through lived experience.

From the conversations with the carers we spoke to, I found that they often knew the disease/condition the person they were caring for inside out, they understood associated treatments and side-effects, knew how to navigate healthcare systems and speak to professionals; in some cases they had expert medical and care skills, often coming up with creative workarounds to solve problems that healthcare professionals hadn't thought of, and they had a critical view on services from a unique perspective. Beside knowledge specific to healthcare, many felt they'd gained other transferable skills and qualities, like time management, perseverance, and ability to work under high stress, organization and responsibility.

Armed with all these skills and driven by a desire to help, carers can be a real force for good in healthcare. Beth Britton, who featured in our second podcast, cared for her dad who had vascular dementia. Like Floris she started a blog – hers called d-for dementia. It's become hugely popular and Beth's now renowned as a consultant, campaigner and writer in the field of dementia care:

Beth Britton: And I'm very fortunate, the way the work has developed for me from the blog, through working on the G8 Dementia summit with the government, working with the department of health, the public health quality commission, and lots of care providers in particular, I have the opportunity now to really sort of influence change in the care that people receive and there's nothing I love more than the consultancy work that I do working with care providers.

There are some truly remarkable examples of carers who had used their ability to find workarounds for the difficulties their loved ones face, to create fixes that could

benefit all. One such example, is Fixing Dad. Fixing Dad is a 12 week programme created by Ian and Anthony Whittington, born out of their experiences of helping their own sometimes stubborn dad overcome diabetes (documented in a film by the same name):

Anthony Whittington: This disease was taking him a piece at a time and now they were talking about potential amputation if he didn't make the progress he needed to.

Dad wasn't the dad that we'd come to know and love. So we decided at Christmas that we were going to step in and try and do something.

So initially we just needed more positively rather than this idea that a disease could be managed, lifelong, incurable it wasn't good enough for us

You know this is you, this is us, and this is your grandchildren this is why we need you on board. We had the photo albums out. It was about really engaging him emotionally and we think that really was the key turning point for fixing dad. After that we were able to set goals and we set goals in fitness nutrition and mind-set so it was all three of those areas

His blood glucose levels have come down through the floor. So he's deemed to be in full remission from the condition.

And we managed to get him off all of his medications, eight of his medications, he's just on one now.

So it's a thirteen week programme and you've got your own coach within the system so you can message them you can get feedback about what you're eating. It's really about getting an understanding about what you're eating

I'd say the biggest single feature that we feel and it's something that was really important to us, you know we did this together with dad, it's

actually networked so that by joining on the app you effectively can be a fixer or a fixee so let's say you had two children two adult children you can nominate them as your fixees.

Based on the three month programme, on average people are losing about seven point seven kilos over that period.

Average daily fast blood glucose reductions about 1.5 mmols per litre. so that is significant because it can be the difference between being categorically type II diabetic for life

We hope that the results we're showing through the app and the programme and through dad is that people can make progress and people are reversing their type II diabetes if you like.

If Fixing Dad can do anything it is inspiring people to try and do this together

Of course not all carers feel able to extend their role to activism or developing apps – some may just want to get on with caring for their loved one and living their own life feeling like they have the support and recognition they need – feeling like they're not invisible. Which is where we started at right at the beginning of this series, with Shazia:

Shazia: I think carers are sort of almost invisible in society. Carers are taken for granted.

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.

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.

Who should be responsible for helping Shazia achieve her aim?

For David Hunt, CEO of healthcare communications agency Havas Lynx Europe, the answer is simple. Whether you're in the public or the private sector, it's everyone's concern:

David Hunt: Our ambition as an agency is to help people, and to really help people live well. So from a pure logical point of view, it just makes sense for us to really support carers and make a difference for them so they in turn can make a difference for patients. But then if you look at it more broadly, as an industry and stakeholders within healthcare and within pharma, I think it should be everyone's priority and also responsibility, to do what they can to make a difference to the lives of unpaid carers.

I think everyone has a role to play within the healthcare space, so not just traditional pharma organisation but also new players. From technology companies that are revolutionising healthcare to other creative agencies like ourselves. From a purely commercial point of view it represents a huge opportunity to do something different and add a lot of value to healthcare. But equally as an individual, I think it's an opportunity to really help and make a difference where it counts.

In the opening podcast of this series Anil Patil from Carers Worldwide said that carers were among us but that we didn't have the eyes to see them. So perhaps the first step is to look for them, and listen to them. Here's Beth Britton again:

Beth Britton: The number one way to value carers is to ask them what they want and then to deliver that. It's to recognise the uniqueness of individual carers. There is no one size fits all.

And that will mean that we have to have a myriad of different solutions and we have to be very flexible about what we offer people.

Appreciating that they are absolutely individual in their own right and that their need to a family life, and what that entails, needs to be supported.

There should be an urgency to act now more than ever. Our healthcare systems are struggling. In the UK, the Care Quality Commission has in recent times described the

NHS as straining at the seams – it's chief inspector of hospitals Professor Mike Richards, said that it 'stands on a burning platform' of outdated care.

Like other healthcare systems the NHS is built upon a heroic model of saving or curing people when they are acutely unwell – we go to hospital when things are broken or get too bad to manage and they fix us up and send us off good as new. But things don't work like that anymore. As we live longer, we're facing unprecedented levels of chronic illness - conditions that can't be cured, and have to instead be managed over a longer period of time. This is draining resources from services that are already overstretched – funding growth for the NHS across this decade stands at 1% a year, whereas historically it's been at 4% a year.

The overwhelming evidence is that healthcare needs to move away from treating sickness and towards promoting wellness, and keeping people out of hospitals and doctors surgeries and at home. Carers are absolutely crucial to this.

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. For Mahiben there needs to be a seamless integration of carers into the healthcare system:

Dr Mahiben Maruthappu: We need to see much better integration. I think we need to see a structured approach to supporting, empowering and recognising carers so that they feel really valued and they are seen *not* as an invisible part of the system but as a visible and central part of the system

Whatever your perspective, the voices of Shazia, Martha, Leanne and the other carers we've heard from in these podcasts outline pretty clear objectives for change.

A 9 year old should never have to face the fact that her mum has a chronic illness alone, armed with no more than the news that it's only going to get worse.

Systems, professionals and services should support and involve carers, so that a mother raising three daughters whilst caring for her own mum doesn't feel isolated and alone to the point of despair.

And carers should be recognised and empowered, so that rather than surviving as they have to, they can live their lives, healthy and full, as they would want to.

There's a lot to be done, but the size of the task shouldn't dissuade those inspired TO from making headway. Here's Anil Patil, from Carers Worldwide one more time:

Anil Patil: So our intervention is like a, if I could give an analogy, it's like a drop of ink in a bucket full of water. You don't need a whole bottle of ink to change the colour.

Outro

This podcast series 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.dash.army.dot.com.

I'd like to thank you for listening and I'd like to thank all of our contributors for their participation and time, especially Martha, Shazia, Leanne, Floris and the other carers and support workers we interviewed throughout our research. I'd also like to thank Emily Holzhausen from Carers UK, Anil Patil from Carers Worldwide, Dr Sarah Jarvis of patient.co.uk, Beth Britton, Anthony Whittington of Fixing Dad, and Dr Mahiben Maruthappu.

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