

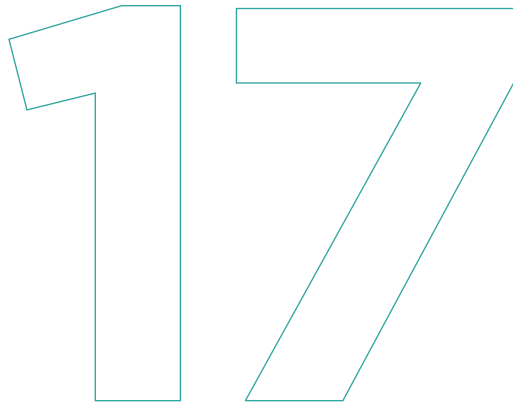
EDITION #17

## IN SEARCH OF THE INVISIBLE ARMY

—  
The caregivers' story

**invisible-army.com**  
#Caring4Carers

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## IN SEARCH OF THE INVISIBLE ARMY

—  
The caregivers' story



*" 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."*<sup>1</sup>

Barack Obama, Former US President

# INTRODUCING HEALTHCARE'S INVISIBLE ARMY



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

To pharmaceutical companies, they are the potential **catalysts** to therapy success and better clinical trial outcomes.

To doctors, they are the **experts-by-experience** turning treatment plans into reality and supporting trial patients through every step of their journey.

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

1 Office of the Press Secretary (2012) <http://bit.ly/2nBqOm7> (Accessed April 2017)

2 Carers UK (2015) <http://bit.ly/2ou7pfp> (Accessed April 2017)

3 Alzheimer's Disease International (2013) <http://bit.ly/2nPw6QK> (Accessed April 2017)

4 Buckner, Yeandle and Carers UK (2015) <http://bit.ly/1LbuEKI> (Accessed April 2017)

5 AARP (2011) <http://bit.ly/2o2D2fp> (Accessed April 2017)

Many of us will be a carer at some stage in our lives, three in five of us in fact.<sup>2</sup> The role can come about unexpectedly and many put their own lives on hold to help someone close to them.

## *3 in 5 of us will be carers<sup>2</sup>*

The value and importance of carers, 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 carer will reach 613 million by 2050.<sup>3</sup> In the UK, carers currently save the economy £132 billion per year, a value close to the UK's annual healthcare spending of £134 billion.<sup>4</sup> Similarly, the value of caring in the US is \$450 billion per year, which trumps the \$361 billion spent on the US social healthcare programme, Medicaid.<sup>5</sup>

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### *Carer*

*'Someone who provides unpaid care by looking after an ill, older or disabled family member, friend or partner. It could be a few hours a week or round the clock, in their own home or down the motorway.'*<sup>2</sup>

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*" Carers 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

- 5 AARP (2011)  
<http://bit.ly/2o2D2fp>  
(Accessed April 2017)
- 6 Cicolini *et al.* (2012)  
*J Adv Nurs.*  
**68**: 2410–7
- 7 Epstein-Lubow *et al.* (2014)  
*J Manag Care.*  
**20**: e349–444
- 8 Trivedi *et al.* (2012)  
*Ann Behav Med.*  
**44**: 66–72
- 9 [www.fixingdad.com](http://www.fixingdad.com)  
(Accessed April 2017)

Of course, it's not just about the money; carers 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, carers can have a positive impact on patient outcomes.<sup>6–8</sup> Patients showed improved adherence to dietary restrictions when supported by a carer and those with carers were more than five times as likely to complete a self-management programme.<sup>6,7</sup> Another study found that having a carer was associated with better adherence to medication and diminished smoking habits in COPD.<sup>8</sup> It is clear that carers are a vital force in the health and wellbeing of the people they care for and many could not manage without them.

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

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

**\$450 bn**

*Value of care provided by unpaid caregivers in the US<sup>5</sup>*

**\$361 bn**

*Value of Medicaid social healthcare programme spending in the US<sup>5</sup>*

*" Carers 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 DAD<sup>9</sup>



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 programme 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

## — Carers



**FLORIS**  
36, NETHERLANDS

Floris cares for his wife who has **multiple sclerosis** (MS). He doesn't see himself as a carer 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](http://www.platform.ms)



**JOHN**  
69, UK

John is a full-time carer 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 carer 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 carer 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 carers, Sue takes care of everything from personal care to physiotherapy. 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 physiotherapy sessions, continues her therapy at home, and helps with her personal care, all whilst working full time.



**SHAZIA**  
22, UK

Shazia has been a carer 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 carers visit the house to help her mother shower, dress, eat and drink.



**LINA**  
74, ITALY

Lina is a carer 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 carer 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 **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 carers.

**LEANNE**  
43, UK

Alongside being a mother to three daughters, Leanne has been a carer 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 carer 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 carers. 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, Carers Trust, and NHS England to create improvements in dementia care.

[@bethyb1886](#)



**ANIL PATIL,**  
CARERS WORLDWIDE

Anil Patil is the Founder and Executive Director of Carers Worldwide, a charity that operates in low- 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 Chief Executive Officer of Carers Trust, a charity that provides support to carers through 150 local charities around the UK. She has a wealth of knowledge in the area and is an active campaigner for carers' rights.

[@gailscottspicer](#)



*Do you feel loved Shazia?*

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

Carers spend a lot of their time focussed 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 carers we spoke to.

<sup>10</sup> Maslow (1954)  
*Motivation and  
personality*

#### PHYSIOLOGICAL NEEDS



Exploring the carer's basic wellbeing 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 carers with more intensive responsibilities reported significant effects on physical and mental wellbeing.*

#### SAFETY NEEDS



How safe and secure the carer 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 carer.

*'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 carers were lifted by it.*

#### ESTEEM NEEDS



Examining the carer'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-ACTUALISATION NEEDS



The carer's ambitions and whether caring has changed these.

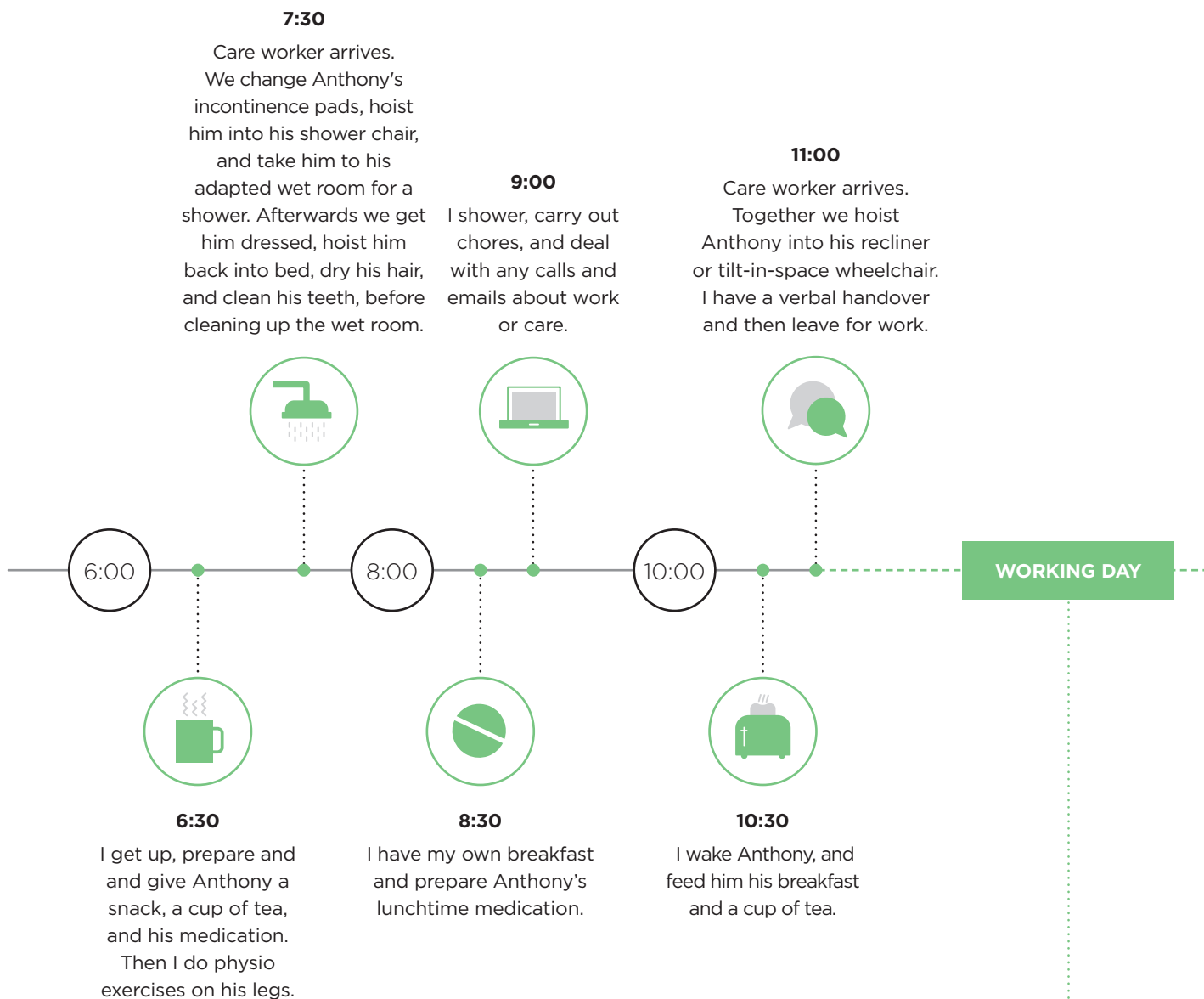
*'Do you feel like you're fulfilling your potential?'*

*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 fulfil. The hierarchy is often visualised 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-fulfilment).<sup>10</sup>

## A DAY IN THE LIFE OF SUE

It's not easy for carers to describe a typical day; appointments, the care recipient's wellbeing, 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.



**17:15**

I prepare and give Anthony his medication, then cook and feed him his supper.



**19:00**

I prepare and eat my own supper.



**22:00**

I check on my husband one last time, repositioning him if necessary, before going to bed.



18:00

20:00

22:00

24:00



**17:00**

I arrive home from work, and have a verbal handover from the care worker before they leave.

**18:30**

Care worker arrives to help me prepare Anthony for bed. We change his incontinence pads and his clothes, clean his teeth and wash him, before positioning him in bed.

**20:30**

I catch up on emails and household chores, checking Anthony several times throughout.

**23:00 – 6:30**

I have a monitor in my room so may get up several times in the night to give Anthony a drink of water, or reposition him as necessary.



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

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

- How quickly the carer is identified in their role and connected with information
  - [Finding Guidance](#)
- The relationships between the carer, the care recipient, and HCPs
  - [Finding Partners](#)
- The support the carer receives from those outside of the core care relationships
  - [Finding Strength in Others](#)
- The effect caring has on the carer's health and their mental wellbeing
  - [Finding Fitness](#)
- The carer'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 carers, was totally unprepared for what was to come. Identification is crucial for carers to start on the right path, whilst ongoing guidance can keep them headed in the right direction.

<sup>11</sup> Carers UK (2013) <http://bit.ly/2oug4OW> (Accessed April 2017)

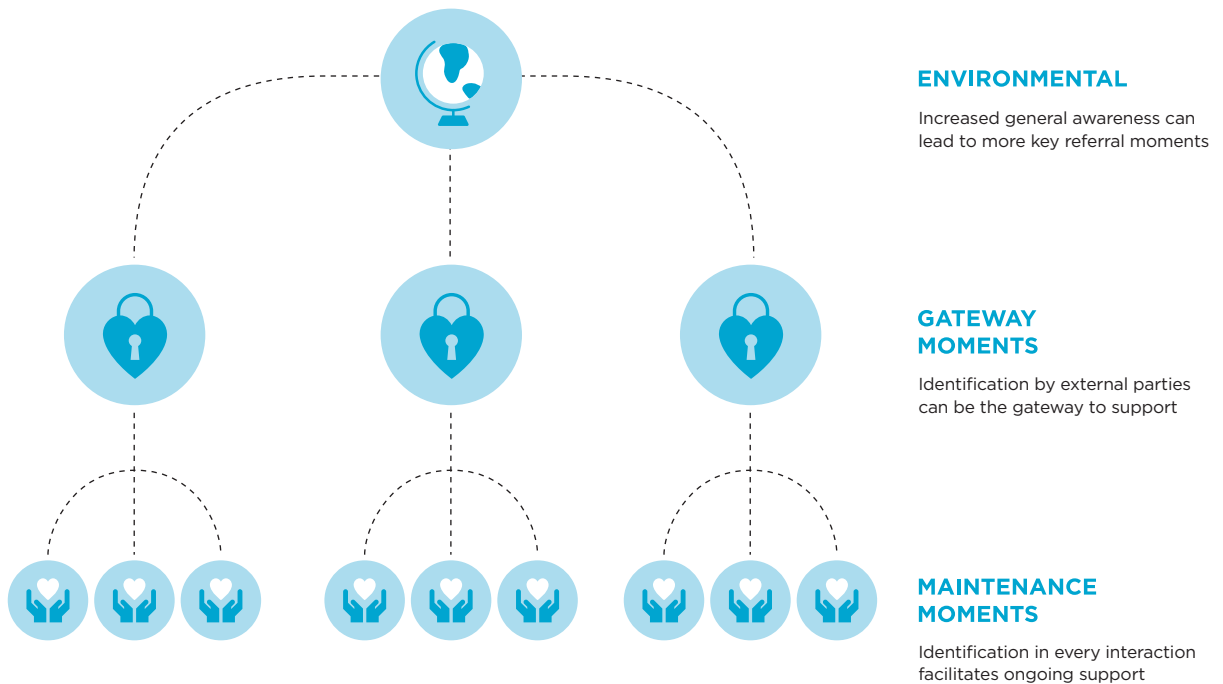
All but one of the carers we spoke to felt unprepared for their caring role and a survey of 2,100 carers found that 75% feel the same way.<sup>11</sup> Support workers and experts alike told us that this situation can be compounded by the fact carers don't always readily identify as carers, and remain 'hidden' from potential support. Indeed, whilst it's important for some to describe their role, others don't like the term 'carer', 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 wellbeing, 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 carers we spoke to struggled to have their role recognised by HCPs; even though HCPs are well placed to identify carers and direct them to sources of help and advice.

**75% of carers feel unprepared<sup>11</sup>**





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



### ENVIRONMENTAL

The first step to improve identification is to increase awareness of the carer role, to create a culture that allows carers 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 carers on the census.

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

### GATEWAY MOMENTS

Mechanisms need to be in place to help carers 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 carers. She talked about unknowingly taking on extra responsibilities as an extension of the family role.

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

— Becky

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

### MAINTENANCE MOMENTS

A 'gateway moment' does not necessarily equate to long-lasting resolution. Carers 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).

Recognising the situation they're in may be an important and difficult step for carers but identification alone isn't enough. All the carers 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

12 Given & Northouse (2011) *Clin J Oncol Nurs*. **15**: 451-2

13 Bruce *et al.* (2017) *Circ Cardiovasc Qual Outcomes*. **10**: e002879

14 National Alliance for Caregiving and Public Policy Institute (2015) <http://bit.ly/1QMscmM> (Accessed April 2017)

For identification to be effective it must be paired with information. Carers need to be informed to provide the best care they can. In a study involving carers 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.<sup>12</sup> As always, the audience needs to be taken into consideration when designing interventions. Our discussions with carers and support workers indicated that the type and timing of information was fundamental to its value.

#### VARIED NEEDS

Carers have a variety of information needs. At diagnosis, some of the carers 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 carer who understands the severity of the illness and options available improves outcomes for the care recipient.<sup>13</sup>

Carer 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, carers we spoke to reported needing information for countless other skills, such as financial management and navigating the healthcare system.

**57%** of carers assist in medical tasks, with only **14%** receiving training<sup>14</sup>



- 15 [www.carersuk.org/upfront](http://www.carersuk.org/upfront) (Accessed April 2017)
- 16 [www.discover4carers.eu](http://www.discover4carers.eu) (Accessed April 2017)
- 17 [www.apple.com/uk/news](http://www.apple.com/uk/news) (Accessed April 2017)
- 18 <http://www.carersinbeds.org.uk/how-we-can-help/hospital-lounges> (Accessed April 2017)

## CHANGING NEEDS

Circumstances can change and carers 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

Carers need to be signposted to information that's readily available. Like most of us, carers 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 carers' 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".

# 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 carers to support can be a lifeline.

Upfront<sup>15</sup> is an online tool created by Carers UK which aims to address the 'you don't know what you don't know' issue by asking carers a range of questions about their needs, and sending content in response to their answers.

DISCOVER<sup>16</sup> is an EU-funded pilot scheme that gathers information from different sources into one hub. Carers can rate and save content and it even offers training on searching for information.

Personalisation according to preferences is something that's commonly used in consumer products like Apple News,<sup>17</sup> 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 carers, updating them with new information or providing timely nudges when they need it most. Of course, not all carers will want to go online (John from the interview group expressed a particular disdain for the internet), and sometimes carers may prefer to talk directly to an advisor. Carer centres are a great source of information and support for carers. Embedding these services within a clinical setting can help identify and support carers at times when they may be vulnerable. In the UK, facilities such as the Carers Lounge in Bedford Hospital<sup>18</sup> have proved popular amongst carers.

# 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."

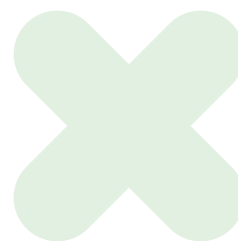
— Shazia, who cares for her mother

## 3. OUR RELATIONSHIP IS WORSE

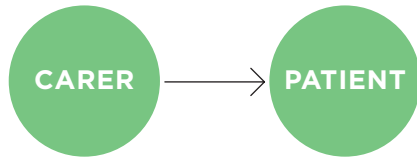
"I used to hate my brother and sister. I just really didn't tolerate them at all. My mum just used to wind me up."

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

Of course, such categorisation doesn't portray the full complexity of emotions and unique dynamics involved. Intervening positively around carer-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.



## MOTHER MODEL



Active 'giver' of care

Needs are second

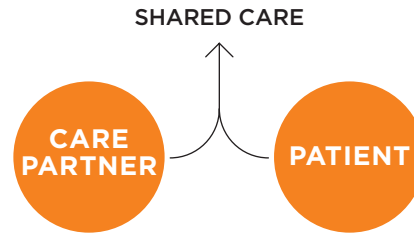
May feel  
solely responsible/  
burdened

Passive recipient

Needs are first

May feel  
unaware/  
disengaged

## PARTNER MODEL



Both active

Decisions made based  
on combined need

Shared responsibility

<sup>19</sup> Sebern & Riegel (2009) *Eur J Cardiovasc Nurs.* **8**: 97–104

<sup>20</sup> Luttik *et al.* (2005) *J Cardiovasc Nurs.* **20**: 162–9

<sup>21</sup> Frasure-Smith *et al.* (2000) *Circulation.* **101**: 1919–24

<sup>22</sup> Murberg (2004) *Int J Psychiatry Med.* **34**: 207–17

<sup>23</sup> Lewis *et al.* (2016) *BJPsych Bull.* **40**: 5–11

Another potential area for support is in how carers 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.<sup>19–22</sup> One of these studies speculates that this is because supportive relationships can drive a ‘shared care’ or partnership approach<sup>19</sup> (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 PROGRAMME (MAP)



Developed by Janssen and Havas Lynx, MAP supported those who have schizophrenia and their carers 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 carers the means to support them. In clinical studies, MAP was shown to reduce the number of hospital admissions by 58%.<sup>23</sup>

## CASE STUDY

### THE IMPORTANCE OF DEFINITIONS: KATE SWAFFER AND THE BACK-UP BRAIN<sup>24</sup>



Even the language used to define a caring relationship is important, for both patient and carer. Kate Swaffer is an author, activist and academic. She also has dementia. She and her husband Peter don't like the term 'carer'. 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 carer and care recipient.





# FINDING PARTNERS

— *Partnering with HCPs*

*"Over time I think they have come to respect me as a carer but it has taken them quite a while to realise that carers have needs as well."*

Sue, talking about her experiences with HCPs

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

<sup>24</sup> Swaffer K. (2015) What the hell happened to my brain?

<sup>25</sup> Svetlini et al. (2015) *J Psychiatr Ment Health Nurs.* **22**: 472-83

<sup>26</sup> Pitschel-Walz et al. (2001) *Schizophr Bull.* **27**: 73-92

Some carers 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 carers' 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 doctors are an extended family for us."  
— Aparna

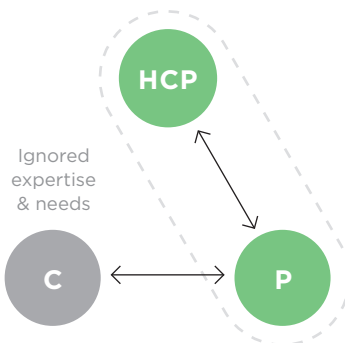
Not all carers felt this way. Some complained that HCPs did not involve them in care discussions, or that HCPs were oblivious to the strain they were under.

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

**92% of carers** believe family support has greater benefit in promoting treatment adherence than a positive HCP-patient relationship<sup>25</sup>

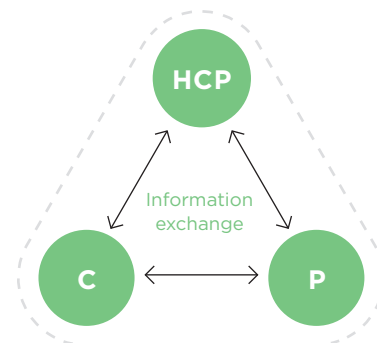
Relapse rates can be **reduced by 20%** if relatives of people with schizophrenia are included in treatment<sup>26</sup>

## PATIENT FOCUS



HCP makes decisions based only on interaction with patient, without an awareness of carer'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 carer to support where needed.

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

28 Alzheimer's  
Association  
(2001) <http://bit.ly/2oudecv>  
(Accessed  
April 2017)

In some cases, relationships with HCPs had significantly deteriorated. Leanne no longer saw HCPs as useful allies. She talked negatively about doctors, 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 carers reported negative experiences of communication with HCPs.<sup>27</sup> In addition, physicians tend to believe they provide more information to carers than carers believe they receive.<sup>28</sup> All evidence points to the need to support better relationships between HCPs and carers.

*“ With very rare conditions, sometimes the carer 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, carers offer “a huge source of evidence” according to Emily Holzhausen. The amount of time carers 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, carers are ideally placed to be a huge influence on the care recipients. David Blair, Head of Industry for Health at Google, emphasises 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 carers (who are present for these ‘moments that matter’) HCPs might be able to better steer patients towards better outcomes.





## 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.<sup>29</sup> The movement grew out of Kate's frustration when the doctor 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 organisations that support the initiative.

<sup>29</sup> [www.healthcare-heroes.com](http://www.healthcare-heroes.com) (Accessed April 2017)

<sup>30</sup> Given BA, Given CW & Kozachik (2001) *CA Cancer J Clin.* **51**: 213–31

<sup>31</sup> [www.patientsknowbest.com](http://www.patientsknowbest.com) (Accessed April 2017)

<sup>32</sup> [www.jointlyapp.com](http://www.jointlyapp.com) (Accessed April 2017)

<sup>33</sup> Mitnick, Leffler & Hood (2010) *J Gen Intern Med.* **25**: 255–260

This relationship might also create opportunities to identify carers 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 carers' drive to take charge of their situation and improve their understanding is valuable, but unguided they may be exposed to misinformation that could be detrimental to their wellbeing. By creating an environment in which all parties feel comfortable to talk openly, HCPs can address any false reports and ensure carers are equipped with the knowledge they need to best support positive patient outcomes. In addition, HCPs are well positioned to assess how carers are coping and to connect them with additional support. Whilst the patient is the HCP's priority, taking the time to refer carers to support groups, training, and community and social services, can help sustain successful caregiving situations that can benefit all.<sup>30</sup>

Patient confidentiality is paramount, but frameworks and interventions need to be in place to support a healthy partnership between carers, HCPs, and patients. Communication is at the heart of this and it doesn't need to take much effort. Anil Patil suggests that carers 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 Best<sup>31</sup> 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 carers, the Jointly<sup>32</sup> app helps those who share caring roles to coordinate care and update each other on things like medication. Combining such concepts could boost HCP-carer-patient communication.

Professional societies have also released ethical guidance to heighten HCP awareness of the importance and complexity of the patient-HCP-carer relationship.<sup>33</sup> The guidance hopes to maximise the benefits of the relationships and minimise the burden on carers. Anil Patil told us that the HCPs he worked with responded very well to the training on supporting carers. 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 carers' 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 carers, Leanne's care responsibilities have isolated her. The circle of relationships around a carer can be hugely important, and the support of other carers can be a lifeline.

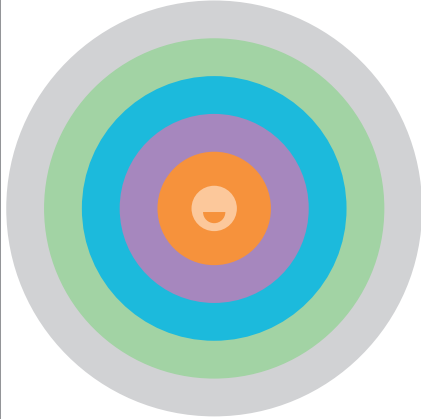
<sup>34</sup> Carers UK (2015) <http://bit.ly/15nqBgO> (Accessed April 2017)

All of the carers 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. Surveys indicate that 57% of carers have lost touch with friends and family as a result of caring.<sup>34</sup> 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.

*8 in 10 carers have felt lonely or isolated due to caring<sup>34</sup>*

## FLORIS

*Loved & supported*



Understanding family

Good partnership with HCPs

Sees friends regularly

Supportive colleagues/employer

Online support of carers

## MARTHA

*Lonely & isolated*



Family uninvolved

Little to no support from HCPs

No social life

Had to give up work

No contact with other carers

## THE IMPORTANCE OF UNDERSTANDING

A sense of being understood was hugely important to carers, 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 carer would want (and all the more reason why they might remain hidden from support).

For some of the carers we spoke to, the greatest sense of empathy and understanding came in conversation with those who knew exactly what they were going through – other carers. 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 carer 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 carers 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 carers. There's also a range of online forums available (run by organisations like Carers Trust, or Carers UK). Still, it seems there's much that can be done to improve the universality of, and access to, these types of services.





<sup>35</sup> [www.babble.carers.org](http://www.babble.carers.org)  
(Accessed April 2017)

<sup>36</sup> [www.matter.carers.org](http://www.matter.carers.org)  
(Accessed April 2017)

## EMPATHY AND EXPERTISE

In helping carers connect with each other, it's important to be aware that they have different needs and expectations of support from peers. Some of the carers we spoke to preferred to connect with carers who'd had similar experiences (e.g. of the same condition) – further emphasising 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. Babble<sup>35</sup> and Matter<sup>36</sup>, for example, are moderated online networks built specifically for young carers and young adult carers to have a place to share experiences. The sense of solidarity and emotional support from other carers 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 carers have, who better to help solve a carer's problems than someone who has already been through it all?



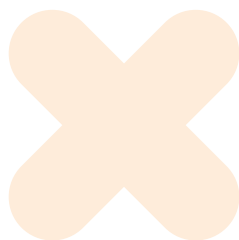
*"I felt quite isolated, as if it was just me and there was no-one else. And I couldn't really talk to my friends because they didn't understand. But then when I went to the [carers'] groups I was able to speak and I knew that I wasn't the only one."*

Becky

<sup>37</sup> Chou, Liu & Chu (2002) *Int J Ment Health Nurs.* **39**: 713-22

<sup>38</sup> [www.patient-innovation.com](http://www.patient-innovation.com) (Accessed April 2017)

<sup>39</sup> [www.openideo.com](http://www.openideo.com) (Accessed April 2017)



*A study found that carers' depression was statistically reduced after participating in a support group<sup>37</sup>*

## CASE STUDY

### MAKING BETTER TOGETHER



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

- Patient-Innovation.com allows carers and patients alike to share, rate and comment on solutions to day-to-day issues<sup>38</sup>
- OpenIDEO.com is a community that brings people from around the world together to solve challenges for social good<sup>39</sup>

## 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 carers to their limits, physically and mentally, and lead them to neglect their own wellbeing. Long term, this can have detrimental consequences for them and the people they look after.

<sup>40</sup> Office for National Statistics, National Records of Scotland, Northern Ireland Statistics and Research Agency. (2017) <http://bit.ly/2nBhqDH> (Accessed April 2017)

<sup>41</sup> Schulz & Sherwood (2008) *Am J Nurs.* **108**: 23-27

<sup>42</sup> Smith & Christakis (2008) *Annu. Rev. Sociol.* **34**: 405-29

<sup>43</sup> The Princess Royal Trust for Carers (2004) <http://bit.ly/2nThQrw> (Accessed April 2017)

A lack of rest was universally reported amongst the carers 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 hospitalised.

More than half the carers 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.<sup>40</sup> 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.<sup>41</sup>

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 carers' 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 carer's wellbeing is pushed beyond its limits, can be damaging for all. As might be expected, studies have indicated a link between declining health in carers and poor health in the care recipient.<sup>42</sup>

**61% feel 'physically drained'**<sup>43</sup>





**Over half**  
*suffer physical  
injuries relating  
to caring*<sup>43</sup>

**40% encounter**  
*significant  
psychological  
distress*<sup>44</sup>

**Over half**  
*are exercising  
less as a result  
of caring*<sup>45</sup>

<sup>44</sup> NHS (2008)  
<http://bit.ly/2nPowFq>  
(Accessed  
April 2017)

<sup>45</sup> Carers UK (2016):  
<http://bit.ly/1XdluXf>  
(Accessed  
April 2017)

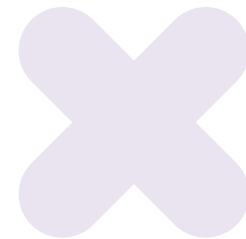
<sup>46</sup> Gogia & Rastogi  
(2009) *Clinical  
Alzheimer  
Rehabilitation*. p. 197

Where carers did ‘find fitness’, it was a boost for their wellbeing; 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 wellbeing 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 carers. 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 carers 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 carers better understand what to do; connect carers to peers so that they feel less isolated.



***“ About 80%  
suffer from  
a stress-related  
illness because of  
some of the strains  
of caring. ”***

Emily Holzhausen OBE,  
Carers UK

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### *Carer burnout*

*Becky’s responses indicated she may have suffered carer burnout – a state of physical, emotional, and mental exhaustion that can cause a change in attitude, from positive and caring to negative and unconcerned.*<sup>46</sup>

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## 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 carers 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.

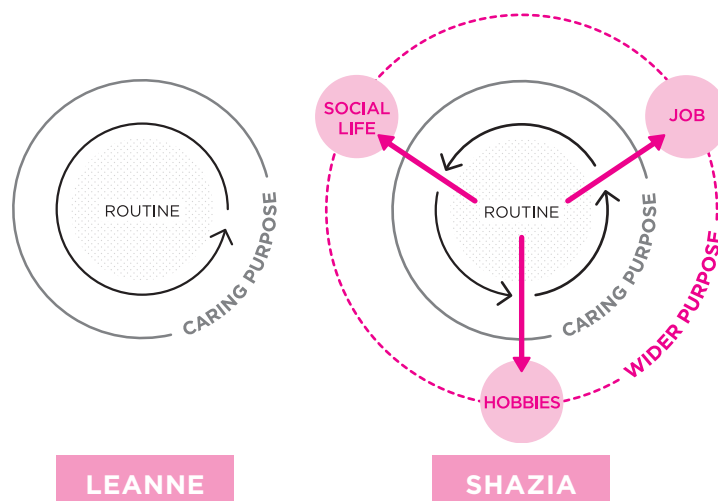
<sup>41</sup> Schulz & Sherwood (2008) *Am J Nurs.* **108**: 23-27

<sup>47</sup> [www.cqc.org.uk](http://www.cqc.org.uk) (Accessed April 2017)

Studies show that caregiving can boost carers' self-esteem by making them feel needed, giving meaning to their lives, and enabling them to learn new skills.<sup>41</sup> Most of the carers 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.





Despite carers 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 scumbag."

— 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.

Carers 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 carers often seek opportunities to help other carers, but many of the interview group reported highly transferable skill sets. Carers 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 carer support website (see Finding Guidance) features a CV builder, whilst mechanisms similar to the endorsement feature on LinkedIn could help carers to convey their skills.

### EXPERTS BY EXPERIENCE

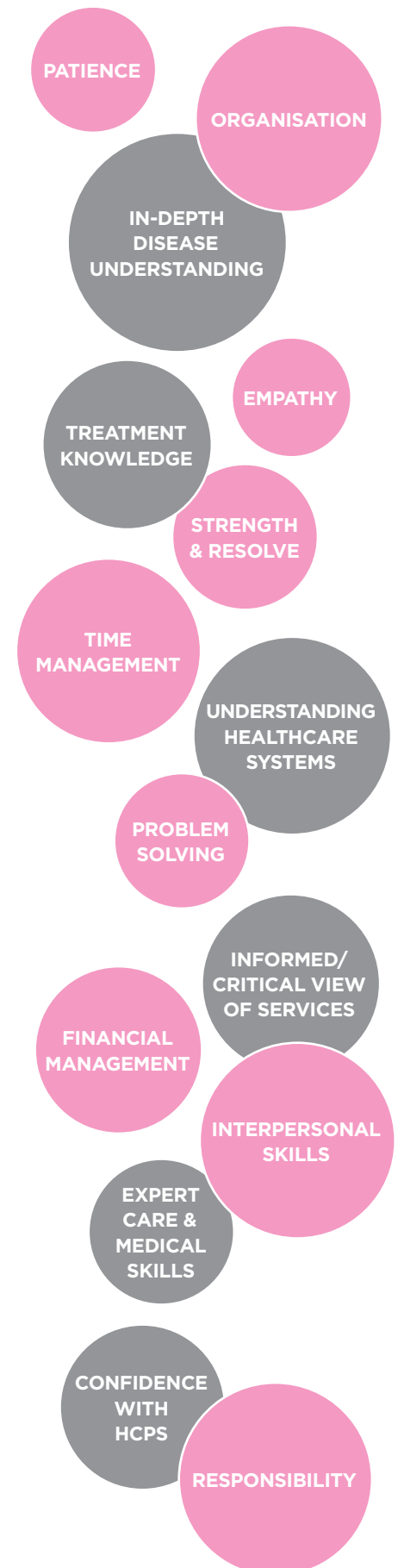
As well as helping HCPs better understand the patients in front of them (see Finding Partners), carers' wealth of insight and drive to help others could benefit healthcare as a whole. Campaigner Beth Britton's experience of caring for her father has led her to do incredible things for dementia care and carer rights, including consulting with the NHS and Care Quality Commission (CQC).<sup>47</sup> In fact, the CQC welcomes carers to apply to their 'Expert by Experience' roles, where they can use their first-hand experience to shape better services for patients.

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

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

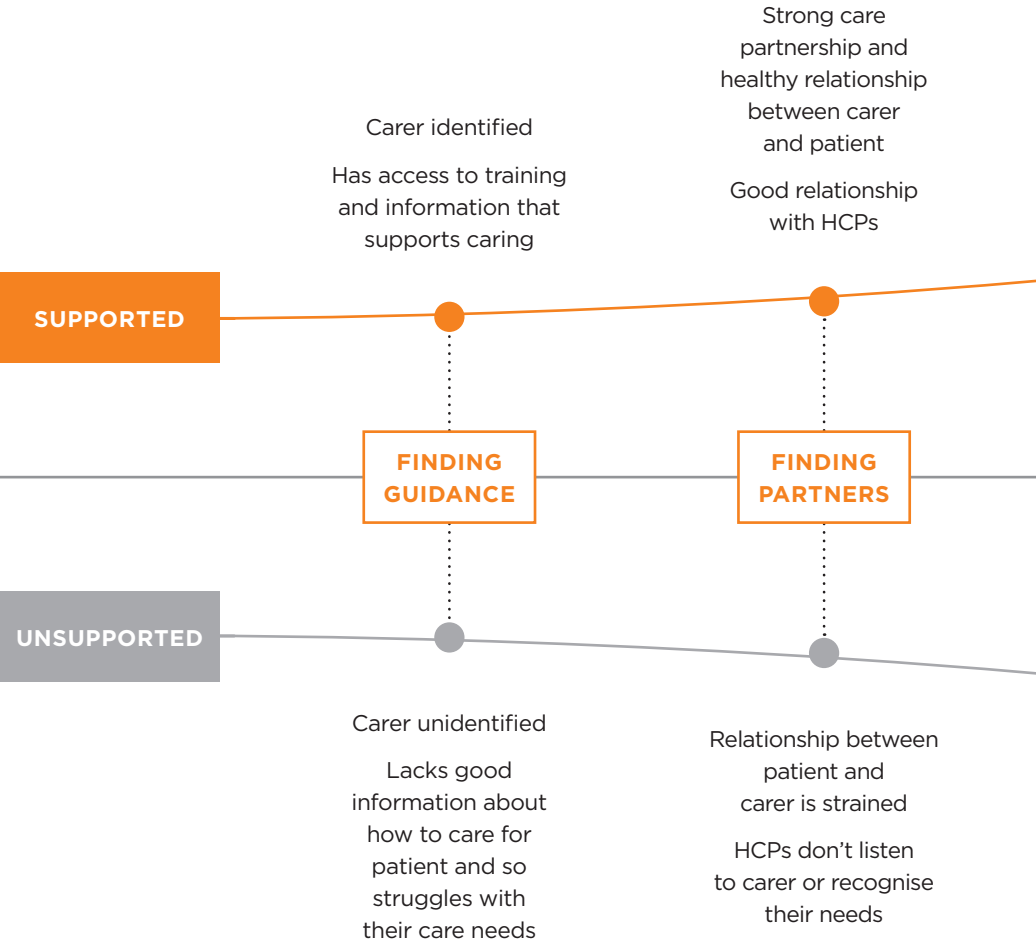
### SKILLS AND ABILITIES THE INTERVIEW GROUP GAINED THROUGH CARING

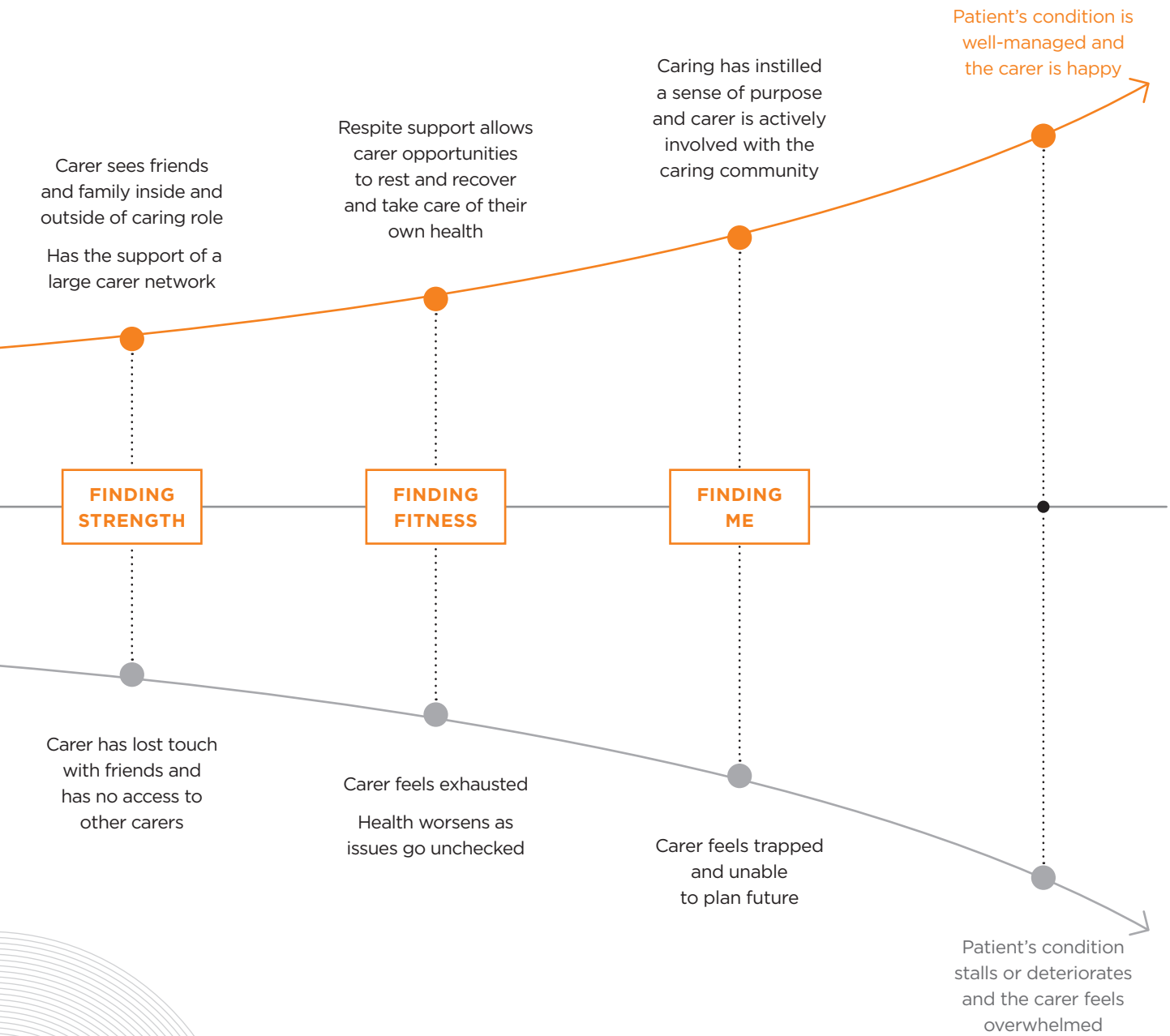
- TRANSFERABLE
- HEALTHCARE



# SUPPORTING BETTER OUTCOMES

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





# LOOKING AFTER

ONE  
AND  
OTHER

*" 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. "*

Anil Patil, Carers Worldwide

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

Carers 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 carer. 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 carer’s understanding the same way we would a professional’s.**

**And protect and care for their wellbeing as we would do a patient’s.**

Havas Lynx  
**faze**

## CARER HACKATHON

If you recognise the incredible value of carers, if you understand the huge impact they have on patients’ lives, if you see their influence on better outcomes, then we want to hear from you. We want to partner with a pharma client on a Carer Hackathon.

---

An opportunity to create effective solutions that will support and assist carers to improve outcomes.

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For more information please contact [mark.evans@havasfaze.com](mailto:mark.evans@havasfaze.com)

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