Carers and Health: developing carer-friendly health services

State of Caring Conference
13 July 2017
What does NHS England do?

- Provide assistance and leadership to the commissioning system
- In-year priority setting
- Work through national, regional and local partners
- Develop resources and solutions through co-production with our partners
- Develop and refine levers and incentives
- Support innovation and sharing of positive practice
- Support development of research areas and programmes
How we are working to support carers

Commissioning for Carers:
Principles and resources to support effective commissioning for adult and young carers
December 2014

www.england.nhs.uk
Who do we work with?

[Logos of various organizations listed below]

www.england.nhs.uk
NHS England’s Commitment to Carers (May, 2014)

- Raising the profile of carers;
- Education, training and information;
- Service development;
- Person-centred, well-coordinated care;
- Primary care;
- Commissioning support;
- Partnership links; and
- NHS England as an employer

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Our intention: to develop a carer-friendly health system

• Develop quality markers for carer-friendly GP practices – based on what carers have told us matters to them

• Quality markers will also provide evidence for CQC, RCGP and NHS England quality assurance processes

• Identify good practice and produce toolkit to support carers in other sectors of healthcare

• Work with CQC to explore how a carer-friendly toolkit can support key lines of enquiry in hospital inspections
Working together to develop quality markers for primary care

Standards and training
Royal College of GPs
NHS England and partners

Care Quality Commission

Regulation, quality and safety

Direction, outcomes and accountability

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What does the GP Patient Survey tell us?

Health of Carers
Young carers are more likely to suffer from a long-term standing health condition compared to young non-carers.

Q30 Do you have a long-standing health condition?
Responses for ‘Yes’ (excluding ‘Don’t know / can’t say’)

The trend is reversed in the 65 or over age group

- Up until the age of 64 carers are more likely to suffer from long-term health condition(s) compared to non-carers.

The five long-term health conditions that carers are slightly more likely to have compared to non-carers are:
- Another long-term condition
- Arthritis or long-term joint problem
- Long-term back problem
- Long-term mental health problem
- High blood pressure

Number of respondents (weighted) GPPS 2015-16: Carers 142,371, Non-Carers 658,489
Young carers are more likely to say they have problems with their mobility compared to their non-carer peers.

Q34a. Describe your own state of health today for...Mobility. Responses include slight, moderate, severe problems or unable.

The largest difference between carers and non-carers is within the 25 to 44 age group with 15.3% of carers reporting a problem with their mobility compared to 9.3% of non-carers. A difference of 6.0 percentage points.

The trend is reversed in the 65 or over age group.
Young carers are also more likely to say they have problems with self-care compared to their non-carer peers.

Q34b Describe your own state of health today for...Self-care
Responses include slight, moderate, severe problems or unable

- The largest difference between carers and non-carers is within the 25 to 44 age group with 6.4% of carers reporting a problem with their self-care compared to 4.1% of non-carers. A difference of 2.3 percentage points.

The trend is reversed in the 45 or over age groups

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Number of respondents (weighted) GPPS 2015-16: Carers 142,371, Non-Carers 658,489
Furthermore, young carers are more likely to say they have problems in carrying out usual activities.

Q34c: Describe your own state of health today for...Usual activities. Responses include slight, moderate, severe or unable.

The trend is reversed in the 65 or over age group.

- The largest difference between carers and non-carers is within the 25 to 44 age group with 23.9% of carers reporting problems carrying out usual activities compared to 13.6% of non-carers. A difference of 10.3 percentage points.

Number of respondents (weighted) GPPS 2015-16: Carers 142,371, Non-Carers 658,489.
And carers across all age groups are more likely to say they suffer from pain or discomfort compared to their non-carer peers.

Q34d Describe your own state of health today for...Pain / Discomfort
Responses include slight, moderate, severe or extreme

- Carers are more likely to experience pain or discomfort as they get older and more likely when compared to non-carers.

- Again, the largest difference between carers and non-carers is within the 25 to 44 age group with 45.9% of carers reporting a pain or discomfort compared to 32.4% of non-carers. A difference of 13.5 percentage points.

Number of respondents (weighted) GPPS 2015-16: Carers 142,371, Non-Carers 658,489
And carers across all age groups are more likely to say they suffer from pain or discomfort compared to their non-carer peers.

Q34d  Describe your own state of health today for...Pain / Discomfort
Responses include slight, moderate, severe or extreme

- Carers are more likely to experience pain or discomfort as they get older and more likely when compared to non-carers.

- Again, the largest difference between carers and non-carers is within the 25 to 44 age group with 45.9% of carers reporting a pain or discomfort compared to 32.4% of non-carers. A difference of 13.5 percentage points.

Number of respondents (weighted) GPPS 2015-16: Carers 142,371, Non-Carers 658,489
Carers, particularly younger carers feel less supported than non-carers by their local services in managing their long-term health condition(s)

Q32 In the last 6 months, have you had enough support from local services or organisations to help you to manage your long term health condition?
Responses for ‘No’ (excluding ‘I haven’t needed such support’)

- Across all age groups those who are carers, and have a long-term condition(s) (LTC), feel they are less supported that their non-carer peers.

- Carers aged 25 to 44 are most likely to say they haven’t had enough support to manage their LTC.

- The largest difference between carers and non-carers is in the 25 to 44 age group. A difference of 5.2 percentage points.

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Number of respondents (weighted) GPPS 2015-16: Carers 142,371, Non-Carers 658,489
Finally, carers across all age groups are more likely to say they suffer from increased levels of anxiety/depression.

Q34e  Describe your own state of health today for...Anxiety/Depression
Responses include slight, moderate, severe or extreme

- Younger carers (18 to 44) particularly are more likely to suffer from an anxiety or depression compared with their non-carer peers.

- Again, the largest difference between carers and non-carers is within the 25 to 44 age group with 43.6% of carers reporting a anxiety or depression compared to 28.7% of non-carers. A difference of 14.9 percentage points.

Number of respondents (weighted) GPPS 2015-16: Carers 142,371, Non-Carers 658,489
Overall Experience of Carers
When considering overall experience of carers, younger carers report a much poorer experience than non-carers of the same age.

Q28 Overall, how would you describe your experience of your GP surgery? Responses for ‘Fairly Poor’ / ‘Very Poor’

- Across all age groups carers report a poorer overall experience (fairly and very poor) compared to non-carers.

- The largest difference between carers and non-carers is within the youngest age group: 18 to 24 where 9.9% of carers report a poor overall experience compared to 6.7% of non-carers, a difference of 3.2 percentage points.

Number of respondents (weighted) GPPS 2015-16: Carers 142,371, Non-Carers 658,489
Carers, in particular younger carers, report a poorer experience of making an appointment

Q18 Overall, how would you describe your experience of making an appointment? Responses for ‘Fairly Poor’/‘Very Poor’

- 17.7% of carers aged 18 to 24 and 18.0% of carers aged 25 to 44 reported their overall experience of making an appointment as poor (fairly or very). Higher than in the older age groups.

- The difference in reported overall experience of making an appointment between carers and non-carers is also higher in the 18 to 24 and 25 to 44 age groups than in the older groups.
Carers across all age groups have a greater desire to see a particular GP

Q8  *Is there a particular GP you usually prefer to see or speak to?*

Responses for ‘Yes’

- **Carers** (who prefer to see or speak to particular GP)
  - 18 to 24: 48.3%
  - 25 to 44: 49.3%
  - 45 to 64: 55.1%
  - 65 or over: 69.1%

- **Non-Carers** (who prefer to see or speak to particular GP)
  - 18 to 24: 37.2%
  - 25 to 44: 37.3%
  - 45 to 64: 48.6%
  - 65 or over: 66.2%

- Across all age groups carers report a greater desire than non-carers to see a preferred GP. The percentage of those who have preferred GP increases with age and the difference between carers and non-carers is smaller in the older age groups.

- The largest difference between carers and non-carers is in the 25 to 44 age group with 49.3% of carers reporting a desire to see a particular GP compared to 37.3% of non-carers. A difference of 12.0 percentage points.

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Number of respondents (weighted) GPPS 2015-16: Carers 142,371, Non-Carers 658,489
Carers are more likely to not get an appointment compared to their non-carer peers.

Q12 Were you able to get an appointment to see or speak to someone?
 Responses for ‘No’ (excluding those who ‘Can’t remember’)

- Across all age groups carers are more likely to not get an appointment to see or speak to anyone. The likelihood of not getting an appointment decreases with age.

- The largest differences between carers and non-carers are also seen in these groups is seen in the 25 to 44 age group.

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Number of respondents (weighted) GPPS 2015-16: Carers 142,371, Non-Carers 658,489
Carers, in particular young carers, are more likely to be dissatisfied with waiting times.

Q20 How do you feel about how long you normally have to wait to be seen?
Responses for ‘I have to wait a bit too long’ or ‘I have to wait far too long’ (excluding ‘No opinion/doesn’t apply’)

- Carers aged 18 to 24 have the highest proportion of individuals reporting that they had to wait too long for their appointment at the surgery (54.9%).

- Across age groups, carers are more dissatisfied than non-carers with waiting times.

- This impression is consistent with the higher proportion of carers (31.3%) who say they wait more than 15 minutes to be seen compared to non-carers (28.8%) (Q19 excluding ‘Can’t remember’ and ‘I don’t normally have appointments at a particular time’).

Number of respondents (weighted) GPPS 2015-16: Carers 142,371, Non-Carers 658,489
Confidence in GPs is low amongst young carers, but the pattern still remains

**Q22 Do you have confidence and trust in the GP you last saw or spoke to?**
*Responses for ‘No, not at all’ (excluding ‘Don’t know/can’t say’)*

- Confidence in GPs increases with age.

- **Young carers** (18 to 24) are the most likely to report **low confidence** in the GP they last saw or spoke to (‘No, not at all’) at 9.1%.

- Whilst **older carers** (65 or over) have higher confidence, only 2.0% reported ‘No, not at all’.

![Bar chart showing confidence levels by age group for carers and non-carers.](chart.png)

Number of respondents (weighted) GPPS 2015-16: Carers 142,371, Non-Carers 658,489
The process - primary care

• Analyse GPPS to identify variations in carer experiences of general practice

• Review insight and feedback from strategic partners

• Discuss and agree provisional quality markers with CQC and RCGP

• Pilot quality markers through our regional colleagues

• Identify local support with implementation for CCGs
Provisional quality markers

- Carers registers
- Support for staff who are carers
- Information for carers
- Appointments and access
- Holistic support needs
- In-practice support

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The process – beyond primary care

- Scope exemplar providers using tools that support carers

- Work with commissioners and providers to co-design a toolkit that would enable trusts to evidence carer-friendly services

- Further work with CQC and NHS Improvement to explore how a carer-friendly toolkit could support key lines of enquiry in hospital inspections
Further Information

• Patient Experience Team
  NHS England
  Tel: 0113 825 1286
  Email: ENGLAND.PEAdmin@nhs.net

https://www.england.nhs.uk/ourwork/pe/commitment-to-carers/
Carers Health Team

NHS Health Care Professionals supporting informal carers across West Sussex
Despite advances in hospital and community services, we are still faced with many carers who are not only under stress, but also suffer from psychiatric and physical illness which may go unnoticed or ignored. Until their needs are met, we cannot claim to have a civilised and effective health service.

(MacLennan 1998)
The team:

The team comprises of health professionals - trained Nurses, Occupational Therapists, Project Co-ordinator and Administrator.

We cover the entire West Sussex area, with our main office in Bognor War Memorial Hospital and a satellite office in Horsham Hospital.

The Service is proactive with a preventative focus.............
Why?

- Over 9 million carers in UK (age uk) – over 90,000 in West Sussex
- Value of the contribution made by carers in the UK is now £132 billion each year – that's a fifth of UK Government spending (carers uk)
- NHS England commitment for carers
- In West Sussex the Joint Commissioning Unit (JCU) identified a gap in specialist clinical support to carers
- JCU in partnership with CCGs commissioned a new specialist team of health clinicians to work directly with carers:
NHS commitments

The Carers Health Team, provided by Sussex Community NHS Foundation Trust is committed to meeting the NHS Carers Priorities by:

• Raising the profile.
• Education and training.
• Service development.
• Person-centred, coordinated care.
• Primary care.
• Commissioning support.
• Partnership links.
Aims of CHT

- To improve the health and wellbeing of the carer and the people they care for.
- Working directly with carers in West Sussex to promote the importance of health and wellbeing.
- Develop individual strategies for each carer with an aim to reduce the strain of coping with their caring role.
- Offering practical advice, information on services available to them and advice on planning for the future.
- Provide education and training.
What we do and how we do it

- Health needs RAG rated assessment of informal carers with a West Sussex GP and who are over 18 years old.
- Contingency planning.
- Liaising and referring to partner services both NHS and charitable.
- Free education and learning programme.
- We see carers in their own home/place and time of their choice
- GP carer clinic
- Outreach carer clinics
- Carer Learning and Wellbeing Programme
Anyone can make a referral and carers can self refer. Referrals accepted by phone, fax, email or post.

Important criteria: the Carer’s consent has been obtained and the carer is registered with a West Sussex GP

**Response:**
Contact with carer within 5-10 working days

**Assessment**
Carer Health Clinicians (CHC) will visit the carer and undertake a holistic assessment of need

**Intervention**
The CHC will work in partnership with carers to develop personalised health plans for them and if required the person they are looking after

**Review**
CHC will review jointly agreed goals, follow up on interventions, plan for self management and/or refer to Carers Support Service/other services as appropriate
Partnerships working

Sussex Community
NHS Trust

Carer Learning & Wellbeing Programme

The Carer Learning and Wellbeing Programme is available for all registered Carers in West Sussex. It includes a number of different sessions to help Carers make a positive difference to their life and their personal wellbeing. The programme is continually developing and growing and is held in a number of towns and villages across the County.

10 Free sessions in 10 Locations Around West Sussex
All sessions are 10am - 12pm. Spaces are limited. Sessions running until July 2017.

Employment & Volunteering: Whether you’re thinking about returning to work or looking at a volunteering role, this session can guide you through the process.

Art Therapy: Teaches the therapeutic benefits of art.

Communicating With Confidence: Provides you with tips and techniques on how to be more assertive when meeting with professionals to ensure you get what you need for yourself and for the person you care for.

Healthy Relationships: Keeping your relationships with others positive when you are in a caring role can be difficult at times. This session offers helpful advice and techniques on how to better manage those relationships.

Managing Medication & Continence Care: This health advice session has tips on how to manage your own and the person you care for’s medication for the first half of the course. The second part focuses advice on the basic aspects of continence care. You can join for one or both parts of the session.

Living with Guilt: Many Carers feel guilty about emotions, feelings and aspects of their lives. This session helps Carers learn to live positively with their emotions.

First Aid & Wound Care: Provides guidance in basic first aid, wound and pressure area care.

Relaxation Techniques: Covers mindfulness and relaxation techniques designed to reduce stress in your every day life.

Wills & Power of Attorney: Offers a step by step guide to writing a will for yourself and the process of gaining the power of attorney for the person you care for.

For a full schedule and more information please visit: www.carerssupport.org.uk
Booking is essential. To book your place please call: 0300 028 8888

Charity Number 1123359
Making a difference – carers outcomes

- Improved physical and emotional wellbeing
- Increased confidence and building resilience
- Increased knowledge and skill in caring role
- Increased choice and control/access to information
- Improved quality of life
- Reduction in unscheduled care
Measuring success

- Potential savings for the NHS - research evaluation conclusion
- Carers managing for longer in the caring role
- Seamless service for carers through partnership working
The carers' health team have had a really positive impact on my life. They are friendly and helpful, they listen, they have information and they help you to help yourself by looking at where your life is now and how it can be improved for better health and wellbeing. Very friendly, helpful and informative. Really helped in making a plan to support good health and wellbeing. The care was amazing. I felt listened to and more able to make more steps towards a better standard of health and living.

I was in crisis and the help I received really helped me cope. My total care was perfect. I can't see room for improvement.
Any questions?
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www.sussexcommunity.nhs.uk/carers