

**NHS  
England's  
Commitment  
to Carers**



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# **NHS England's Commitment to Carers**

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## Foreword

Carers are a hugely important asset to the NHS. However, too often carers do not receive the recognition and support that they need and deserve from the NHS. We need to do more to help identify, support and recognise their vital roles. Helping carers to provide better care and to stay well themselves will contribute to better lives for those needing care and more effective use of NHS resources.

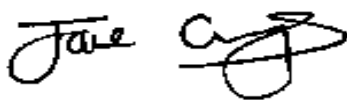
This document sets out a series of commitments to carers. It reflects what NHS England has heard from carers over the past three months during a number of engagement events. Whilst the commitments have been well-received by carers organisations, we are clear that this document, and the commitments within, simply represent the start of a journey and a step in the right direction. We will keep listening and refining our commitments. Ultimately, we want to improve the quality of life for carers and the people for whom they care by supporting what carers have told us is important to them:

- “Recognise me as a carer” (this may not always be as ‘carers’ but simply as parents, children, partners, friends and members of our local communities);
- “Information is shared with me and other professionals”;
- “Signpost information for me and help link professionals together”;
- “Care is flexible and is available when it suits me and the person for whom I care”;
- “Recognise that I may need help both in my caring role and in maintaining my own health and well-being”;
- “Respect, involve and treat me as an expert in care”; and
- “Treat me with dignity and compassion<sup>1</sup>”.

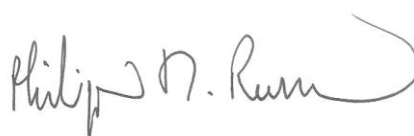
We are committed to continue this collaboration and highly value the contribution that so many people have made to the development of this document.



Sir Bruce Keogh  
Medical Director



Jane Cummings  
Chief Nursing Officer



Dame Philippa Russell DBE  
Chair Standing Commission on  
Carers

## **1.0 Introduction to carers**

A carer is anybody who looks after a family member, partner or friend who needs help because of their illness, frailty or disability. All the care they give is unpaid.

Many carers don't see themselves as carers. It takes carers an average of two years to acknowledge their role as a carer<sup>2</sup>. It can be difficult for carers to see their caring role as separate from the relationship they have with the person for whom they care, whether that relationship is as a parent, a son or daughter, or a friend.

It's likely that every one of us will have caring responsibilities at some time in our lives with the challenges faced by carers taking many forms. Many carers juggle their caring responsibilities with work, study and other family commitments. Some, in particular younger carers, are not known to be carers. They don't tell relatives, friends or health and care professionals about their responsibilities because of fear of separation, guilt, pride or other reasons.

This means that the sort of roles and responsibilities that carers have to provide varies hugely. They can range from help with everyday tasks such as getting out of bed and personal care such as bathing, to emotional support such as helping someone cope with the symptoms of a mental illness.

The Department of Health's mandate to NHS England includes ensuring that the NHS becomes dramatically better at involving carers as well as patients in care. NHS England has held a number of participation exercises with carers and this document sets out how it will support the NHS to deliver what carers have said is important to them.

## 2.0 Carers: Key facts

- There are around 5.4 million people in England who provide unpaid care for a friend or family member<sup>3</sup>.
- Between 2001 and 2011, the number of unpaid carers has grown by 600,000 with the largest increase being in the unpaid care category, fifty or more hours per week<sup>4</sup>. This equates to 1.4 million people providing fifty or more hours of unpaid care per week<sup>5</sup>.
- Unpaid care has increased at a faster pace than population growth between 2001 and 2011<sup>6</sup> and an ageing population and improved life expectancy for people with long term conditions or complex disabilities means more high level care provided for longer.
- Increasing hours of care results in the general health of carers deteriorating incrementally. Unpaid carers who provide high levels of care for sick, or disabled relatives and friends, are more than twice as likely to suffer from poor health compared to people without caring responsibilities, with nearly 21% of carers providing over 50 hours of care, in poor health compared to nearly 11% of the non-carer population<sup>7</sup>.
- Caring responsibilities can have an adverse impact on the physical and mental health, education and employment potential of those who care, which can result in significantly poorer health and quality of life outcomes. These in turn can affect a carer's effectiveness and lead to the admission of the cared for person to hospital or residential care<sup>8</sup>.
- 84% of carers surveyed for the 2013 State of Caring Survey said that caring has had a negative impact on their health, up from 74% in 2011-12<sup>9</sup>.
- Carers attribute their health risk to a lack of support, with 64% citing a lack of practical support<sup>10</sup>.
- Carers make a major contribution to society. Estimates show that the care provided by friends and family members to ill, frail or disabled relatives is equivalent to £119 billion every year<sup>11</sup>.
- 70% of carers come into contact with health professionals yet health professionals only identify one in ten carers with GPs, more specifically, only identifying 7%<sup>12</sup>.
- 66% of carers feel that healthcare staff don't help to signpost them to relevant information or support, and when information is given, it comes from charities and support groups<sup>13</sup>.

### 3.0 NHS England's responsibility to carers

NHS England has a number of responsibilities towards carers that have been outlined in the Department of Health's mandate to NHS England; the NHS Outcomes Framework and within NHS England's Business Plan and Planning Guidance. One notable objective in the mandate and business plan is *'to ensure that the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment'*<sup>14</sup>. In addition, the NHS Outcomes Framework (2014/15) incorporates an indicator that seeks to measure the health related quality of life for carers<sup>15</sup>.

In reply to these responsibilities, NHS England is publishing this commitment to carers document. The first step in developing this document was through a participation exercise undertaken by NHS Improving Quality (IQ), with carers' organisations, carers themselves and other key partners. This included an online engagement process, webinar and culminated with a 'Commitment to Carers' event held on the 5<sup>th</sup> December 2013.

The aim of the participation exercise and event was to:

- Understand the health service responsibilities towards carers as described in the mandate and the carers strategy refresh by the DH in 2010: *Recognised, Valued and Supported: next steps for the carers strategy*;
- Recognise and value the voice of carers of all ages;
- Determine the role of the healthcare system to support the needs and aspirations of carers;
- Identify specific barriers, processes and interventions that prevent optimum levels of care and support being offered to carers;
- Reach a consensus on the next steps to improve carer experience and support; and
- Develop a clear set of commitments for action to take forward by NHS England.

The event demonstrated a wealth of passion, enthusiasm and will to work together to improve the care and support for carers. The event included highlighting emerging themes (Section 4.0) and priorities (Section 5.0) for NHS England to build on in order to recognise and value carers both in terms of personal experience and supporting continuous improvement in the quality of care<sup>16</sup>.

A report has been published by NHS IQ: *'Commitment to Carers: Reports and Findings'*<sup>17</sup> that captures the findings and outcomes of the engagement exercise and this document should be seen as NHS England's response to this report as well as a contribution to the updated action plan of the Government's national carers strategy which will be published shortly.



## 4.0 Emerging themes

The engagement process highlighted a number of themes that NHS England have worked through to establish a set of commitments. The themes, which are in line with feedback received through similar listening exercises that have previously been held by other organisation such as the Carers Trust and Carers UK, are as follows:

- Recognise me as a carer (this may not always be as ‘carers’ but simply as parents, children, partners, friends and members of our local communities);
- Information is shared with me and other professionals;
- Signpost information for me and help link professionals together;
- Care is flexible and is available when it suits me and the person I care for;
- Recognise that I also may need help both in my caring role and in maintaining my own health and well-being;
- Respect, involve and treat me as an expert in care; and
- Treat me with dignity and compassion<sup>18</sup>.

Due regard to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited in under the Equality Act 2010) and those who do not share it, has been given throughout the development of the commitments set out in this document.

## **5.0 What NHS England will do: Priorities**

Based on the emerging themes NHS England has developed 37 commitments around the following eight priorities, which are within NHS England's gift to deliver and move forward:

1. Raising the profile of carers;
2. Education, training and information;
3. Service development;
4. Person-centred, well-coordinated care;
5. Primary care;
6. Commissioning support;
7. Partnership links; and
8. NHS England as an employer.

Commitment	Timescale
1. NHS England to raise the profile of what a carer does and how they can be supported with health care staff.	Ongoing
2. NHS England signed up and supports and promotes annual Carers Week campaign.	Ongoing
3. Establish a NHS England board level 'Carer Champion' and support NHS England board level members to shadow a carer.	Sep 2014
4. A senior NHS England Carers Group to take ownership of the 'Commitment to Carers' document and NHS England's support for carers.	Ongoing
5. Collaborate with carers' organisations to establish how carers award schemes might be extended to commissioners to support improving the experience of carers across England.	Dec 2014
6. NHS England in partnership with NHS IQ to hold a national NHS Young Carers event to support how young carers can be better supported and the wellbeing of young carers promoted by the NHS.	Oct 2014
7. NHS England to support a Carers Champions Network bringing together the healthcare and carers groups.	Ongoing
8. NHS England will continue to implement the Equality Delivery System for the NHS, involving staff, patients, carers and the community to ensure equality is embedded within all of its core business including workforce development.	Ongoing
9. NHS England is committed to supporting innovation in the NHS and will ensure that innovative ways of engaging with and providing care for carers are considered through the national innovation fund schemes.	Ongoing

<b>Commitment</b>	<b>Timescale</b>
10. NHS England to support the relevant bodies, including Health Education England, to support the use of packages for health care staff that increase carers awareness, and support staff to identify, involve and recognise carers as experts, and as individuals with their own needs, choices and aspirations.	March 2015
11. NHS England to support the relevant bodies in signposting carers to information and advice about support available.	March 2015
12. NHS England to contribute to increasing the awareness within the NHS of the duties and functions of local authorities with regards to carers.	April 2015
13. NHS England and NHS IQ to liaise with carers organisations and the Royal College of General Practitioners (RCGP) in order to support their work on identification, implementation and sharing of best practice models.	April 2015

<b>Commitment</b>	<b>Timescale</b>
14. NHS England to investigate approaches to measure the skills, confidence and knowledge of carers and potential benefits on care and carers.	March 2015
15. Data sharing: As part of the Patient Online programme, NHS England to scope the potential for carers to access the GP medical records of the patients they care for, where applicable, and the patient has given their consent.	June 2014
16. NHS England's new ambitions for End of Life Care, to be published in June 2014, will include the intentions for support for carers and bereaved relatives.	June 2014
17. NHS England to support timely dementia diagnosis and the best available treatment for everyone who needs it, including support for their carers. For example, the revised Dementia Enhanced Service will include an offer of a health check for carers and signposting for information and support.	March 2015
18. Develop a programme of work to support the health and wellbeing of carers through the community nursing strategy.	April 2015
19. NHS England's widening digital participation programme to reduce inequalities: '100,000 citizens trained in basic online skills to boost health literacy' will apply to carers as well as patients.	April 2015

**Priority 4****Person-centred, well-coordinated Care**

<b>Commitment</b>	<b>Timescale</b>
20. NHS England will promote and work towards parity of esteem for carers so that mental health and wellbeing is considered and supported alongside physical health needs.	March 2015
21. Through work on developing the House of Care toolkit, NHS England will work to bring together all the relevant national guidance, published evidence, local case studies and information to support carers to be informed and engaged in care.	March 2015
22. NHS England to include carers in work around developing standards and service components for personalised care planning to help ensure carers are integral to the care and support planning process and are consistent with the National Voices principles of care and support planning. <sup>19</sup>	March 2015
23. Patients who can benefit will have the option to hold their own personal health budget resulting in direct benefits to carers, including feeling more in control and perceived health improvements.	Ongoing

<b>Commitment</b>	<b>Timescale</b>
24. Scope how NHS England can most effectively support the RCGP and other partners in the work they intend to develop around carers.	July 2014
25. NHS England will consider how carers can be supported through commissioning of primary care including through future developments to the GP contract and enhanced services.	March 2015
26. NHS England to work with NICE and other partners to develop measurement and best practice guidance in order to increase identification of carers.	March 2015

Commitment	Timescale
27. NHS England to undertake a series of regional evidence summits for carers to establish an independent assessment of the evidence in order to capture, disseminate and encourage good practice.	2014/15
28. NHS England to maximise opportunities to capture feedback and incorporate into discussions and work to improve quality and inform best practice.	Dec 2014
29. NHS England to undertake a piece of work to understand the impact of current commissioning incentives and system drivers in supporting carers. For example, through the GP contract, revisions to enhanced services for unplanned admissions and dementia.	Oct 2014
30. NHS England to review current national processes in place to gather bereaved carers' views on the quality of care in the last three months of life in order to address gaps in evidence.	March 2015
31. Where commissioners identify the need for support, co-produce practical tools and a support programme of implementation with NHS IQ.	March 2015



Commitment	Timescale
32. NHS England to coordinate effective ways of working by developing partnership links between health, social services and other organisations, including the voluntary sector to establish how carers can be supported as effectively as possible.	March 2015
33. NHS England to continue to work with the Standing Commission on Carers.	Ongoing
34. NHS England to remain a member of the cross government carers strategy board and will encourage and support carers organisations to play an active role in the Collaboration for Coordinated Care.	Ongoing
35. Establish an annual meeting with key partners including carers organisations to monitor progress and review objectives.	Ongoing

**Commitment****Timescale**

36. NHS England to continue as a corporate member of Employers for Carers. Ongoing

37. NHS England to continue to implement and support established policies on flexible working, leave and employment breaks and agile working that support staff that are carers. Ongoing

## **6.0 Next steps**

The numbers of people providing care is already significant and is likely to continue to grow over the coming years. We know that when carers are well-supported, they provide better care to the person they care for and report better well-being outcomes themselves.<sup>20</sup>

NHS England is committed to improving the quality of life and experience of carers and the people for whom they care. This document sets out from a strategic perspective how we are planning to make those improvements. NHS England will work to deliver these commitments against the timescales identified in this report. We will also continue to listen to carers and other partners to develop and strengthen how commitments are delivered and to review progress against the delivery of the commitments through feedback from carers and carers' organisations and progress towards the relevant outcomes indicators and mandate objectives.

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