

EDITION #17

IN SEARCH OF THE INVISIBLE ARMY

—
The caregivers' story

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#Caring4Carers

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INTRODUCING
HEALTHCARE'S
INVISIBLE ARMY

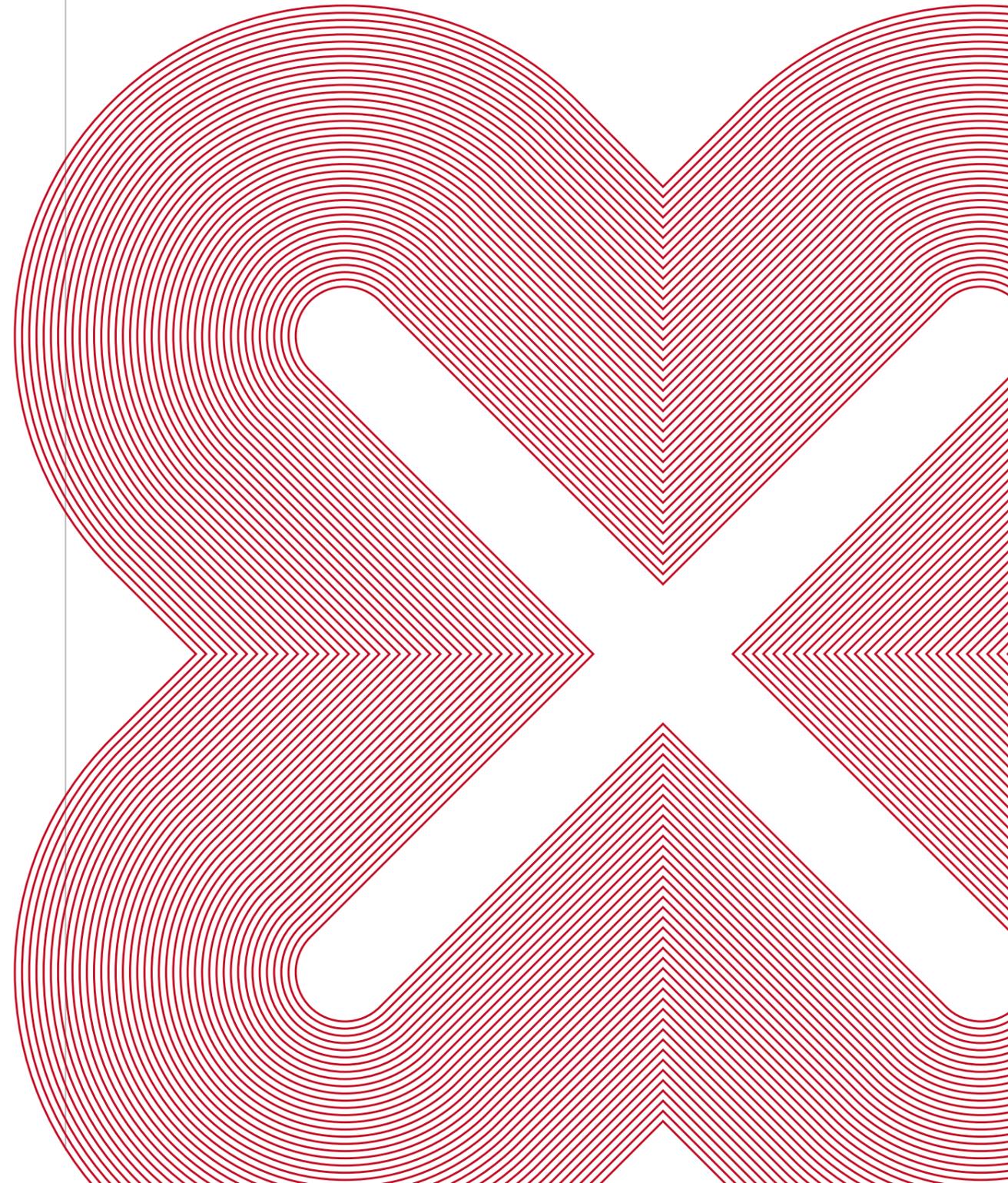
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*" Family caregivers have an immeasurable impact on the lives of those they assist, but their hours are long and their work is hard. Many put their own lives on hold to lift up someone close to them."*¹

Barack Obama, Former US President

INTRODUCING HEALTHCARE'S

VISIBLE

ARMY

To healthcare systems, they are the **unpaid army** keeping everything going.

To pharmaceutical companies, they are the potential **catalysts** to therapy success.

To physicians, they are the **experts-by-experience** turning treatment plans into reality.

And to patients, they are the **indispensable** brothers, mothers, husbands, grandmothers, friends, and neighbors that make each day possible.

1. Office of the Press Secretary. Presidential Proclamation -- National Family Caregivers Month, 2012. Available at: bit.ly/2nBq0m7 Accessed: July 2019.
2. National Alliance for Caregiving. (2015). Available at: bit.ly/2JD8RVg Accessed: July 2019.
3. Alzheimer's Disease International. World Alzheimer Report 2013. Journey of Caring. Available at: bit.ly/2nPw6QK Accessed: July 2019.
4. Family Caregiver Alliance. Caregiver Statistics: Demographics. (2019). Available at: bit.ly/2LnKBcO Accessed: July 2019.
5. Buckner, Yeandle and Carers UK. (2015). Available at: bit.ly/1LbuEKI Accessed: July 2019.

Many of us will be a caregiver at some stage in our lives, one in five of those in the US in fact.² The role can come about unexpectedly and many put their own lives on hold to help someone close to them.

1 in 5 of us will be caregivers²

The value and importance of caregivers, to healthcare and broader society, is ever-increasing. With the prevalence of long-term conditions on the rise, it's estimated that the number of people who need a caregiver will reach 613 million by 2050.³ In the US, the estimated value of services provided by informal caregivers was \$470 billion in 2013, exceeding the value of paid home care and total Medicaid spending in the same year, and nearly matching the value of the sales of the world's largest company, Wal-Mart (\$477 billion).⁴ In the UK, caregivers currently save the economy £132 billion per year, a value close to the UK's annual healthcare spending of £134 billion.⁵

Caregiver

*'Someone who provides unpaid care to a relative or friend to help them take care of themselves.'*²

" Caregivers are really important to the people that they support and look after. Because actually, those people wouldn't be able to cope without them."

Gail Scott-Spicer, Carers Trust

- 6. Cicolini G et al. (2012). *J Adv Nurs*. **68**: 2410-7.
- 7. Epstein-Lubow G et al. (2014). *J Manag Care*. **20**: e349-444.
- 8. Trivedi RB et al. (2012). *Ann Behav Med*. **44**: 66-72.
- 9. Fixing Dad. Available at: fixingdad.com. Accessed: July 2019.

Of course, it's not just about the money; caregivers have an immeasurable impact on the people they take care of. The hours they spend with the care recipient gives them invaluable insight and experience that makes them 'experts-in-care.'

According to studies, caregivers can have a positive impact on patient outcomes.⁶⁻⁸ Patients showed improved adherence to dietary restrictions when supported by a caregiver and those with caregivers were more than five times as likely to complete a self-management program.^{6,7} Another study found that having a caregiver was associated with better adherence to medication and diminished smoking habits in COPD.⁸ It is clear that caregivers are a vital force in the health and well-being of the people they care for and many could not manage without them.

Despite their evident value and contribution, caregivers often feel marginalized, underappreciated and overlooked. Not only do caregivers face emotional challenges but they are expected to navigate through complex systems with little formal guidance and direction. Their well-being is vital to patient well-being but it tends to be ignored. It's not only healthcare professionals (HCPs) that overlook caregivers; the healthcare communications sector talks to patients, physicians, nurses, pharmacists but rarely the caregiver. It's for these reasons that caregivers are so often described as the 'invisible army.'

Caregivers need to be universally recognized and valued. To move towards achieving this goal, we sought to gain an understanding of caregivers' needs from their perspective. We spoke to caregivers, support workers and experts from across the globe to investigate the impact of caring, including caregivers' needs and the role they play in improving patient outcomes.

\$470 bn
Value of care provided by unpaid caregivers in the US⁴

\$477 bn
Value of the sales of the world's largest company, Wal-Mart⁴

" Caregivers are invisible. They are hidden behind the curtain. They're among us, but we don't have eyes to see them."

Anil Patil, Carers Worldwide

CASE STUDY

FIXING DAD⁹



At 62, Geoff was well on the road to having his foot amputated thanks to severe type II diabetes. Worried they might not have a dad for much longer, his sons Ian and Anthony decided enough was enough. Fixing Dad is the story of how, against the odds, they helped their dad to overcome a lifetime of bad habits (and his own stubbornness) to cure his diabetes. And they didn't stop there. The family created a 12-week program so others can 'fix' a loved one, or themselves. The results, like their own story, are remarkable.

" My family could've resigned me to my ill-health...I'm standing here today because they didn't."

Geoff, the dad in Fixing Dad



WHO WE SPOKE TO

— Caregivers



FLORIS
36, NETHERLANDS

Floris cares for his wife who has **multiple sclerosis** (MS). He doesn't see himself as a caregiver but as a loving husband. His current caring role is related to his wife's exhaustion; she sometimes struggles to find the energy to look after their two-year-old daughter, go shopping, and do the cooking. Floris told us he gets energy from sharing his experiences and has created a blog about MS and caring for his wife.

www.platform.ms



JOHN
69, UK

John is a full-time caregiver for his wife of 12 years who has **spinal stenosis** – the condition can cause pain, numbness and loss of motor control. He does the cooking, heavy work around the house and paperwork. His wife's spine condition has been a result of her carrying their daughter who has severe physical and learning difficulties. Their daughter is now in a residential home, which they often visit.



MARTHA
50, KENYA

Martha cared for her late mother who had **cervical cancer**, which spread to her lungs. Notably, her mother also had **diabetes** which proved difficult to manage due to the eating difficulties associated with her cancer. Martha travelled 20km to her mother's home every day to make sure her mother's insulin injections were given correctly. Her mother's cancer eventually spread and caused a stroke, rendering her immobile. She was unable to eat, talk, wash, dress, or take herself to the toilet, relying entirely on Martha for her care.



KAREN
43, UK

Karen is a full-time caregiver for her partner, Yvette, who has chronic pain and mobility problems due to **degenerative disk disease**. Yvette also suffers with arthritis, anxiety and depression. Karen helps with Yvette's personal care, takes her to appointments and provides emotional support, as well as doing the washing, cooking and shopping.



SUE
55, UK

Sue is a caregiver for her husband, Anthony, who has **posterior cortical atrophy** (PCA) – a form of **dementia**. It has rendered Anthony visually impaired, immobile and totally reliant upon his wife. With the help of professional caregivers, Sue takes care of everything from personal care to physical therapy. She also works part-time.



APARNA
38, INDIA

Aparna cares for her nine-year-old daughter, Saanvi, who has **hemiplegia**. The condition causes paralysis on one side of her body. Aparna takes Saanvi to intensive physical therapy sessions, continues her therapy at home, and helps with her personal care, all whilst working full-time.



SHAZIA
22, UK

Shazia has been a caregiver for her mother, who has **Parkinson's disease**, from the age of nine. Shazia's wide-ranging support includes personal care and housework. She has a full-time job so professional caregivers visit the house to help her mother shower, dress, eat, and drink.

LINA
74, ITALY

Lina is a caregiver for her husband, Michele, who has **chronic obstructive pulmonary disease** (COPD). Her caring role involves helping with his personal care, and encouraging him to take his medication and use oxygen therapy, despite his stubbornness to comply. Lina lives near to her family, finding comfort in the support they provide to her.

BECKY*
23, UK

Becky has been a caregiver from the age of 13, caring for her siblings and mother who was diagnosed with post-natal **depression**. Alongside school and college, she washed, cleaned, cooked, took all three siblings to school, gave medication reminders to her mother and brother who has attention deficit hyperactivity disorder (**ADHD**), and provided emotional support. Becky now lives with her partner and daughter but still provides emotional support to her mother and siblings. Becky also works as a support worker, offering emotional and practical support to other caregivers.

LEANNE
43, UK

Alongside being a mother to three daughters, Leanne has been a caregiver for many family members. She cared for her late father, who had **lung cancer**, and her grandmother. Since her late teens, Leanne's also been a full-time caregiver for her mother who has **schizophrenia**. Her caring role involves taking her mother to appointments, giving her medication reminders and keeping her company – as well as doing the shopping, housework and cooking.

*name has been changed at the request of the individual

— Experts



EMILY HOLZHAUSEN OBE,
CARERS UK

Emily Holzhausen is Director of Policy and Public Affairs at Carers UK. She has been at the charity since 1996 and has been presented with an OBE for her services to caregivers. Emily is also responsible for Carers Week, which comprises thousands of events and is one of the UK's biggest awareness weeks.



BETH BRITTON

Beth Britton is a renowned campaigner, consultant, writer, and blogger with a passion for dementia care. Beth cared for her father who had vascular dementia for the last 19 years of his life. She began her D4Dementia blog to provide support and advice to those faced with similar situations. Beth has worked with the Care Quality Commission (CQC), Carers Trust, and NHS England to create improvements in dementia care.

[@bethyb1886](https://twitter.com/bethyb1886)



ANIL PATIL,
CARERS WORLDWIDE

Anil Patil is the Founder and Executive Director of Carers Worldwide, a charity that operates in low-income and middle-income countries like India, Bangladesh and Nepal. Anil has extensive experience in delivering positive change in the fields of mental health and disability, as well as community-based interventions in developing countries.



GAIL SCOTT-SPICER,
CARERS TRUST

Gail Scott-Spicer is the former Chief Executive Officer of Carers Trust, a charity that provides support to caregivers through 150 local charities around the UK. She has a wealth of knowledge in the area and is an active campaigner for caregivers' rights.

[@gailscottspicer](https://twitter.com/gailscottspicer)



Do you feel loved Shazia?

*“ Yeah. By my mum definitely...
I must admit, I’ve never been asked
that before! ”*

10. Maslow AH. (1954).

TIME TO TALK ABOUT
YOUR NEEDS

Caregivers spend a lot of their time focused on the needs of other people, but we wanted them to talk to us about **their own needs**. As such, we used Maslow’s hierarchy of human needs* to shape our discussions with the caregivers we spoke to.

PHYSIOLOGICAL NEEDS



Exploring the caregiver’s basic well-being needs (such as food, sleep and health) and how caring affects their ability to look after themselves.
‘Has caring affected your sleep?’

RESPONSES FROM THE INTERVIEW GROUP

Lack of rest was a universal issue and stress was common. Some caregivers with more intensive responsibilities reported significant effects on physical and mental well-being.

SAFETY NEEDS



How safe and secure the caregiver feels; whether caring has changed their life and how stable it feels.
‘Do you ever feel anxious or worried?’

Nine in ten felt unprepared for caregiving. Some said their caring role had brought significant uncertainty and change into their life, affecting their ability to make plans. All felt anxiety and worries relating to caring.

BELONGING AND LOVE NEEDS



Looking at the state of the relationships around the caregiver.
‘Do you feel loved?’

Most said caregiving had changed the relationship with the person they look after (some for better, some for worse). All felt loved, but some felt lonely, and cut off from friends and family. Those who had access to support from other caregivers were lifted by it.

ESTEEM NEEDS



Examining the caregiver’s self-esteem and the respect or appreciation that other people show them.
‘How has caring affected how you feel about yourself?’

Most felt confident in their ability to care, and believed caregiving had taught them new skills (from medication management to empathy). For some, caring had boosted their self-esteem and drawn the respect of friends and family. However, for others, it had deprived them of validation markers like jobs and friends, leaving them feeling low and undervalued.

SELF-ACTUALIZATION NEEDS



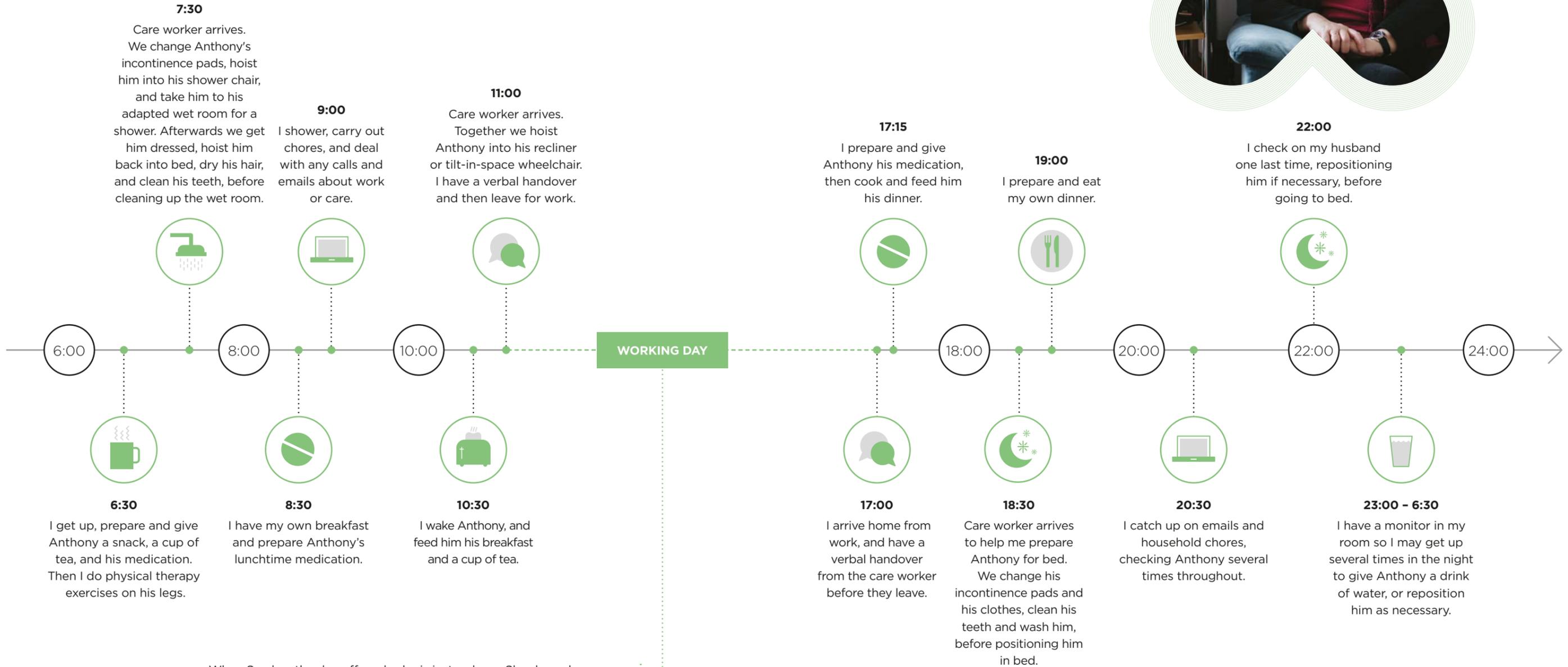
The caregiver’s ambitions and whether caring has changed these.
‘Do you feel like you’re fulfilling your potential?’

For some, caring had inspired new purpose and ambition – a desire to use the skills they’d learned to help others. But for others, caring had put life on hold, and they felt helpless to improve their situation. Most said ambitions were tempered by the ‘you-never-know-what’s-coming’ aspect of caring.

*Maslow’s hierarchy of human needs is a psychological theory, which outlines five interdependent levels of ‘need’ that everyone is motivated to fulfill. The hierarchy is often visualized as a pyramid, with the most fundamental needs at the bottom (e.g. the need for food and rest), and the less essential needs at the top (e.g. the need for self-fulfillment).¹⁰

A DAY IN THE LIFE OF SUE

It's not easy for caregivers to describe a typical day; appointments, the care recipient's well-being, and changes in support arrangements are just some things that make each day different. Sue - whose husband, Anthony, has PCA - told us how a day in her life can look.



When Sue has the day off work, she is just as busy. She does chores, work admin and checks on Anthony several times throughout the day. She prepares lunch and feeds him, does sensory activities with him, reads to him and they listen to music together. A care worker arrives for 15 minutes to help her change his incontinence pads, and reposition him or they use the hoist to get him in his wheelchair.

On some days a care worker arrives for a few hours in the afternoon so Sue can do food shopping and go to meetings. Sue gets five hours respite care once or twice a month so she can go out.



FINDING THE WAY

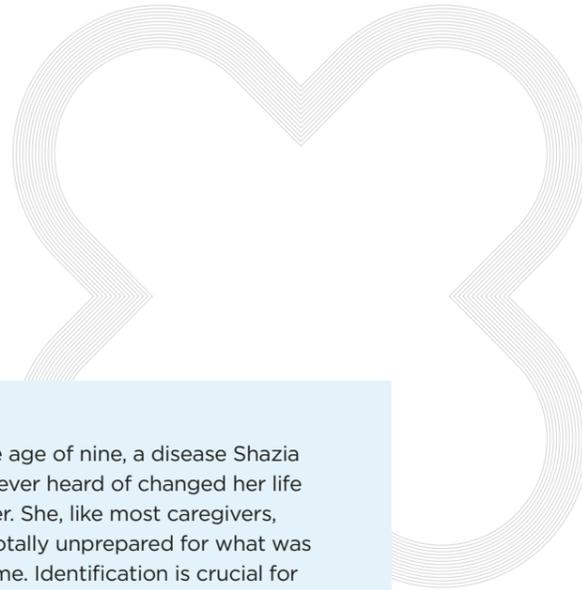
Caring can be daunting, testing, but also inspirational. And one thing's for sure, **it's unlikely to be straightforward**. More often than not caregivers find themselves on an unmarked track, with little idea of what lies ahead.

From our conversations with caregivers, support workers, and experts, and our secondary research, we found five key areas that determine the caring experience:

- How quickly the caregiver is identified in their role and connected with information
 - [Finding Guidance](#)
- The relationships between the caregiver, the care recipient and HCPs
 - [Finding Partners](#)
- The support the caregiver receives from those outside of the core care relationships
 - [Finding Strength in Others](#)
- The effect caring has on the caregiver's health and their mental well-being
 - [Finding Fitness](#)
- The caregiver's sense of identity and purpose
 - [Finding Me](#)



FINDING GUIDANCE



" One day she was fine and the next... it was almost overnight. The illness just came out of nowhere. "

Shazia

At the age of nine, a disease Shazia had never heard of changed her life forever. She, like most caregivers, was totally unprepared for what was to come. Identification is crucial for caregivers to start on the right path, whilst ongoing guidance can keep them headed in the right direction.

11. Reuters. Few family caregivers get formal training. (2019). Available at: reut.rs/2xSFIVW Accessed: July 2019.

All but one of the caregivers we spoke to felt unprepared for their caring role. In the US, more than 90% of caregivers do not receive any training for their role.¹¹ Support workers and experts alike told us that this situation can be compounded by the fact caregivers don't always readily identify as caregivers, and remain 'hidden' from potential support. Indeed, whilst it's important for some to describe their role, others don't like the term 'caregiver,' feeling it disparages the relationship behind the role. According to Gail Scott-Spicer (Carers Trust), identification is not about adopting a label, but "acknowledging that they're not just a daughter or a husband and that they're providing care...so that they can reach out for support." If they do this early on, it can be hugely beneficial to all, helping them to stay in work for longer, improve their health and well-being, and even improve the care that they're providing. Emily Holzhausen (Carers UK) told us that "overall it improves everyone's quality of life, so it's hugely important." In addition to the issue of self-identification, some of the caregivers we spoke to struggled to have their role recognized by HCPs; even though HCPs are well placed to identify caregivers and direct them to sources of help and advice.

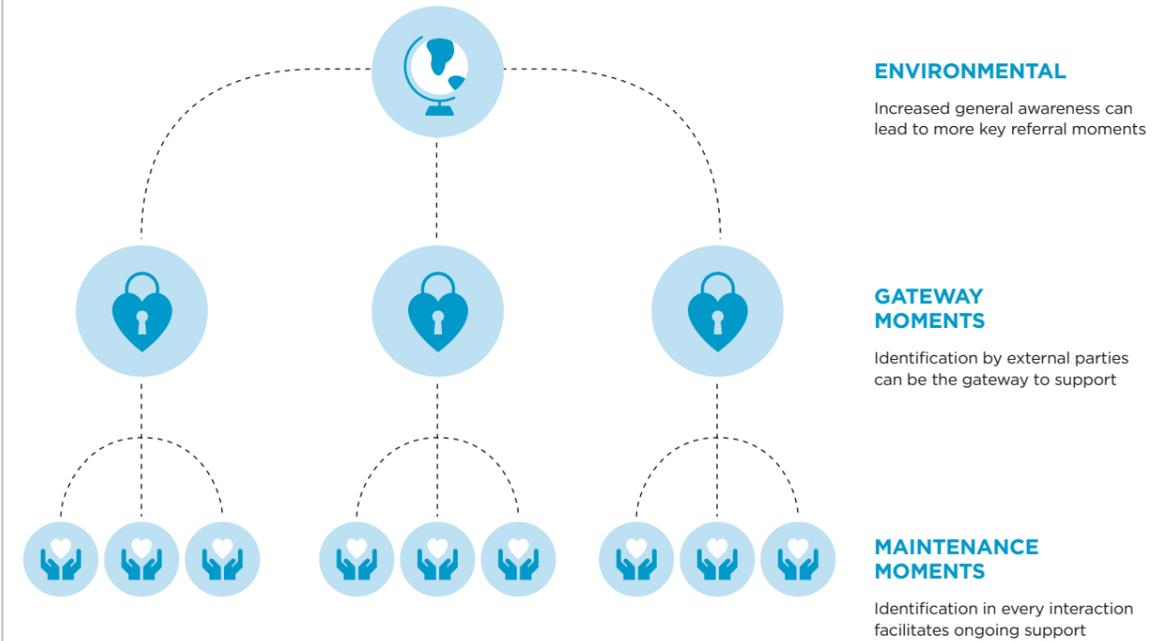
Over 90% of caregivers haven't received any training in their role¹¹



12. Office of the Press Secretary. Presidential Proclamation -- National Family Caregivers Month, 2014. Available at: bit.ly/2YamxQP Accessed: July 2019.

FINDING THE WAY: FINDING GUIDANCE

Our discussions with caregivers outlined three tiers of need for identification.



ENVIRONMENTAL

The first step to improve identification is to increase awareness of the caregiver role, to create a culture that allows caregivers to come forward.

Martha told us that caregiving does not exist as a role in Kenya. Anil Patil (Carers Worldwide) confirmed that this was an issue across the developing world, with countries like India not having the option for people to identify themselves as caregivers on the census.

Emily Holzhausen and Gail Scott-Spicer also said that there was a lack of understanding of the caregiver role in countries like the UK, where caregivers do have more of a profile than in developing countries.

In the US, initiatives such as the 2014 National Family Caregivers Month help to raise the profile of caregivers.¹²

GATEWAY MOMENTS

Mechanisms need to be in place to help caregivers self-identify in a way that opens doors to support networks and information. Becky's case highlights the need for external parties to have a role in helping caregivers. She talked about unknowingly taking on extra responsibilities as an extension of the family role.

"Being a caregiver, you don't get told 'you're going to be a caregiver now'...you just naturally help out. It's only when you're doing it every day, the same thing, you start to realize, 'oh, I'm a caregiver.'" — Becky

Experts described interventions that engage pharmacists, primary care physicians, hospital staff, schools, employers, and even banks in identifying caregivers.

MAINTENANCE MOMENTS

A 'gateway moment' does not necessarily equate to a long-lasting resolution. Caregivers should be identified by HCPs in every interaction with them so they get the support and advice they need as their situation changes (see Finding Partners).

Recognizing the situation they're in may be an important and difficult step for caregivers but identification alone isn't enough. All the caregivers we spoke to self-identified but that didn't mean that they were all being supported. Lina and Martha were largely isolated, with almost no professional support or guidance to help them.

"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."

Emily Holzhausen OBE, Carers UK

- 2. National Alliance for Caregiving. (2015). Available at: bit.ly/2JD8RVg Accessed: July 2019.
- 13. Given BA and Northouse L. (2011). *Clin J Oncol Nurs*. 15: 451-2.
- 14. Bruce CR et al. (2017). *Circ Cardiovasc Qual Outcomes*. 10: e002879.

For identification to be effective it must be paired with information. Caregivers need to be informed to provide the best care they can. In a study involving caregivers of cancer patients, over 70% reported that they needed more information to provide care and were worried that the care provided was less than optimal.¹³ As always, the audience needs to be taken into consideration when designing interventions. Our discussions with caregivers and support workers indicated that the type and timing of information was fundamental to its value.

VARIED NEEDS

Caregivers have a variety of information needs. At diagnosis, some of the caregivers we spoke to hadn't even heard of the condition that the care recipient was faced with. High-quality disease education is important at this stage. A study by Bruce and colleagues showed that having a caregiver who understands the severity of the illness and options available improves outcomes for the care recipient.¹⁴

Caregiver responses indicated that information needs were varied but also very specific to individual circumstances. Lina found information about treatments but could not find anything to help her care for her husband, whilst Martha said that she had difficulty in knowing how to carry her mother.

Alongside information on caregiving and disease education, caregivers we spoke to reported needing information for countless other skills, such as financial management and navigating the healthcare system.

57% of caregivers assist in medical tasks, with only **14%** receiving training²



CHANGING NEEDS

Circumstances can change and caregivers need timely information along the way to help them navigate their journey. Martha's mother was diagnosed with cancer long after being diagnosed with diabetes, and Karen had to adjust to changes in the structure of her support, bringing new information needs in both instances.

UNKNOWN NEEDS

Caregivers need to be signposted to information that's readily available. Like most of us, caregivers will look online and whilst the internet is a treasure trove of information, finding the jewels can be difficult. According to Emily Holzhausen, the changeability of caregivers' situations means they need help with where to look and what to look for, quoting the old saying "you don't know what you don't know."

- 15. Mashable. 10 daily apps to help caregivers take care of their loved ones. (2016). Available at: bit.ly/2JK173V Accessed: July 2019.
- 16. CareZone. Available at: carezone.com Accessed: July 2019.
- 17. Apple News. Available at: apple.co/32sY8VY Accessed: July 2019.
- 18. Healthcare Finance. Hospitals employ caregiver support centers to support successful patient transitions to home. (2017). Available at: bit.ly/2JCXMVa Accessed: July 2019.

CASE STUDY

INFORMATION IN THE RIGHT PLACE, AT THE RIGHT TIME



With such a range of information needs, having trusted go-to hubs and tools that help direct caregivers to support can be a lifeline.

AARP Caregiving has developed an app that empowers caregivers with information on how to effectively care for an aging loved one. The app allows users to monitor symptoms, coordinate care with other family or caregivers, and keep track of appointments and medications. It also features a help center, where caregivers can find answers to urgent or commonly asked questions.¹⁵

CareZone helps caregivers keep track of medical information by organizing medication, allergies, insurance cards and ID cards all in one place. Through the app, caregivers can also create to-do lists to keep track of appointments and medication times. The app also curates news relevant to your loved one's illness, disability or condition.¹⁶

Personalization according to preferences is something that's commonly used in consumer products like Apple News,¹⁷ which updates users on news stories specific to the sources and topics they're interested in.

It's easy to see how such concepts could be incorporated into solutions for caregivers, updating them with new information or providing timely nudges when they need it most. Of course, not all caregivers will want to go online (John from the interview group expressed a particular disdain for the internet), and sometimes caregivers may prefer to talk directly to an advisor. Caregiver support centers are a great source of information and support for caregivers. Embedding these services within a clinical setting can help identify and support caregivers at times when they may be vulnerable. Montefiore's caregiver support center, staffed by a social worker and an administrative aide, is one of 11 that have popped up over the last decade in New York, New Jersey, Pennsylvania, Connecticut, Michigan, and Iowa, based on a model created in 2006 at Northern Westchester Hospital in New York.¹⁸

FINDING PARTNERS

— Partnering with patients

"I used to be his wife and now I feel like his mother; a very strict mother... He's a very difficult person to handle."

Lina, talking about her husband

It's not her husband's care needs that Lina finds challenging, it's his sheer unwillingness to cooperate with her. Caring often changes relationships, for better and worse. It's a complex area, but building a sense of partnership can help sustain relationships and even improve patient outcomes.

The interview group gave a range of responses about the state of their relationships, but three common themes emerged:

1. WE'RE CLOSER THAN EVER

"It made our relationship stronger. Sometimes she says 'I love you more than I did because you are taking such good care of me.'"

— Floris, who cares for his wife

2. OUR ROLES ARE DIFFERENT NOW

"It's sort of a bit of a role reversal. It can get a little difficult at times. And telling her what to do is a bit weird for me."

— Shazia, who cares for her mother

3. OUR RELATIONSHIP IS WORSE

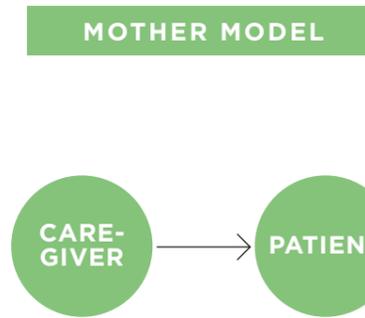
"I used to hate my brother and sister. I just really didn't tolerate them at all. My mum just used to wind me up."

— Becky, talking about when things were at their worst caring for her family

Of course, such categorization doesn't portray the full complexity of emotions and unique dynamics involved. Intervening positively around caregiver-patient relationships might not be easy, but Emily Holzhausen told us that support and information that eases the burden of the overall situation can help.



FINDING THE WAY: FINDING PARTNERS



Active 'giver' of care

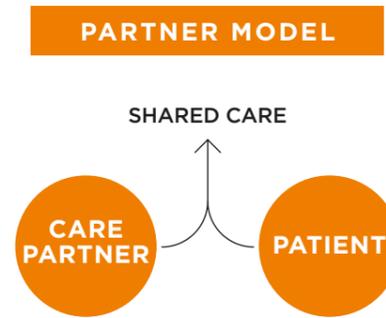
Needs are second

May feel solely responsible/
burdened

Passive recipient

Needs are first

May feel unaware/
disengaged



Both active

Decisions made based
on combined need

Shared responsibility

Another potential area for support is in how caregivers and care recipients approach care. Lina and Karen both care for life-partners but reported remarkably different situations.

Lina described feeling like a "mother to a child." As the active 'giver' of care, she felt "overwhelmed" by responsibilities and described her husband as a "stubborn" and uncooperative recipient. Their relationship is strained as a result and her husband is not actively engaged in controlling his COPD, which is deteriorating. In comparison, Karen described working "as a team" with her partner Yvette, with both taking active roles in tasks such as remembering medication. Their relationship is as strong as ever, and Yvette's condition is well-managed.

For some conditions, studies have shown more supportive relationships, like Karen and Yvette's, to improve outcomes for the care recipients.¹⁹⁻²² One of these studies speculates that this is because supportive relationships can drive a 'shared care' or partnership approach¹⁹ (as in Karen's case), which encourages the care recipient to take better care of themselves.

The appropriateness and terms of partnership will depend entirely on individual circumstances. But promoting a sense of 'shared-care goals' – which actively involves all parties, stimulates understanding of each other's needs, and is acknowledged by HCPs – may help support happier, healthier relationships.

CASE STUDY

MAINTAINING ADHERENCE PROGRAM (MAP)



Developed by Janssen and Havas Lynx Group, MAP supported those who have schizophrenia and their caregivers by giving them education and information on topics like symptoms and signs of relapse. By doing so, MAP empowered patients to take control of their own care and gave caregivers the means to support them. In clinical studies, MAP was shown to reduce the number of hospital admissions by 58%.²³

19. Sebern M and Riegel B. (2009). *Eur J Cardiovasc Nurs.* **8:** 97-104.

20. Luttik ML et al. (2005). *J Cardiovasc Nurs.* **20:** 162-9.

21. Frasure-Smith N et al. (2000). *Circulation.* **101:** 1919-24.

22. Murberg TA. (2004). *Int J Psychiatry Med.* **34:** 207-17.

23. Lewis L et al. (2016). *BJPsych Bull.* **40:** 5-11.

CASE STUDY

THE IMPORTANCE OF DEFINITIONS: KATE SWAFFER AND THE BACK-UP BRAIN²⁴



Even the language used to define a caring relationship is important, for both patient and caregiver. Kate Swaffer is an author, activist and academic. She also has dementia. She and her husband Peter don't like the term 'caregiver.' They believe it defines a one-way dynamic in which she is passive and helpless and Peter takes charge. Instead, Kate describes Peter as her Back-Up Brain, or B.U.B., there to support her when she needs it, but not to take over when she doesn't. B.U.B. might not work for everyone, but it raises a valid point about the effect of the terms we use to define roles; there's a difference implied by the term 'care partner' as opposed to caregiver and care recipient.



FINDING PARTNERS

— Partnering with HCPs

"Over time I think they have come to respect me as a caregiver but it has taken them quite a while to realize that caregivers have needs as well."

Sue, talking about her experiences with HCPs

It's taken many years for Sue to feel respected as a caregiver by her husband's healthcare professionals. When the relationship between caregivers and HCPs works well, it can be a real source of support and beneficial to the patient's medical care. But the caregivers we spoke to gave mixed reports.

- 24. Swaffer K. (2015). What the hell happened to my brain?
- 25. Sveltini A et al. (2015). J Psychiatr Ment Health Nurs. 22: 472-83.
- 26. Pitschel-Walz G et al. (2001). Schizophr Bull. 27: 73-92.

Some caregivers we spoke to felt consulted and respected for their role in the care recipient's health, and felt HCPs understood their needs. The value of this was far-reaching and well-appreciated; it boosted caregivers' knowledge, enabled them to access support and was a comforting source of recognition.

"They understand how I am feeling and how we manage our family."
— Floris

"Her therapists and her physicians are an extended family for us."
— Aparna

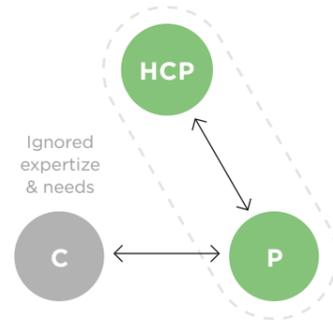
Not all caregivers felt this way. Some complained that HCPs did not involve them in care discussions, or that HCPs were oblivious to the strain they were under.

"I don't think the physicians or anyone really thought about the effect that it would have on me."
— Shazia

92% of caregivers believe family support has greater benefit in promoting treatment adherence than a positive HCP-patient relationship²⁵

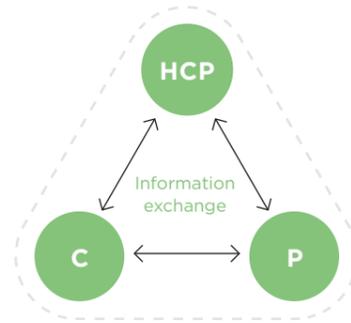
Relapse rates can be **reduced by 20%** if relatives of people with schizophrenia are included in treatment²⁶

PATIENT FOCUS



HCP makes decisions based only on interaction with patient, without an awareness of caregiver's needs or insight.

CARE FOCUS



HCP makes better informed decisions based on a full view of overall care situation. All parties feel informed and involved, and the HCP directs caregiver to support where needed.

CASE STUDY

#HELLOMYNAMEIS



The successful #hellomynameis campaign aimed to improve compassionate care through communication. It was created by Dr. Kate Granger, one of the healthcare heroes in our recent publication.²⁹ The movement grew out of Kate's frustration when the physician who informed her that her cancer had spread did so with no introduction, eye contact or compassion. #hellomynameis asked HCPs to make a simple pledge to introduce themselves to patients. Kate's legacy lives on in over 400,000 health workers across 90 organizations that support the initiative.

27. McCarthy B. (2011). *Eur J Oncol Nurs.* 15: 428-41.

28. Alzheimer's Association Alzheimer's Disease Study: Communication Gaps Between Primary Care Physicians and Caregivers. (2001). Available at: bit.ly/2oudecv Accessed: July 2019.

In some cases, relationships with HCPs had significantly deteriorated. Leanne no longer saw them as useful allies. She talked negatively about physicians, hospitals and psychiatrists, referring to appointments as "a waste of time." This would be less of an issue if both Leanne and her mother were doing well, but Leanne showed signs of needing more support.

Leanne's case indicates a classic example of a communication breakdown. In a review of 34 studies, the majority of caregivers reported negative experiences of communication with HCPs.²⁷ In addition, physicians tend to believe they provide more information to caregivers than caregivers believe they receive.²⁸ All evidence points to the need to support better relationships between HCPs and caregivers.

"With very rare conditions, sometimes the caregiver is the person that knows more than the professional sitting in front of them."

Emily Holzhausen OBE, Carers UK

Improving this connection is beneficial for all. For HCPs, caregivers offer "a huge source of evidence" according to Emily Holzhausen. The amount of time caregivers spend with care recipients gives them a unique insight. Through lived experience, they build a wealth of knowledge about the day-to-day needs of the recipient and solutions that work for them. Writer and campaigner Beth Britton told us how she and her mother helped come up with solutions to her father's swallowing problems that his HCPs "never even thought of." Moreover, caregivers are ideally placed to be a huge influence on the care recipients. David Blair, Head of Industry for Health at Google, emphasizes that the critical actions affecting outcomes do not necessarily occur in consultations with HCPs, but in the many moments that happen outside of them. By fostering a good relationship with caregivers (who are present for these 'moments that matter') HCPs might be able to better steer patients towards better outcomes.



29. Healthcare Heroes. Available at: healthcare-heroes.com Accessed: July 2019.

30. Given BA, Given CW and Kozachik S. (2001). *CA Cancer J Clin.* 51: 213-31.

31. Patients Know Best. Available at: patientsknowbest.com Accessed: July 2019.

32. Jointly app. Available at: jointlyapp.com Accessed: July 2019.

33. Mitnick S, Leffler C and Hood VL. (2010). *J Gen Intern Med.* 25: 255-260.

This relationship might also create opportunities to identify caregivers and direct them to quality information (as discussed in Finding Guidance). Despite living in an information-rich age, misinformation can pose a huge challenge for HCPs. Patients' and caregivers' drive to take charge of their situation and to prove that their understanding is valuable, but unguided they may be exposed to misinformation that could be detrimental to their well-being. By creating an environment in which all parties feel comfortable to talk openly, HCPs can address any false reports and ensure caregivers are equipped with the knowledge they need to best support positive patient outcomes. In addition, HCPs are well positioned to assess how caregivers are coping and to connect them with additional support. Whilst the patient is the HCP's priority, taking the time to refer caregivers to support groups, training, community and social services, can help sustain successful caregiving situations that can benefit all.³⁰

Patient confidentiality is paramount, but frameworks and interventions need to be in place to support a healthy partnership between caregivers, HCPs and patients. Communication is at the heart of this and it doesn't need to take much effort. Anil Patil suggests that caregivers need only one question from a HCP to reveal how they are feeling.

There are guidance documents and tools for improving patient-HCP communication.

Patients Know Best³¹ is an app that puts patients in charge of their own medical records, allowing them to choose which professionals to share their records with, review care plans, receive lab results and letters, and communicate directly with HCPs. For caregivers, the Jointly³² app helps those who share caring roles to coordinate care and update each other on things like medication. Combining such concepts could boost HCP-caregiver-patient communication.

Professional societies have also released ethical guidance to heighten HCP awareness of the importance and complexity of the patient-HCP-caregiver relationship.³³ The guidance hopes to maximize the benefits of the relationships and minimize the burden on caregivers. Anil Patil told us that the HCPs he worked with responded very well to the training on supporting caregivers. On a wider scale we only have to look at Kate Granger's #hellomynameis campaign to see the huge impact a little respect and courtesy can make.

"It's really important that caregivers' opinions are sought out. They should be partners in the care of the person that they care for."

Gail Scott-Spicer, Carers Trust



FINDING STRENGTH IN OTHERS

" I used to have so many friends but because of my situation I couldn't go out with them. So they keep calling you... 'would you like to go out?' and then I say 'no, sorry, maybe next time'... and you repeat that all the time. So I'm on my own now. So there's no social life at all. "

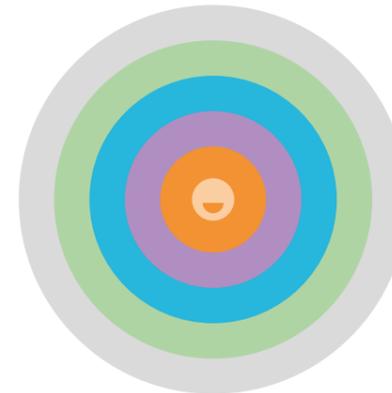
Leanne

Like many caregivers, Leanne's care responsibilities have isolated her. The circle of relationships around a caregiver can be hugely important, and the support of other caregivers can be a lifeline.

FINDING THE WAY:
FINDING STRENGTH
IN OTHERS

FLORIS

Loved & supported



- Understanding family
- Good partnership with HCPs
- Sees friends regularly
- Supportive colleagues/employer
- Online support of caregivers

MARTHA

Lonely & isolated



- Family uninvolved
- Little to no support from HCPs
- No social life
- Had to give up work
- No contact with other caregivers

THE IMPORTANCE OF UNDERSTANDING

A sense of being understood was hugely important to caregivers, as it is to most of us. Floris, for example, spoke of how easy it was to talk to his family about his wife's MS because they'd experienced progressive conditions before and worked in the care sector. But others felt (or feared) that people just didn't 'get it'; Sue and Lina felt forgotten about by friends, whilst Becky and Shazia told us how shy they'd felt about talking of their situation whilst at school. It's easy to imagine that in the sometimes unforgiving world of school, standing out is the last thing a young caregiver would want (and all the more reason why they might remain hidden from support).

For some of the caregivers we spoke to, the greatest sense of empathy and understanding came in conversation with those who knew exactly what they were going through - other caregivers. Those in the interview group that had

access to support groups were very positive about their experiences. Our conversations with support workers and experts reinforced this sentiment. Anil Patil told us about a caregiver he'd worked with who said going to support groups had brought her back from the brink of suicide.

Buddying systems and groups are available, but not for all. Lina told us she'd love to meet other caregivers but didn't know how, and Anil Patil informed us that on-the-ground support offerings are scarce in developing countries. Nevertheless, location doesn't need to be a barrier in the modern era. Sue, who lives on the Isle of Skye, uses Facebook to connect with other caregivers. There's also a range of online forums available. Still, it seems there's much that can be done to improve the universality of, and access to, these types of services.

34. Family Caregiver Alliance. Caregiver Isolation and Loneliness. Available at: bit.ly/32v1Yhl Accessed: July 2019.

All of the caregivers we spoke to said they felt loved, but that didn't mean they didn't feel lonely. From the interview group, those with a larger network of social contacts reported more positive care experiences. Karen, Aparna, and Floris in particular, were surrounded by people who offered various different levels and functions of support, from those that supported them within their caring role to those who took them out of it. Conversely, Lina, Leanne, Sue, and Martha felt lonely and isolated due to their caring duties, which kept them busy or bound to the house. Statistics reveal that between 40% and 70% of family caregivers experience clinical symptoms of depression, which can often be caused by feelings of isolation and loneliness associated with the caregiving experience.³⁴ Leanne felt locked away mentally and physically - her days looking after her mother would leave her emotionally drained, and by the time she got home she had nothing left for her daughters. She spoke with shame and sadness about shutting herself away from them.

Up to 7 out of 10 caregivers experience symptoms of depression³⁴





EMPATHY AND EXPERTIZE

In helping caregivers connect with each other, it's important to be aware that they have different needs and expectations of support from peers. Some of the caregivers we spoke to preferred to connect with caregivers who'd had similar experiences (e.g. of the same condition) – further emphasizing the need for a common ground of empathy and mutual understanding. Online and offline, there are groups and services available that connect people according to treatment area, age and culture. The sense of solidarity and emotional support from other caregivers was extremely important to some in the interview group, but great value was also placed on the practical advice they could offer. Given the level of experience caregivers have, who better to help solve a caregiver's problems than someone who has already been through it all?



FINDING THE WAY:
FINDING STRENGTH
IN OTHERS

"I felt quite isolated, as if it was just me and there was no one else. And I couldn't really talk to my friends because they didn't understand. But then when I went to the [caregivers'] groups I was able to speak and I knew that I wasn't the only one."

Becky



A study found that caregivers' depression was statistically reduced after participating in a support group³⁵

35. Chou KR, Liu SY and Chu H. (2002). *Int J Ment Health Nurs.* **39**: 713-22.

36. Patient Innovation. Available at: patient-innovation.com Accessed: July 2019.

37. OpenIDEO. Available at: openideo.com Accessed: July 2019.

CASE STUDY

MAKING BETTER TOGETHER



Many caregivers have a willingness to collaborate with each other and a natural tendency to problem solve. Having platforms for caregivers to strengthen partnerships with others and share solutions to their daily challenges could play to their problem-solving strengths:

- Patient-Innovation.com allows caregivers and patients alike to share, rate and comment on solutions to day-to-day issues³⁶
- OpenIDEO.com is a community that brings people from around the world together to solve challenges for social good³⁷

FINDING FITNESS

"I've been admitted [to hospital] a couple of times...I've been dehydrated and exhausted from so many months of work...your body just gives up."

Aparna

Aparna's dedication to her daughter has caused her a range of issues, from extreme exhaustion to back problems. Caring can push caregivers to their limits, physically and mentally, and lead them to neglect their own well-being. Long term, this can have detrimental consequences for them and the people they look after.

A lack of rest was universally reported amongst the caregivers we spoke to. Disturbed nights (e.g. due to medication schedules) and long, exhausting days left some regularly surviving on as little as three or four hours sleep. For some, exhaustion clouded their ability to think, and for Aparna it resulted in her being hospitalized.

More than half the caregivers we spoke to said caring had caused or worsened physical health issues, with back problems and irritable bowel syndrome (IBS) being just two examples. The strain of intensive caring is known to be linked to health issues; those providing over 50 hours of care a week are twice as likely to be in poor health as those not providing care.³⁸ Moreover, caregiving fits the criteria for chronic stress so well that it's used as a model for studying the health effects of the condition.³⁹

Lack of exercise, weight gain and lifestyle issues were also reported amongst the interview group, with Leanne describing 'bad habits' (smoking and comfort eating) as a coping mechanism.

"I don't have time to eat...when you're depressed and you feel low you eat naughty food."

— Leanne

Intertwined with caregivers' physical issues, the psychological burden of caring was obvious. All of the interview group reported anxieties related to caring, and Becky, Leanne and Martha had suffered with depression. For Becky, things became so bad that she felt she couldn't take it any longer and left home. Desperate situations like this, where the caregiver's well-being is pushed beyond its limits, can be damaging for all. As might be expected, studies have indicated a link between declining health in caregivers and poor health in the care recipient.⁴⁰

More than half of all caregivers report feeling overwhelmed by the amount of care their loved one needs.⁴¹

FINDING THE WAY: FINDING FITNESS



1 in 5 caregivers report a high level of physical strain as a result of their caregiving duties²

40% consider their caregiving situation to be highly stressful²

Over half are exercising less as a result of caring⁴²

Where caregivers did 'find fitness,' it was a boost for their well-being; Shazia said trips to the gym were a release, a chance for some 'me time' that left her feeling rejuvenated. The responses of the group suggested interventions can work; meditation, counselling, and health and well-being education were amongst the things they listed as helpful. Applying the principles of creativity and community, used in apps like Nike+, may help make healthier habits more accessible and appealing to caregivers. But such efforts would serve to ease a symptom rather than address a cause.

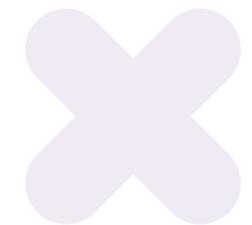
"Every time I rushed to take care of her I forgot about my health."

— Martha, who cares for her mother

The prevailing attitude amongst the caregivers we spoke to was that the pressures of caring meant their own health "must fall into the background" (Karen). Rather than trying to make healthier habits appealing, it may be more worthwhile and effective to: provide support that alleviates the strains and anxieties of caring; give information that helps caregivers better understand what to do; connect caregivers to peers so that they feel less isolated.

Caregiver burnout

Becky's responses indicated she may have suffered caregiver burnout – a state of physical, emotional and mental exhaustion that can cause a change in attitude, from positive and caring to negative and unconcerned.⁴³



Caregivers have a 23% higher level of stress hormones and a 15% lower level of antibody responses.⁴²

38. Office for National Statistics, National Records of Scotland, Northern Ireland Statistics and Research Agency. (2017). Available at: bit.ly/2nBhqDH Accessed: July 2019.

39. Schulz R and Sherwood PR. (2008). *Am J Nurs.* 108: 23–27.

40. Smith KP and Christakis NA. (2008). *Annu. Rev. Sociol.* 34: 405–29.

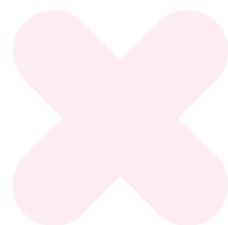
41. Caregiver Homes. The State of Caregiving 2018. Available at: bit.ly/2JPRO2t Accessed: July 2019.

2. National Alliance for Caregiving. (2015). Available at: bit.ly/2JD8RVg Accessed: July 2019.

42. Family Caregiver Alliance. Caregiver Health. Available at: bit.ly/2YUF9S9 Accessed: July 2019.

43. Gogia PP and Rastogi N. (2009). *Clinical Alzheimer Rehabilitation.* p.197.

FINDING ME



"I think caring for my mum made me very strong. I noticed a lot of strengths that I didn't know I had. I noticed that I can face challenging situations. I noticed that it takes a lot of joy when a sick person gets some love. It makes you feel grateful about everything so it made me appreciate life."

Martha

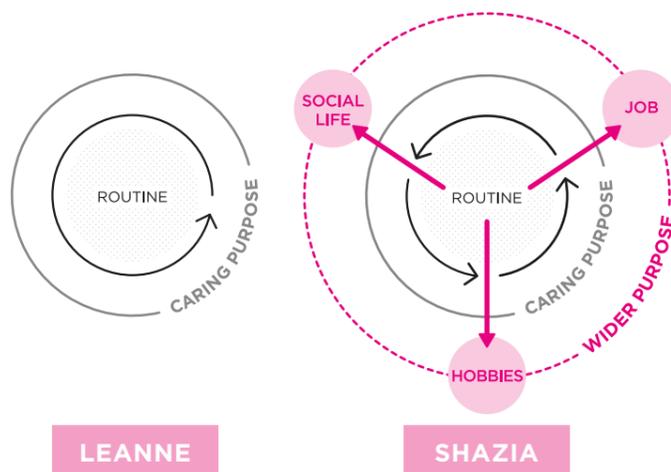
Martha's time caring for her mother was as valuable and illuminating as it was lonely and challenging. Caring can provide caregivers with inspiration and understanding that can transform their lives, and make them a force for good in healthcare. But it can also swallow up their sense of who they are.

39. Schulz R and Sherwood PR. (2008). *Am J Nurs.* 108: 23-27.

Studies show that caregiving can boost caregivers' self-esteem by making them feel needed, giving meaning to their lives, and enabling them to learn new skills.³⁹ Most of the caregivers we spoke to confirmed this. Like Martha, many felt that caring had taught them skills, revealed strengths and nurtured an innate sense of

care for others. Even those who had intensive care routines took satisfaction in supporting someone they loved. However, this didn't guarantee that they felt good about themselves. What seemed to be pivotal was how caring impacted on their sense of purpose and identity beyond their caring role.

Leanne has little to take her out of her routine whereas Shazia has friends, a career and hobbies that give her a wider purpose beyond her caring role.



FINDING THE WAY: FINDING ME

Despite caregivers being highly important on individual and societal levels, Leanne felt her role carried little status.

"I feel like a failure. I'm 43 years old and I've done nothing yet... Because caring is not a job is it? I feel like a lowlife."

— Leanne

Caring had stripped her of access to a job, close personal relationships, and good health – things that people commonly derive status and wider purpose from. Sue and Lina described similar experiences.

Caregivers who had a balance between their care routine and other pursuits and relationships reported more positive experiences overall. And for some, caregiving itself had opened up sources of validation and purpose that extended beyond the people they look after. Floris, Karen and Becky had been empowered by advocacy and employment roles that allowed them to make use of the skills they acquired through caregiving, including their sense of empathy.

"I get a lot of energy from helping people...I create ambitions right now from all the energy I get from taking care of my wife and writing about it."

— Floris

Our conversations with support workers indicated that caregivers often seek opportunities to help other caregivers, but many of the interview group reported highly transferable skill sets. Caregivers are unlikely to have any certification to show for their time caring, so helping them to document their skills in ways that can be applied to a professional capacity could be very helpful. The DISCOVER caregiver support website (see Finding Guidance) features a resume builder, whilst mechanisms similar to the endorsement feature on LinkedIn could help caregivers to convey their skills.

EXPERTS BY EXPERIENCE

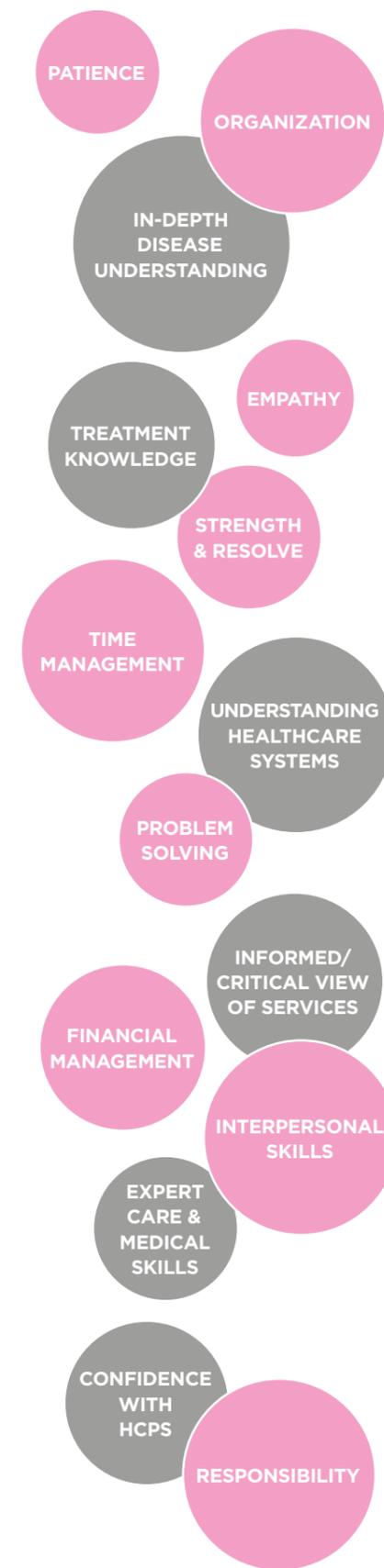
As well as helping HCPs better understand the patients in front of them (see Finding Partners), caregivers' wealth of insight and drive to help others could benefit healthcare as a whole. In the UK, campaigner Beth Britton's experience of caring for her father has led her to do incredible things for dementia care and caregiver rights, including consulting with NHS England and Care Quality Commission (CQC) – the independent regulator of all health and social care services in England. In fact, the CQC welcomes caregivers to apply to their 'Expert by Experience' roles, where they can use their first-hand experience to shape better services for patients.

Caregivers might be invaluable, but it's important that they feel valued. Our conversations with caregivers revealed a range of opportunities to help better support their sense of self, and thus drive better caregiving experiences:

- Raising the status of caregivers through awareness (see Finding Guidance)
- Driving HCPs to support and validate caregivers (see Finding Partners)
- Easing the burden of care through information and support so that caregivers can engage in other activities
- Helping caregivers to document their skills
- Providing expert caregivers with opportunities to share their knowledge

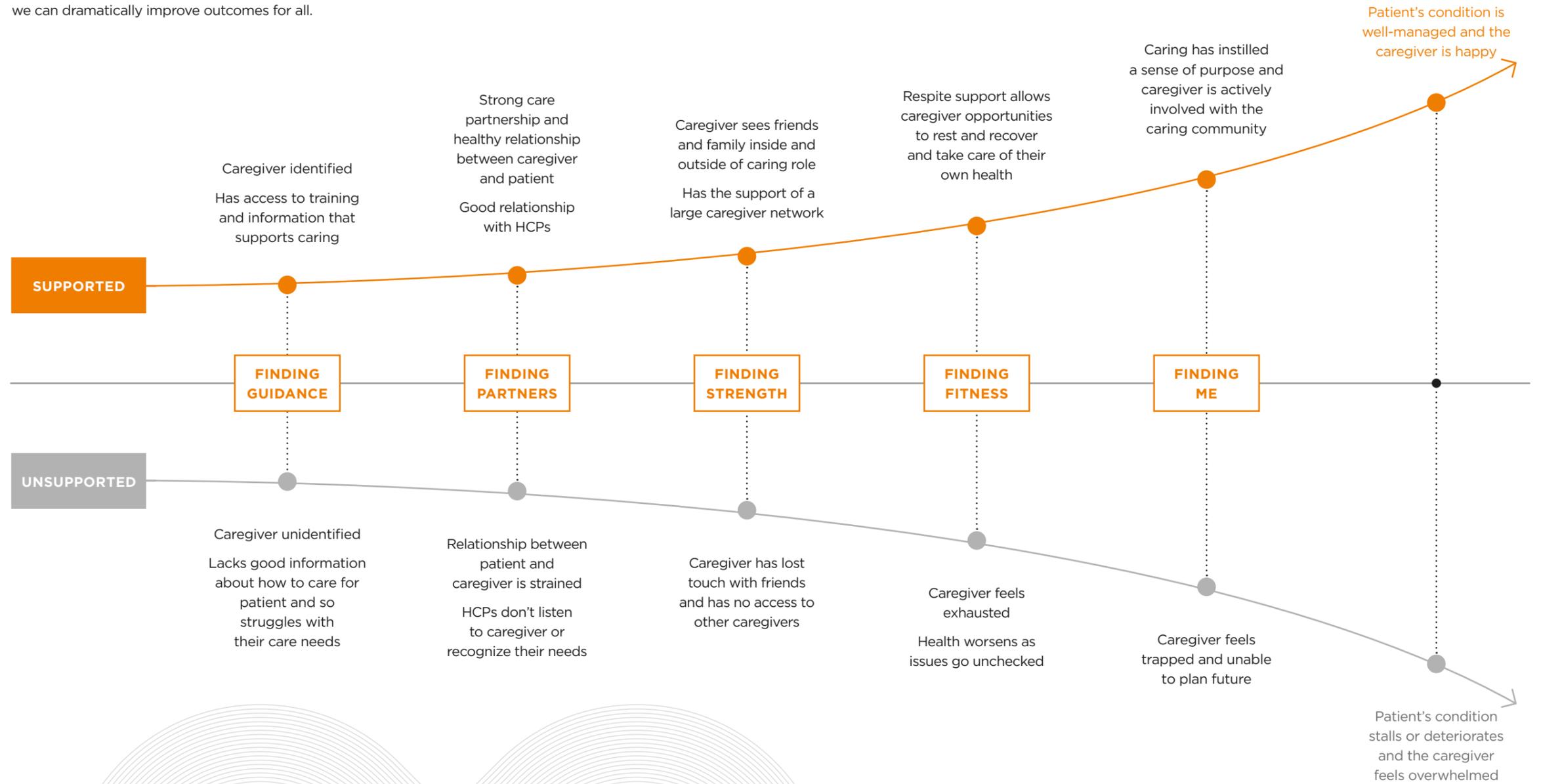
SKILLS AND ABILITIES THE INTERVIEW GROUP GAINED THROUGH CARING

- TRANSFERABLE
- HEALTHCARE



SUPPORTING BETTER OUTCOMES

There are opportunities throughout the caring experience to help caregivers to 'find the way'. By providing support to caregivers we can dramatically improve outcomes for all.



LOOKING AFTER

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“ 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 color. ”

Anil Patil, Carers Worldwide

Anil Patil told us that caregivers “are among us but we don’t have eyes to see them.” It’s time that we open our eyes.

Caregivers do incredible things for the people they look after. Their knowledge, skills and heart are the foundation of the healthcare industry. Yet we often ignore them. In doing so, we miss the chance to help them deliver care that can transform outcomes for patients, professionals and treatments. We let the opportunity to learn from their wealth of knowledge and experience slip through our fingers. And we fail to give them the recognition that they deserve; recognition that might help people like Leanne see their great value and worth.

There’s a lot to do to change this, but that shouldn’t be a deterrent. As Anil’s comment about ink in water so eloquently

demonstrates, it doesn’t take much to make a big difference. A connection to someone who’s been through the same experience can give a sense of belonging where there was isolation. A well-directed conversation in a consultation can build an empowering partnership between professional, patient and caregiver. And the right information at the right time can be the difference between feeling overwhelmed and feeling in control.

We need to respect and support a caregiver’s understanding the same way we would a professional’s.

And protect and care for their well-being as we would do a patient’s.

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