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White paper: Empowering the carer within health and social care

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I would like to thank CEO Helena Herklots and her team at Carers UK for their time, contribution and valuable insight that helped inform this paper. Carers UK is a charity set up to help the millions of people who look after an older, disabled or seriously ill family member or friends, who want society to respect, value and support carers and who believe that no one should have to care alone.

Executive summary

Connectivity between the pharmaceutical industry and patients is typically regarded as being moderated by prescribers (doctors) and payers (managers) – those essential decision-makers with the appropriate knowledge of clinical- and cost-effectiveness to determine the course of prescription medical intervention for the patient. However, a third group of individuals play an absolutely pivotal role in this healthcare ecosystem and are frequently overlooked – the carers. There are well over 6 million carers in the United Kingdom, who provide essential support to the people they care for (and their families) with regards to their health, social needs and psychological wellbeing.

Without carers fulfilling their important duties, all other stakeholders stand to lose out. The people they care for will lack the daily support that strained healthcare providers and social care systems struggle to provide, which can lead to unrecognised new comorbidities, failure to identify treatment side effects or non-adherence to treatment schedules. This can cause an economic impact on the healthcare system, as acute incidents increase, and also negatively impacts the pharmaceutical industry, as medicines are not used appropriately.

As such, it is in the interests of pharmaceutical companies and all other healthcare stakeholders, especially patients, for the industry to take a more prominent role in supporting the needs of carers. Through provision of information and advice, facilitating their engagement with other healthcare stakeholders and directly providing services to support them, pharmaceutical companies can deliver beneficial outcomes for all sides – the industry, healthcare providers / payers, patients and, of course, the carers themselves.

This white paper outlines some of the issues faced by carers, reviews the type of support they themselves need and presents a blueprint for how the pharmaceutical industry can take a lead on addressing these issues, with the view to creating further dialogue, engagement and ultimately, practical solutions.

The United Kingdom's National Health Service (NHS) has been very much in the spotlight in recent years, with an increasingly elderly population stretching recession-strapped government budgets to the limit. As the NHS celebrated its 65th birthday this year, much of the attention has focussed on structural reform of services in England and questions around how the provision of 'free' national health services can continue within a system facing severe budgetary challenges, especially as the Quality, Innovation, Productivity and Prevention (QIPP) initiative asks for the service to provide more with less across both health and social care.

Cost-effectiveness has therefore become the mantra of the NHS, with the type of budgetary decision-making traditionally assigned to the National Institute for Health and Care Excellence (NICE) being driven down to individual GP level by the creation of new consortia with their own spending responsibility, combined with the local authorities holding their own public health budgets. For the new system to succeed there is an urgent need to balance management of short-term costs while also delivering a more personalised level of care that can drive longer term improved outcomes, and consequent savings to the healthcare system.

A key success factor for achieving these aims is to ensure medical services can be delivered, wherever possible, outside the confines of hospitals that are overstretched and under-resourced. This language is reflected in a number of official publications, including the UK Government's Mandate to the new NHS Commissioning Board, drafted by the Health Secretary Jeremy Hunt, which contains the following quote in paragraph two under section six – '*Freeing the NHS to innovate*' – that states:

*"The Board's **objective** is to get the best health outcomes for patients by strengthening the local autonomy of clinical commissioning groups, health and wellbeing boards, and local providers of services."*¹

The NHS England's business plan to 2016, entitled '*Putting Patients First*', reinforces this in no uncertain terms; a message which is also exemplified in its manifesto document '*The NHS belongs to the people: a call to action*', endorsed by several high profile figures including the Chief Executive of NHS England, David Nicholson, and the head of NICE, Andrew Dillon, which supportively states:

"Patients with multiple long-term conditions must be managed differently. A hospital-centred delivery system made sense for the diseases of the 20th century, but today patients could be providing much more of their own care, facilitated by technology, and supported by a range of professionals including clinicians, dieticians, pharmacists and lifestyle coaches."^{2,3}

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A number of core messages therefore resonate around what the NHS must deliver to survive as a 21st century institution, including:

- moving treatment decision-making closer to the individual patient;
- delivering more personalised care for improved outcomes by designing services around the patient;
- moving budget planning decision-making closer to the patient, to reinforce more personalised cost- as well as clinical-effectiveness decisions;
- improving patient communication about, and into, every treatment decision – “*no decision about me, without me*”; and critically,
- taking care out of the hospital and back into the community, wherever possible.

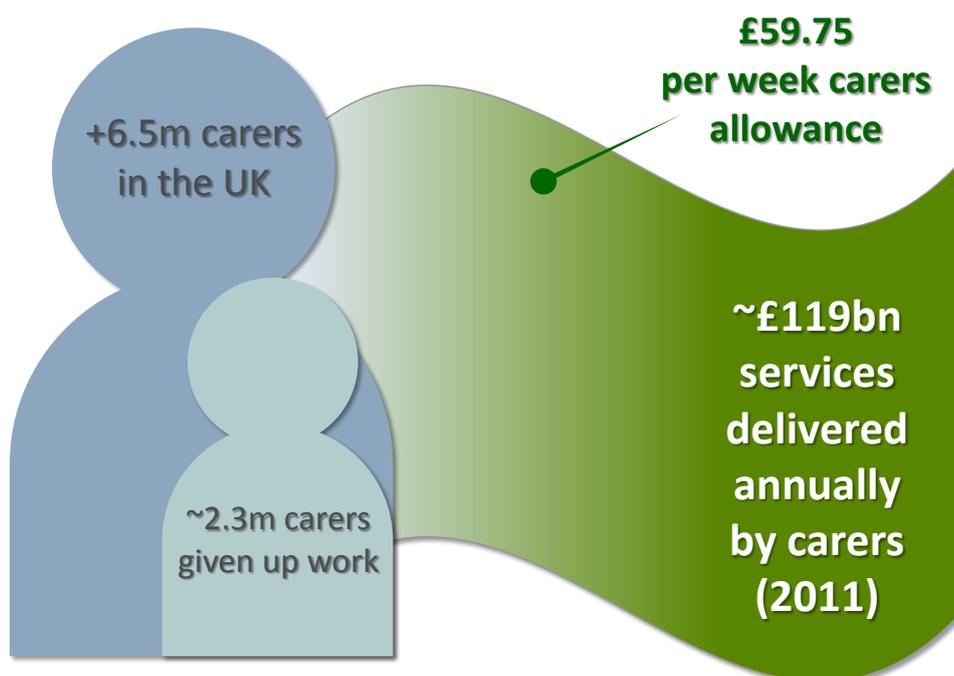
However, to achieve the objective of a more effective, community based NHS, one group of individuals is absolutely vital and all too absent from these statements – the carer.

A carer is defined as someone who “*provides unpaid care by looking after an ill, frail, or disabled family member, friend or partner*” by Carers UK, a national organisation representing carers. Carers UK also analysed 2011 census data to show there were over 6 million such individuals within England, Wales and Northern Ireland, with an estimated 500,000+ in Scotland.⁴ Cumulatively, over 6.5 million people – over 10% of the total population – are therefore acting as carers, with the number rising rapidly as the population ages.

Typically carers, whether family members or friends, are extremely close to the person they care for. Carers have intimate knowledge of their ailments (physical and psychological), response to, and compliance with, treatment intervention and associated needs beyond medicines. If decision-making tailored to the patient is the key to treatment success and managing healthcare costs, then a new NHS mantra of ‘no decision about me, without me and my carer’ could easily be adopted.

As the figure below shows, a study jointly conducted by Carers UK and the University of Leeds in 2011 calculated that carers delivered services worth an estimated £119 billion per year to patients, which is approximately the same as the total NHS budget.⁵ These services include, but are not limited to, managing the patient’s affairs, coming out of hospital and planning for emergencies.

Number of carers and health budget impact



Yet despite the significant number of carers delivering extremely valuable patient support, the level of systematic support they themselves receive is minimal. For an NHS that desperately needs more efficient community-based patient care and a pharmaceutical industry that recognises the value of moving 'beyond the pill' there are clear and unequivocal arguments for understanding the needs of carers and investing in greater levels of support for them.

Challenges for carers and opportunities for support

Carers UK regularly polls the opinion of carers to understand the challenges they face. Its most recent survey of 3,000 individuals from 2013 demonstrates the scale of the problems carers will encounter in their journey.⁵ Broadly speaking, the personal impact of being a carer can be divided into three main categories: financial, health and social.

Financial

The direct financial impact of being a carer, in addition to the indirect financial impact caused by associated disruption to employment is significant. A YouGov poll commissioned by Carers UK suggested that 2.3 million adults have had to give up work to care for someone, with over half doing so consequently being out of work for more than 5 years.^{6,7} Even where employment can be maintained, carers are having to work extra hard to cope with the demands on their time, with 65% using annual leave to care and 47% doing overtime to account for time off as a result of their caring duties.⁶

Financial support is available to carers, in the form of the carer's allowance, but the £59.75 per week on offer rarely covers the additional costs incurred by carers, and there are strict stipulations around who can receive this. For example, claimants must be caring for at least 35 hours per week, not be in full-time education and below pension age. In the context of over one-third of carers struggling to pay utility bills, a fifth being around £10,000 to £15,000 per annum worse off from caring, and 44% falling into debt as a result of doing so, the allowance seems modest, at best.⁶

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Health

The combined emotional and financial hardship endured by carers inevitably has an impact on their own health. A staggering 83% of carers stated that caring had a negative impact on them physically, with an ever higher proportion of 87% claiming an associated impact on their mental health.⁸

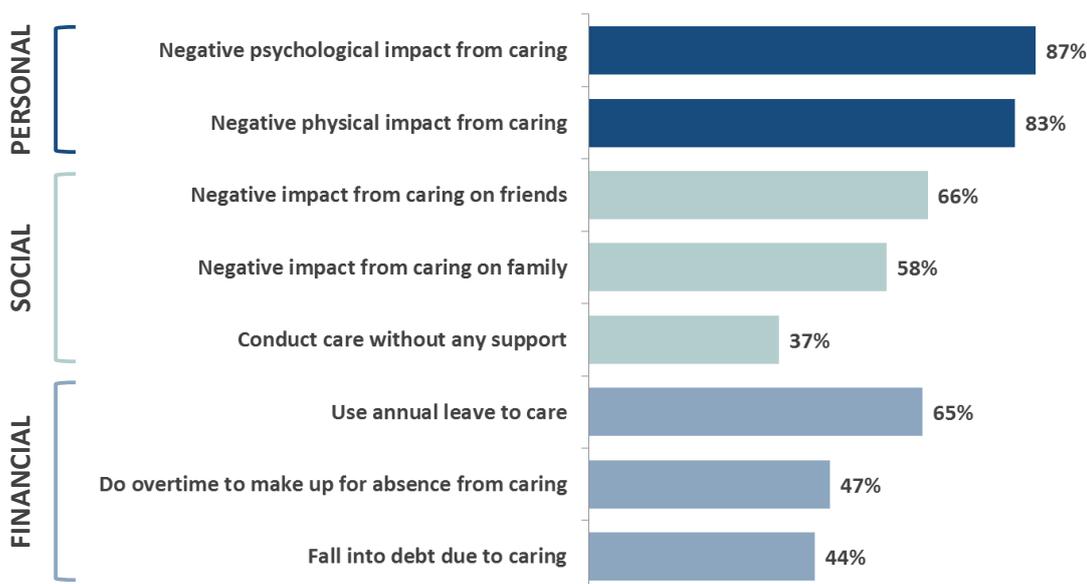
The problem here is twofold. Firstly, the lack of support currently provided to carers can exacerbate the emotional and physical hardship they endure, whilst the demands of caring on their time mean they are unlikely to monitor their own health appropriately, or find time to visit the doctor when a problem arises. As one carer we spoke to succinctly put it, "a lot of carers are so busy caring that they don't think about themselves; the last thing they've got the energy for is to go to their GP".

Social

In the same way that patients have a significant impact on the lives of their carers, the demands of being a carer also have a significant impact on the families and friends of the carers. Being a carer can be a lonely job, with 37% of carers reporting they did so without any support at all from friends, family or external services. In addition, two-thirds reported a negative impact from caring on their friendships, with 58% reporting a similar impact on their family.⁴

In speaking with a carer to produce this white paper, their story clearly illustrated the severe impact that caring had on their family. In order to care for a parent, they had to relocate half way round the world and endure a sustained period of living apart from their partner, who finally retired to support in the caring activities, alongside one of their children.

Statistics on the personal, social and financial impact of caring



The strain this process put on the family group was clear from this moving story; as they relayed the point where their partner stated that “*I didn’t sign up to this when I got married*”.

But are the wheels in motion to provide increased support to carers in the future?

To some extent, yes, both in terms of education and legislation around improved support. But progress is slow. The current focus is on the new Care Bill, which at the time of writing is progressing through the House of Lords.⁹ The important aspect of this Bill is that whereas carers currently need to request an assessment from Social Services in terms of the support they require, the new legislation puts the emphasis on the Social Services to conduct such assessment proactively and provide concomitant support as a result.

Whilst the Care Bill has been welcomed by a number of organisations, there are some concerns around how stringent the criteria for provision of services will be. “*The Government will draw up eligibility criteria for the level of need that would trigger service support, and the real risk is that this is set at a very tight level, so you might end up with a situation where lots of carers will get an assessment, but not get anything at the end of it*”, observed the CEO of Carers UK, Helena Herklots.

Even if the Care Bill can drive more social support for carers, there is a disconnect between this and the health services side of the equation, with carers seemingly too often a forgotten force with regards to health policy. Carers describe how support for them is often described as being ‘implicit’ when health bodies talk about patients, but it needs to go beyond that into ‘explicit’ to have an impact. Here, the Carers Measure in Wales (which is subject to change) is an interesting model to watch, as it places a duty on the NHS and local Welsh authorities to jointly deliver information and guidance for carers, plus involve them in future decisions about carer support.¹⁰

However, as powerful as legislation can be in driving change, it is important to remember that it is not all about providing financial or service support. As the carer we spoke to eloquently noted, “*sometimes, all that carers need is someone to ask ‘how are you coping?’. I get concerned that all you hear in the media is about carers wanting [financial] benefits, but that’s not always the case*”. This emotive element is reinforced by Helena Herklots, who describes how “*carers often feel quite invisible, ignored and not really understood... people don’t necessarily understand or appreciate what carers are doing, so the issue of recognition is a key one*”.

Stepping back it is clear that investment in supporting carers would not only yield benefit for the carers, but also for the broader healthcare system within which they reside – and commercial organisations that operate within that system, such as pharmaceutical companies.

You have to ask how do we actually make sure that we can hear the voice of as many carers as possible?

Broadly speaking, the support required can be broken down into three core areas: information and advice, facilitating engagement, and direct support services.

Information and advice

Carers, like patients, can sometimes lack the knowledge of healthcare systems, specific treatments and financial planning that are inherent components of any medical training programme familiar to doctors. Simply understanding the best support routes, benefits and appropriate health and social care interventions open to carers seems to inherently depend on how proactive in offering advice the people are with whom the carer comes into contact are.

As the carer we interviewed stated, *“You do have to go out there and find information and advice; it doesn’t necessarily come to you – possibly not all carers are like me in that they would go out and find the right information”*.

But imagine if carers were provided with upfront and proactive support on where to obtain suitable information and support. Not only would the financial and emotional burden on the carer be reduced from the start (with consequent benefits for their own health), but the patient with whom they are caring for would also benefit from such advice. Imagine also if such advice also included guidance on the medicines the patient was taking, how they should be taking them, what to watch out for in terms of non-adherence or side effects, and who to approach where a problem was identified.

Facilitating engagement

The idealistic notion of ‘no decision about me, without me’ that the NHS champions with regards to patients can also run into the same challenge as involving carers more closely in decision-making – namely, making it easy for them to get involved. In the same way that forcing patients to go to hospital is not always the most efficient way to administer treatment, forcing carers to attend physical locations for support and feedback can prove challenging.

As one carer noted, with regards to consultations offered by their local authority on the role of carers, *“there were not many carers that attended those consultations. So if you genuinely want to hear from carers and influence policy that will benefit everyone, the patients as well as the carer, you have to ask how do we actually make sure that we can hear the voice of as many carers as possible?”*.

Access to support, information or medical advice can all now be administered remotely, if the right systems are in place. This is something recognised by NHS England in its call to action:

“The digital revolution can give patients control over their own care. Patients should have the same level of access, information and control over their healthcare matters as they do in the rest of their lives. The NHS must learn from the way online services help people to take control over other important parts of their lives, whether financial or social, such as online banking or travel services.”³

So if there is a push to provide this for patients, then why not for carers also?

Support services

We have already highlighted the need for a more proactive approach to assessing the support required by carers (a matter which is in discussion within the Care Bill) and the fact that emotional support is just as important as other services. However, the realm of ‘beyond the pill’ services which is such a focus for patients at the moment has been relatively unexplored when it comes to carers.

For example, joint working is currently a hot topic. Essentially, it is where the NHS and pharmaceutical companies

work together in a collaborative way to address specific healthcare challenges. Such collaborative support services can yield financial benefits for both the local healthcare systems and pharmaceutical companies, all whilst improving care for the patient. But how many of these initiatives actively incorporate the carer in their design?

And it is not just about healthcare or pharma companies. Carers UK has shown that such support services can go much broader than that, by running its 'Employers For Carers' forum, which educates organisations around recognising carers who work for them and providing appropriate support. *"It has about 70 companies in it ranging from BT, to Sainsbury's to the Department for Work and Pensions and others. We work with them to have in place the right policies and practices to support working carers"*, elaborates Helena Herklots.

A blueprint for pharma providing better support for carers



A blueprint for more carer-centric healthcare systems

It would be beyond the boundaries of this white paper to deliver a perfect blueprint for how carers should be better integrated into the health and social care system, but we can make some initial observations that will hopefully trigger further discussion. Based on our situation analysis, there is scope for improved carer support from healthcare providers, associations and the pharmaceutical industry, with the latter having the potential to play a pivotal role. Fundamental to this is the recognition that, like patients, carers will go on a journey that begins with caring for a loved one and while some only care for a limited period of time, many ultimately end with their death or relocation into permanent care. As they progress along that pathway, the needs of the carer will adapt and evolve. So too, must the support available for them.

Healthcare providers

It has already been alluded to that support for carers from trained medical professionals, such as doctors and nurses, is variable. This is through no fault of their own – they are traditionally trained in medical practice relating to patients; not the broader empathic approach that is required to recognise and support carers. While investment in such training would certainly be beneficial to carers, an interesting role emerges for the pharmacist here, who often has greatest contact with the carer.

“The role of pharmacy is important, as pharmacists are recognising where a carer is coming in to pick up the medication and being really proactive about seeing if they need advice”, Helena Herklots explains. It is an observation echoed by the carer we spoke with, who added *“pharmacists usually have a bit more time than GPs to give you that information and support”*.

Associations

Organisations such as Carers UK are playing a vital role in driving awareness, support and appropriate legislative change for carers. However, such bodies are dwarfed in number by patient, disease and industry associations, for whom carers tend to form a secondary consideration after the patient, rather like the NHS. This is not to suggest their focus should be diverted from the patient, but instead that the carer should be given a more active voice in such organisations, as with the NHS, to drive this agenda of more community-outsourced care that can deliver both for patients and the healthcare systems.

The pharmaceutical industry

The pharmaceutical industry has already demonstrated a strong track record of bringing its commercial experience to bear on potentially challenging areas such as disease awareness, via joint working and / or digital campaigns and addressing adherence. It could therefore play a vital role in delivering a new model of carer support, which benefits the carers themselves, the patients they support and healthcare systems, whilst also achieving its own commercial objectives.

Bearing in mind the opportunities for healthcare providers and associations outlined above, such support could cover all three core areas of need.

- **Information and advice:** Having identified the crucial role of pharmacists in connecting with carers, provision of information and advice could be focused around the pharmacy. In simple terms, this could mean disease information leaflets being distributed through these channels, but could develop into medicine specific plain-English information for the carer, or broader training for pharmacists on providing carers with exactly what they need. The downstream benefit of earlier diagnosis, more appropriate medication and improved adherence could benefit all parties.

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- **Facilitating engagement:** As mentioned above, the pharmaceutical industry has already shown it can facilitate engagement between healthcare providers and patients, patients and physicians and, in some cases, patients to other patients, through joint working and connective digital campaigns. Such skills could be well translated to bringing carers together (there are numerous patient forums, but how many for carers?) or helping to orchestrate alignment across carer, disease and patient associations for mutual benefit.
- **Support services:** As the pharmaceutical industry moves ‘beyond the pill’ much of its attention has focused on the core areas of earlier diagnosis, whether for common or specialised ailments, or in initiatives designed to specifically challenge difficult areas such as medicines adherence. Carers would also benefit from such initiatives, especially in disease areas where the patient is often impacted sufficiently that they cannot be relied upon to monitor their own disease, or administer medication, properly.

Whilst these areas represent some specific activities that pharma could invest in, they are just the tip of the iceberg when you consider the multitude of ways in which the industry could get involved. In addition, to reflect on the earlier points around recognition, one should not underestimate the beneficial impact that emotional support facilitated by pharmaceutical companies to carers could deliver on all sides. The *quid pro quo* here could be useful advice imparted back to the industry about real-world outcomes or even trial design for new treatments – the notion of a carer advisory board.

Their role should be valued more by healthcare providers, associations and the pharmaceutical industry, with associated investment in supporting them.

The benefits of supporting carers

Carers are an absolutely vital, and under recognised, component of the healthcare system. While firmly appreciated by patients, their role should be valued more by healthcare providers, associations and the pharmaceutical industry, with associated investment in supporting them.

The benefits of doing so include:

- Improved standard of care for patients.
- More cost-effective treatment.
- Reduced stress and burden for carers.
- Better understanding of the patient journey.

In today's world of connected healthcare, it is important to focus on all relevant stakeholders to address the key challenges in fighting disease. The renewed vigour with which the pharmaceutical industry is being patient-centric is a positive progression, but with the carer being so close to the patient, this important group of individuals cannot be ignored. Recognising the needs of the carer, and empowering them, will yield benefits for patients, healthcare providers, the pharmaceutical industry and, of course, the carer themselves.

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Boehringer Ingelheim

Boehringer Ingelheim was founded in 1885 and is a family owned company. We are the largest privately owned pharmaceutical company.

Our vision, 'Value through Innovation', reflects our belief that, as well as being financially profitable, products should be pioneering and of genuine benefit to patients. Our independent status frees us from stock market expectations, and allows for long-term strategies, rather than short-term priorities.

We believe that we share one fundamental principle with the NHS: we both put patients at the heart of what we do.



Hannah has worked at Boehringer Ingelheim since 2011 in government affairs and patient engagement. Hannah currently Co-Chairs the ABPI Patient And Pharma Working Group and is a Trustee of a UK health charity in her spare time.

Prior to working at Boehringer she worked at Marie Curie Cancer Care as their Public Affairs Manager and

previous to this in the creative industries.

As well as Hannah's professional insights into the UK Health and Social Care System, Hannah's passion and concern for this subject derives from her experience as a patient where her mother was her full time carer.

Hannah's current work at Boehringer is to understand and work with patients, families and carers so Boehringer can create the best information, products and services with them and for them and look beyond the traditional Pharma model to new innovations and solutions.

To discuss the issues raised in this white paper, Hannah can be contacted by emailing Hannah.Gagen@boehringer-ingelheim.com or calling +44 (0)1344 746860.

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