



# 6

## **Briefing paper**

### Supporting carers

Author: Emily Holzhausen – Carers UK



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### Key messages:

- 1.4 million people in the UK provide over 50 hours of care per week. Although the vast majority of people caring are of working age, the fastest growing group of carers are those over the age of 65 growing at a rate of 35% in just 10 years.
- Identification of carers by healthcare professionals in all settings and across all disciplines remains a priority so that interventions and better tailored responses can be put in place.
- There should be a focus on developing a 'carer friendly health service', whereby carers are identified, provided with adequate information and advice, and their expertise listened to and respected. Carers should also be supported to look after their own health, as well as that of the person they are caring for.

This briefing intended to explore ways of ensuring carers are properly supported, with a focus on those caring for older people, and older people who have caring responsibilities.

## An introduction to the topic and overview of the issue

In the UK today, there are a staggering 6.5 million people providing a level of unpaid care to a relative, close friend or neighbour.<sup>1</sup> The replacement value of carers' support is worth a staggering £132 billion a year, equivalent to a second NHS.<sup>2</sup> Most people will provide care at some point in their lives. 58% of carers are women, 42% men but this relationship is reversed in the over- 85 age cohort, men are more likely than women to be caring (59% to 41%).<sup>3</sup> Women are significantly more likely to provide substantial care ie over 20 hours by the time they are 59, ie in the peak of their careers. Men have the same likelihood by the time they are 74.<sup>4</sup>

Although the largest group of carers are providing just a few hours of care per week, the numbers providing over 50 hours of care per week and more are rising faster than simple population increases. 1.4 million people provide over 50 hours of care per week, a rise of 11% in only 10 years.<sup>5</sup> Although the vast majority of people caring are of working age, the fastest growing group of carers, are the 1.3 million over the age of 65 growing at a rate of 35% in just 10 years<sup>6</sup>, outstripping the rate of population growth. It is estimated that by 2030, the number of older carers will rise to 1.8 million.<sup>7</sup>

Caring is as diverse as the UK population. Earlier 2011 Census results showed a relatively younger BAME (Black, Asian and minority ethnic) carers who were slightly less likely to be caring, but population data shows that the 600,000 BAME carers are set to grow in future as longer established BAME populations age.<sup>8</sup> Although more evidence and experience is emerging about LGBT (lesbian, gay, bisexual and transgender) carers, there is less collected evidence and documented experience. Carers UK's best estimates are that there are around 390,000 people who are LGBT carers.<sup>9</sup> One in 20 (5%) of staff in the social care profession have witnessed poorer treatment or discrimination for a patient or service user because they were LGBT.<sup>10</sup>

*"Having contacts from my community to discuss with people who understand LGBT issues is vital – whether its early onset dementia or mental health/ anxiety. Its so very important to know that other people understand."*

Importantly for the medical profession, research has shown that every year, roughly one-third of the carers cohort is replaced, meaning that 2.3 million people start caring, and 2.3 million stop caring either because the person they care for has died, or recovered.<sup>11</sup>

The largest cohort of carers, by far, are the 4 million people of working age, around 3 million of whom juggle work and care.<sup>12</sup> Some have younger families as well as caring for parents or partners, sometimes referred to as the "sandwich generation" – 2.4 million people are

currently in this situation. Although the studies show they tend to provide fewer hours of care, the stress and strain on the individual is likely to be higher.

### Evidence

42% of carers providing over 50 hours per week said they haven't received any training for their caring role, or information to keep them well.<sup>13</sup>

The amount of care that someone provides varies considerably. From a few hours of care a week from shopping, collecting medication and taking someone to medical appointments to caring around the clock performing nursing care, full time advocate and financial and administrative management. Of the total population of carers, 82% provide practical help such as preparing meals, doing the laundry or shopping, 49% help with financial matters, 47% help deal with care services and 38% help with aspects of personal care.<sup>14</sup>

*In an effort to understand and explain their complex lives, some carers have mapped contact with professionals. One carer said, "as a management exercise I mapped out every professional that we had contact with in relation to my wife's MS. The result was 32 professionals, some of whom we see regularly. That's a huge amount to keep track of and interact with. What I find difficult is having to repeat information to each professional. I need care to be better co-ordinated so that I can keep working for as long as possible to keep the roof over our head for my wife, my kids and myself. We all need things to work better".*

In terms of health issues, the Census 2011 suggests that those providing over 50 hours of care per week are twice as likely to be in bad health compared with non-carers.<sup>15</sup> The GP Patient Survey showed that whilst 51% of non-carers had a long standing health condition, this rose to 63% of all carers and 70% of those caring for 50 hours or more. The survey also highlighted higher incidences of arthritis, high blood pressure, long term back problems, diabetes, mobility problems, anxiety and depression.<sup>16</sup> Carers' own experiences suggest that long term back problems and mobility problems are caused by long term physical stress, moving and handling without the right equipment or training. Anxiety and depression rates are high, with Carers UK's survey of carers providing significant care – 77% recording anxiety and 83% recording depression since becoming a carer.<sup>17</sup>

For those juggling work and care, carers are more likely to be suffering from ill-health and stress in the workplace. Many experience a dip in income, especially if they have to give up work to care and this results in higher levels of stress and depression associated with money worries alongside caring.

### Carers experience of services

Carers have a mixed experience of services and this is common across the UK. We asked carers whether they felt prepared for caring in a survey and most said they were not prepared for caring.

*"No-one trained to do this role. I never expected to do what I'm doing now, but there is no-one else to help me. I just have to get on with it."*

42% of carers providing over 50 hours per week said they haven't received any training for their caring role, or information to keep them well.<sup>18</sup> In Carers UK's survey, carers' experiences of health services are rated better than care services. 34% reported very positive experiences of hospitals and surgeries, 16% reported negative experiences and 42% said their experiences were mixed.

*"I have an excellent relationship with all the professionals involved in my husband's care, and the specialist nurse in particular has empowered me to learn about and manage his condition myself, so I rarely resort (touch wood) to any emergency services."*

Those most likely to experience good health services are those caring for a partner or a spouse. Those reporting worst experiences of health services tend to be those caring at a distance.<sup>19</sup> These carers' experiences have a bearing on how carers are identified within the NHS, how knowledge and information is shared and how families and close friends are prepared for caring. It also has a bearing on exploring confidentiality needing more explanation, permissions to be explored and good recording.

### Identification of carers

Identifying carers is not always straightforward. Decades of research has shown that people do not identify themselves as carers and many people do not use the term. It does not always translate well into different languages where the word, concept and culture do not read across. People see themselves as mothers, sons, close friends, fathers, nieces and brothers first, and as carers second. Carers tend to put themselves second and often say that they become "invisible" as the person who does the caring, at times not being consulted, involved, or valued. However, when the opposite occurs, which is what they want, carers' lives can be transformed:

*"My doctor is brilliant. He always takes the time to ask me how I am, how I am coping. And it makes such a difference".*

### Discussion of evidence

Caring is something that most people do, but which most people are not prepared or trained for, and which can have a devastating impact on carer's lives in terms of work, health, income, family and other relationships. With the different stages of caring meaning that someone can move from knowing very little about a condition to becoming an expert over time, doctors and medical professionals have to be able to adapt information and knowledge so that it supports carers to do the role they want – supporting and improving outcomes for the patient, too. One woman caring for her husband with dementia said,

*"It never occurred to me that the way his brain was working with dementia was not just about forgetting things, but it affected the way he thought about things too, meaning he could not do simple tasks like make a cup of tea. Now that I understand that, we both get on better. He is much calmer and doesn't fly into rages and I don't get quite so depressed and tired all the time. All in all, we're much better off. A little bit of knowledge goes a long way."*

Most people who are caring also know the wishes and preferences of those being cared for, which is valuable in delivering more person-centred care for the patient.

The evidence also points to extra challenges for those who have multiple caring roles or conditions that span different areas and disciplines. For example, a parent of a severely disabled child who has learning difficulties, challenging behaviour and physical disabilities has to act as an advocate for her child, the parent also has her own health conditions which are a result of caring, her mental health is poor, she also has an increasingly frail parent. The difficulty of modelling an NHS on a patient by patient basis is that the whole caring situation cannot be examined in the round. This parent often talks about how laws and services are organised around specialisms and segments which complicate her life further. Many carers say that they need their whole needs and lives considered, not just one segment.

One particular area that comes up time and again with carers is the issue of confidentiality and this is particularly key for those caring for people with mental illness. Maintaining confidentiality is key, but good practice has also shown when clear consent and sharing of details can be explored, it can improve health, well-being and outcomes for all – patient and carer.

One particular challenge in measuring the efficacy of different interventions for carers' health and well-being are the inter-dependencies between different services and support mechanisms. Some services, however, have very clear outcomes. Herts Valley CCG has set up a scheme to improve the identification of carers and this is its biggest referral to the local voluntary sector: Carers in Herts. Of those who were registered, 52% of carers took up the

offer of flu jabs and 85% see the benefits of being registered with GPs in terms of their health, well-being and ability to manage. In developing a Carer Friendly Hospital, Lister reduced severe stroke re-admissions due to carer breakdown from 10 to zero, gaining 142 bed days as a result of improving carers' knowledge of stroke, and providing basic support at home. Until this initiative, around one quarter of readmissions were due to the fact that the carer could not cope/carers breakdown.<sup>20</sup>

### Suggestions for solutions

- **Identification of carers still remains a top priority:** Identifying carers by doctors in all settings and across all disciplines remains a priority so that interventions and better tailored responses can be put in place. The new CCG guidance in England states that carers should be identified and supported. In Scotland, legislation has been in place for over a decade which requires health organisations to have plans in place to identify carers and similar legislation existed in Wales until recently until it was replaced by the new Health and Social Services Act. In Northern Ireland, following Carers Week 2016, there is renewed interest in carers issues around health and well-being from the NI Assembly and Ministers. Patient records have read codes that allow for the identification of carers.
- **Community based solutions matter:** As awareness campaigns demonstrate, whole community responses to disability and long term conditions and caring can make a difference, whether it is understanding mental illness better, dementia friendly communities or carer friendly communities. Carers UK's recent research for Carers Week found that when carers found their local communities carer friendly, they were between two and three times more likely to be able to maintain their own health and well-being.<sup>21</sup>
- **Balancing prevention with alleviating key pressure points:** The challenge for health services is to get the balance right between these two areas. With prevention, a ground-breaking study by Professor Zarit shows improved cortisol levels for carers of people with dementia when they received a break compared with those who did not get a regular break reducing a number of health risks and ability to manage<sup>22</sup>. Consultations with carers show breaks and support that provides a break are invaluable. Key pressure points for carers are hospital discharge back into the community and responses in an emergency - preventing an A&E admission, or quick admission into residential care that is avoidable.
- **Supporting carers starts at home:** One in nine workers juggles work and caring for a relative or close friend, unpaid, and this likelihood rises for women and those aged 45 and over. The NHS 5 Year Forward View rightly suggests that employers within the NHS at all levels need to support workers who are juggling work and care. NHS England is a member of Carers UK's Employers for Carers forum that supports businesses who are supporting their employees who are carers.<sup>23</sup>
- **Electronic patient records – an opportunity for carers and health professionals alike?** Electronic patient records offer the opportunity to speed up and integrate. Providing patients with access to their own medical record can allow them to share information with carers as needed, and carers' lives can be made easier by enabling online ordering of repeat prescription and appointment bookings. Patients and carers can be saved from having to repeat the same information many times by enabling systems to share electronic patient records held by the GP with other relevant health and social care professionals. The benefits of information sharing between professionals between primary and secondary care and within specific teams could be beneficial, particularly for complex cases that might involve out of hours services, A&E, or a variety of consultants. The evidence from Carers UK so far shows that carer awareness of their own online patient records remains fairly low, but is increasing. Whilst some remain sceptical about the benefits, others are keenly embracing the technology.<sup>24</sup>
- **Carers' passports in hospitals** are schemes being developed in Trusts as a means of identifying carers, as well as improving information and advice to them and additional support to the person cared for. The results show savings on the bottom line for health services. During a pilot at the Central Manchester University Hospitals NHS Foundation Trust, which trialled open visiting as part of a Carer Passport, nearly two-thirds (59%)

of staff felt it had improved communication between staff, patients and their relatives. There was also a change for carers and patients. Prior to the pilot only 23.5% thought staff were available to discuss care and treatment and this rose to 100% at the end of the pilot. The pilot also saw a reduction in the number of falls compared to the same time a year previous which the Ward Manager felt open visiting contributed to.<sup>25</sup>

- **The power of NHS Choices and good Googling:** All advice and information services are seeing a change in the way that people are now consuming information – queries are becoming more tailored and specific. How people consume information about conditions and how to manage them is also changing and an opportunity to increase self-care with managed information and support.
- **Tech-enabled care and tech solutions:** With the rise of apps and online management applications being used increasingly in mental health, tackling other long term conditions, everyday tech monitoring basic health, to specialist telehealthcare, tech is changing the way that we manage care individually and potentially how we organise care. Carers UK has stepped into this sphere with its care-coordination app – *Jointly* - based on carers experiences of having to coordinate many different people in order to deliver care, it creates care circles, assigning tasks and syncs with diaries. With the advent of social prescribing and the new tech tariff in the NHS, a new opportunity to look for different tech solutions for carers is now possible.
- **Boosting and recognising skills:** In some areas, carers are invited to different training programmes, improving health and well-being. Other training and structured learning programmes have been developed, many of which are on-line or with supported discussions. Carers UK, for example, has launched a new e-learning programme aimed at helping carers learn about good nutrition for someone with a long term condition.
- **Understanding caring:** For every doctor from every profession, understanding caring is becoming increasingly important. When medical interventions are shifting to a greater input and element of self-care and self-management, in many instances this will require and will have the input of a carer. Understanding caring also means understanding how caring can impact on a carer's own health and well-being and their ability to manage this. Relevant training needs to remain up to date as well as core training for all junior doctors, mainstreaming caring as an important element.
- **The power of experience:** A mixture of good experiences which are empowering and poor experience which demonstrate the need for change – both have the power to invigorate services and support.

**Actions doctors can take:**

- a) Understanding the caring role, from first diagnosis new to caring through to expert carer.
- b) Understanding the two sides to caring: i) the need to be able to manage caring better and get the right support and ii) the ability of a carer to manage their own health and well-being.
- c) Giving carers choices about caring ie it's not always possible to care and it's important not to make assumptions about whether someone can care or not.
- d) Giving advice/information and training, making sure families and friends care well, safely, etc knowing what is involved.
- e) Respecting feedback from carers.
- f) Looking at a wide range of support mechanisms eg social prescribing including apps, looking at telecare/telehealth solutions to help support carers.
- g) Linking carers into other services – doctors are not experts on the welfare system, but links to organisations and communities who are is invaluable – which is true of both consultants and GPs. This could happen at diagnosis, key treatment times, etc.
- h) Looking at staff internally – who are also juggling work and caring. They could be the theatre nurse, the receptionist, the porter, the practice manager, the finance officer, all parts of the team might be experiencing exactly the same issues as any carer of a patient being treated. With trained, skilled and knowledgeable staff at a premium, retention of staff is critical and supporting staff who are juggling work and care becomes a higher priority. Some organisations find it can also transform services, making them more carer friendly.
- i) Leadership matters and clinicians leading by example makes a difference to the whole team. Anecdotally, some of the highest performing GP surgeries in terms of carers are those GPs who lead by example.

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