

Commissioning for Carers:

Principles and resources to support
effective commissioning for adult and
young carers

December 2014



OFFICIAL

NHS England INFORMATION READER BOX

Directorate

Medical	Commissioning Operations	Patients and Information
Nursing	Trans. & Corp. Ops.	Commissioning Strategy
Finance		

Publications Gateway Reference: 02518

Document Purpose	Resources
Document Name	NHS England's Commissioning for Carers: Principles and resources to support effective commissioning for adult and young carers
Author	Medical Directorate and Nursing Directorate
Publication Date	05 December 2014
Target Audience	CCG Clinical Leaders, CCG Accountable Officers, NHS England Regional Directors, NHS England Area Directors, Communications Leads
Additional Circulation List	
Description	This work has been developed with input from carers, leading charities and partner organisations, to develop ten principles to help commissioners to deliver the level of care and support carers have said they need. The work draws on the latest research, case-studies and best-practice collected at four regional evidence summits held across England.
Cross Reference	Commitment for Carers and NHS Improving Quality Evidence Summit Report
Superseded Docs (if applicable)	
Action Required	
Timing / Deadlines (if applicable)	
Contact Details for further information	David Bramley Domain Team Lead Medical Directorate Quarry House, Leeds LS2 7UE 7900715097

Document Status

This is a controlled document. Whilst this document may be printed, the electronic version posted on the intranet is the controlled copy. Any printed copies of this document are not controlled. As a controlled document, this document should not be saved onto local or network drives but should always be accessed from the intranet

Commissioning for Carers

Principles and resources to support effective commissioning for adult and young carers.

Version number: Final

First published: 5 December 2014

Updated: (only if this is applicable)

Prepared by:

Classification: OFFICIAL

Contents

Contents	4
1 Introduction.....	5
2 Who is considered a carer?.....	7
3 Carer Facts – why investing in carers matters.....	9
4 What Carers Want.....	11
5 Background to developing the Commissioning for Carers Principles – how we collected evidence and examples of what works.....	12
5.1 Building the evidence base.....	12
5.2 Evidence Summits.....	12
6 How to use the Commissioning for Carers Principles.....	14
6.1 Principle 1, Think Carer, Think Family; Make Every Contact Count	15
6.2 Principle 2, Support what works for carers, share and learn from others	18
6.3 Principle 3, Right care, right time, right place for carers	20
6.4 Principle 4, Measure what matters to carers	22
6.5 Principle 5, Support for carers depends on partnership working	24
6.6 Principle 6, Leadership for carers at all levels	26
6.7 Principle 7, Train staff to identify and support carers.....	28
6.8 Principle 8, Prioritise carers’ health and wellbeing	30
6.9 Principle 9, Invest in carers to sustain and save.....	33
6.10 Principle 10, Support carers to access local resources.....	36

Developed in partnership with:



and



Supported by:



1 Introduction

The five and a half million unpaid carers in England make a critical and underappreciated contribution not only to loved ones, neighbours and friends, but to the very sustainability of the NHS. To make this contribution, carers often make great sacrifices to support the people they look after. The [NHS Five Year Forward View](#) commits the NHS to find new ways to support carers, to build on the new rights created by the Care Act and to help the most vulnerable carers – the approximately 225,000 young carers and the 110,000 carers who are themselves aged over 85.

Whilst commissioners and practitioners cannot solve all of the challenges faced by carers, much more could be done to support them and help ensure that they receive the recognition and support that they need and deserve from the NHS.

The *Commissioning for Carers: Principles and resources to support effective commissioning for adult and young carers* (referred throughout the document as Commissioning for Carers Principles), is a practical tool and part of a suite of products that will help commissioners to deliver what carers say is important to them in ways that have been shown to work effectively and efficiently in practice. The Principles are based on the latest research, case-studies and best-practice and are the vital and common ingredients to deliver better outcomes for carers, patients, commissioners, practitioners and local communities. They are:

1. Think Carer, Think Family; Make Every Contact Count
2. Support what works for carers, share and learn from others
3. Right care, right time, right place for carers
4. Measure what matters to carers
5. Support for carers depends on partnership working
6. Leadership for carers at all levels
7. Train staff to identify and support carers
8. Prioritise carers health and wellbeing
9. Invest in carers to sustain and save
10. Support carers to access local resources

The Commissioning for Carers Principles form part of [NHS England's Commitments to Carers](#), published on 7 May 2014, and the [RCGP Supporting Carers in General Practice Programme](#), to help in identifying, supporting and recognising the vital roles that carers play to support them to provide better care and to stay well themselves. This report noted that the improving support for carers was a journey and the Commitments represented a first step in this journey. This work provides a further

OFFICIAL

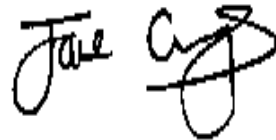
step forward in support for carers by synthesizing research, case-studies and best-practice from evidence summits into the ten principles. NHS England remains committed to and will continue to work with the support of partners including NHS Improving Quality, the Royal College of General Practitioners and supported by Carers UK, Carers Trust, Children's Society, Commissioners, Standing Commission on Carers, Providers and Practitioners.

The Commissioning for Carers Principles are accompanied by:

- RCGP Caring for Carers Hub.
- 'Supporting Carers: a social impact evaluation'. RCGP has worked with Baker Tilly to identify the social return on investment which can be made when CCGs invest in services which support carers, specifically the effect this has on cashable savings which a CCG could make over six years.
- Additional library resource of the evidence gathered from the Carers Regional Evidence Summit Events which is available on [NHS Improving Quality](#)



Sir Bruce Keogh
National Medical Director
NHS England



Jane Cummings
Chief Nursing Officer
NHS England

2 Who is considered a carer?

A carer is anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid. When we refer to carers in this document, this is inclusive of both adult and young carers.

Many carers don't see themselves as carers and it takes them an average of two years to acknowledge their role as a carer¹.

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, child, sibling, partner, 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 a fear of separation, guilt, pride or other reasons.

This means that the sort of roles and responsibilities that carers have to provide varies widely. 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. The importance of carers is noted in the NHS Five Year Forward View which notes that to support carers properly we need to have multi-agency and community integration.²

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need 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 under the Equality Act 2010) and those who do not share it.

OFFICIAL

- Given regard to the need to reduce inequalities between patients in access to, and outcomes from, healthcare services and in securing that services are provided in an integrated way where this might reduce health inequalities.

3 Carer Facts – why investing in carers matters

- There are around 5.4 million people in England who provide unpaid care for a friend or family member³.
- A carer is anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid.
- Between 2001 and 2011, the number of unpaid carers grew by 600,000 with the largest increase being in those who provide fifty or more hours of care per week⁴. This equates to 1.4 million people providing fifty or more hours of unpaid care per week⁵.
- Unpaid care increased at a faster pace than population growth between 2001 and 2011⁶ and an ageing population with improved life expectancy for people with long term conditions or complex disabilities means more high level care provided for longer.
- Increasing hours of care often 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 population⁷.
- 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 care⁸.
- 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 2011-12⁹, for example this negative impact may be responsible for the increased risk that carers will suffer from conditions, for example, there is a 23% increased risk of stroke for spousal carers¹⁰.
- Carers attribute their health risk to a lack of support, with 64% citing a lack of practical support¹¹.

OFFICIAL

- 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 year¹².
- 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%¹³.
- 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 groups¹⁴.
- The 2011 Census counted 166,363 young unpaid carers (5 to 17-years-old) in England. Evidence has shown that, providing unpaid care may have an adverse effect on young carers' general health. There is growing evidence pointing to the adverse impact on the health, future employment opportunities and social and leisure activities of those providing unpaid care, particularly in young carers.¹⁵
- There is an increasing prevalence of 'sandwich carers' (2.4 million in the UK) - those looking after young children at the same time as caring for older parents. It can also be used much more broadly to describe a variety of multiple caring responsibilities for people in different generations¹⁶.
- Many young carers remain hidden from sight for a host of reasons, including family loyalty, stigma, bullying, not knowing where to go for support. Carers may be as young as five years old.¹⁷

4 What Carers Want

The Commitment to Carers engagement process highlighted a number of themes that carers said were important to them. The themes, which are in line with feedback received through similar listening exercises that have previously been held by other organisations such as Carers Trust and Carers UK, were as follows:

- Recognise and respect me as a carer
- Ensure information is shared with me and other professionals
- Signpost information for me and help link professionals together
- Flexible care, available to suit me and the person I care for
- Think about the whole family, including young carers and young adult carers
- 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 expert in care
- Treat me with dignity and compassion

5 Background to developing the Commissioning for Carers Principles – How we collected evidence and examples of what works

The Commitments to Carers, published in May 2014, was informed by the first national listening exercise with carers to understand what was important to carers. From this work the following 8 themes were identified.

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
8. NHS England as an employer

Under the theme of Commissioning support, we wanted to progress from commitments towards focusing on the services that support carers and identifying the practices that work well for commissioners, carers and others. To do this two related activities were taken forward by NHS England, NHS IQ and RCGP.

5.1 Building the evidence base

A call for case studies was issued through the carers' organisations, NHS England Regional and Area Teams, and the RCGP GP Champions for Carers. From this call, over 50 case studies were received including initiatives from GP practices across England.

The case studies covered a wide spectrum of services provided by the NHS, social care and the non-statutory sector with many being jointly commissioned. Some services are provided at minimal or no additional cost while others require an investment to achieve a benefit in the longer term. A few of the case studies include valuable independent evaluations to measure impact and outcomes.

These case studies are available on the [NHS Improving Quality](#) website and have been categorised to allow them to be searched more easily.

5.2 Evidence Summits

To help gather and review the evidence, four evidence summits were held jointly by NHS England, NHS IQ and RCGP. A total of 314 people participated across the four summits and delegates included commissioners, acute and community service

OFFICIAL

providers, carers and carer organisations, community pharmacies, Health and Well Being Boards, local authority and primary care. The summits considered examples of best practice from within each region and addressed questions such as how best to commission services for carers.

Evidence was also gathered from a Young Carers Call to Action event held on 30 October 2014 in London.

Supported by these activities, ten Commissioning for Carers Principles were identified to support commissioning necessary to achieve the best outcomes using the evidence received. These were:

1. Think Carer, Think Family; Make Every Contact Count
2. Support what works for carers, share and learn from others
3. Right care, right time, right place for carers
4. Measure what matters to carers
5. Support for carers depends on partnership working
6. Leadership for carers at all levels
7. Train staff to identify and support carers
8. Prioritise carers' health and wellbeing
9. Invest in carers to sustain and save
10. Support carers to access local resources

6 How to use the Commissioning for Carers Principles

The Commissioning for Carers Principles focus on key actions that are most likely to achieve the best outcomes from the evidence and case studies that have been received.

To help commissioners consider current commissioning practices with regards to carers and how this could be improved, we have provided a simple self-assessment questionnaire designed for you and your team to rate yourself and provide an opportunity to see if there is anything you could do to enhance your existing services. Supplementary questions have been included to help trigger conversations and stimulate ideas. The intention is to help with decision making processes to support a return on investment and help make the business planning process easier. Links to detailed case studies have been included.

The Commissioning for Carers Principles help identify different approaches for adaptation or adoption to fit with local priorities and engage through the whole commissioning cycle. The simple checklist for each principle is an easy way to identify what already exists or to highlight areas that need further support and possible investment. This will help to frame your assessment criteria for funding within the business planning commissioning process. The checklists may help record a commitment to carers' baseline which could then be repeated to record the progress made.

Each Commissioning for Carers Principle has an 'Ask Yourself' section with trigger questions derived from the round table discussions at the carers' regional evidence summit events and the Young Carers Call to Action. The purpose is to stimulate discussions within your organisation in response to each of the Commissioning for Carers Principles.

COMMISSIONING FOR CARERS PRINCIPLES

6.1 Principle 1 - Think Carer, Think Family; Make Every Contact Count

Evidence shows that carers have poorer health outcomes than the non-carer population but that early identification of carers can improve their health and wellbeing. However, carers are not easy to identify and may not consider themselves to be carers. 70% of carers come into contact with health professionals and yet, of those, only 10% are identified, with GPs more specifically only identifying 7%.¹⁸ Encouraging services to think carer, think family, can help to improve the identification of carers and support better health and wellbeing outcomes. Over 80% of carers surveyed for the 2014 State of Caring Survey said that caring has had a negative impact on their health.¹⁹

(Select one colour only. Rate where red lowest-----and green highest)

How assured are you that that carer views have helped to shape the development of service specifications?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

What could you do to improve the rating? -----

How assured are you that your providers have appropriate mechanisms for identifying carers in primary and secondary care?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

What would improve your rating? -----

How assured are that carers are identified by primary and secondary care services you commission?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

What would improve your rating? -----

Ask yourself ...

OFFICIAL

- Is identification of carers part of the assurance process in your contracts with all the services you commission?
- Ask or use illustrative questions to identify carers for example, 'Do you look after or give support to someone?' or 'when your mum is getting ready in the morning, do you help her with getting washed and dressed?' (as the response to 'are you a carer' can often elicit a negative response)
- Do services you commission have set procedures for identifying carers?
- Do you involve carers in commissioning?
- How do you ensure that young carers and young adult carers supporting someone have access to information and specialised support?
- Do you have a carers' policy within the contract of every provider?
- Do your care and support planning templates include sections for carers?
- Are your commissioning strategies integrated into a local multi-agency strategy led by local authorities with social services responsibilities?
- Do your voluntary organisations commissioned by the statutory sector have outcomes as their core business, for example asking carers about experience of services they have received?
- Have you considered local incentives such as a Local Enhanced Service for carers?
- Have your five year commissioning plans adequately considered carers? Have they been reviewed to ensure they are carer friendly?
- Do staff routinely consider carers and have mechanisms for identifying them?
- Your census data will give you an indication of carers in your area, but do you know how many carers are using your services?
- Do you know how effective your area is in generating referrals or signposting to local statutory and voluntary support services?
- How integrated are the systems for signposting? For example do you have an integrated strategy which everyone links into?
- Do you know if GP practices in your area have a carers register and if they regularly review this?
- Have you considered commissioning annual carers' health check?
- Do you know if carers are offered a flu jab?
- Are you assured that carers support and /or awareness training is included in inductions for staff or in mandatory training?
- Are you assured there is a carers lead or champion in services you commission?
- Do services you commission have formal mechanisms for linking with local authorities under the stipulation of the new Care Act 2014?

Good Practice examples:

- Northamptonshire Carers; Identification at GP practices and referral into Northamptonshire Carers includes flu vaccinations as part of annual health and wellbeing check. http://www.nhs.uk/media/2535967/carers_case_study_-_northamptonshire_carers_centre.pdf
- Carers Northumberland-Identification and support for carers http://www.nhs.uk/media/2543454/carers_gp_support_project_northumberland.pdf
- Falsgrave Surgery- one of the 10 RCGP Exemplary Practices which have implemented a number of initiatives to increase the identification and support of carers. http://www.nhs.uk/media/2580979/gp_carers_falsgrave_surgery.pdf

6.2 Principle 2 - Support what works for carers, share and learn from others.

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.²⁰ Sharing good practice and information greatly improves carers experience of services provided at a local level and provides peer support. Using local knowledge of what works well, commissioners can improve quality and continuity of services.

(Select one colour only. Rate where red lowest-----and green highest)

How assured are you that you are using varied evidence regarding carers from different sources to support decisions on business cases for all your services?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

How could you increase your rating? -----

How assured are you as a CCG about benchmarking yourself with comparator localities or regions of good practice with regard to supporting carers?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

What could increase your rating? -----

Having benchmarked your CCG against other comparators of good practice how assured are you that the services you commission support carers?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

What could increase your rating? -----

Ask yourself...

- How do you make sure your business cases include carers in their submission criteria?

OFFICIAL

- Have you considered including carers in all your Equality Impact Assessments for all services you commission?
- Are you using data from local carers' surveys to support your commissioning process?
- Have you considered commissioning integrated information and advice services?
- Do you have a joined up commissioning strategy for carers with all relevant commissioners?
- Are you able to demonstrate how carers are involved in the treatment, planning of care and discharge for the person they look after? Who is collecting the data about impact because this is potentially an invest to save area?
- Do you use several approaches when assessing evidence to commission new services, such as carers' stories, case studies, and local data and carers surveys combined with social return on investment statistics?
- Do you consider networking and engaging with community voluntary services (CVS) to deliver on the strategic plans through joint bids?
- Have you liaised with the voluntary sector to establish if they collect routine data on carers in your locality? If so have you used the data?
- Have you considered utilising the knowledge and expertise of the third sector on carers in informing strategic planning?
- Have you considered using voluntary and community sector evidence to help consider different ways to support carers?
- Are you aware of how the [House of Care framework](#) can support your delivery of person centred coordinated care?
- Are you aware of how the [Triangle of Care framework](#) can be used within your carers' services?
- Are the standards of Triangle of Care included in all your commissioning and service specifications?
- Have you liaised with your Health and Wellbeing Board with regard to identifying any local issues around supporting carers?

Good practice examples:

<http://www.nhs.uk/implementation/programmes/experience-of-care/commitment-for-carers/case-studies.aspx>

6.3 Principle 3 - Right care, right time, right place for carers

Access to healthcare is often an area of difficulty for carers given the time commitments and pressures that they face. Carers identified provision of reliable and flexible care that is available to suit them and the person they look after as being essential to enable them to continue caring with confidence.²¹ Poor access can contribute to the negative health outcomes that carers' experience. By offering flexibility with appointments for example outside normal clinic times and offering a home visit for those carers who cannot leave the person for whom they care in order to attend a surgery appointment improves access.

(Select one colour only. Rate where red lowest-----and green highest)

How assured are you that carers of all ages have access to the right services at the right time and right place?



What could you do to improve your rating? -----

How assured are you that services are accessible to carers of all ages?



What could you do to improve your rating? -----

How assured are you about the level of engagement with carers with regard to access to services in you commission?



What could you do to improve your rating? -----

How assured are you that all interactions with health care professionals results in the offer of support for the carer to an appropriate local service?



What could you do to improve your rating? -----

Ask yourself...

- Do the services that you commission provide flexible appointment times to support carers?
- How do you ensure that out of hours services understand the carers' perspective?
- Is there specialist support for young carers and young adult carers?
- Are there good mechanisms for handing over to out of hours services?
- How do you ensure that carers supporting someone with a stigmatised condition (mental ill health or substance misuse) have access to information and specialised support?
- Do you know what percentage of your commissioning budget is spent on carers?
- To what extent does your Joint Strategic Needs Assessment include carers?
- Can you quantify how many carers have become unwell due to their caring role?
- Do you offer self-care support programmes such as the Expert Patient Programme?
- Does your commissioning and signposting maximise the opportunities that technology brings to help carers manage care? For example telecare and new apps like Jointly.²²
- How assured are you that you have considered young carers in your commissioning plans? (click [here](#) for further information)

Good Practice examples:

- Wiltshire-recognising good practice in carers support Bronze, Silver and Gold awards. Evaluated by an accreditation panel
http://www.nhs.uk/media/2541623/carers_case_study_recognising_good_practice_in_carer_support.pdf
- Suffolk family carers-caring for carers in hospital runners up in the Patient Experience Network Awards 2013.
http://www.nhs.uk/media/2541596/carers_case_study_suffolk_family_carers.pdf

Useful resources:

- Supporting carers will help reduce unplanned admissions/emergencies and repeated visits to hospital. [Carers assessment](#) and [care planning](#)
- The Carer Friendly Hospital project at Lister in 2011-12 showed a reduction in readmission of Older People within 28 days.²³

6.4 Principle 4 - Measure what matters to carers

Good quality data and evidence was identified as being crucial to help commissioners in the decision making process when developing and prioritising business cases for services to support carers. Accurate data assists with accountability and transparency within the commissioning process.

(Select one colour only. Rate where red lowest-----and green highest)

How assured are you that carers' data you have collected locally is quality assured for accuracy, is accessible and is easy to understand?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

What could you do to improve your rating? -----

How assured are you that you are measuring what matters to improve the outcomes for carers?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

How could you improve your rating?-----

Ask yourself...

- Do you know what your carer data means?
- Are you able to compare the experience of different groups of people?
- How do you measure the experience of young carers and young adult carers?
- Do you have baselines of carers' needs and outcome measures? If not how can you achieve this?
- How have you included carers' measures in service specifications and evaluation of services?
- Do you have carers involved in data scrutiny and action planning?
- Do you use the carers' measures in the Long Term Conditions Commissioning Dashboard?
- How do you measure carers' experiences and quality of life?
- Do you link with others to share data for example, social care on care breakdowns?

OFFICIAL

- Have you considered ways to ensure the data is quality assured to remove bias and ensure organisational consistency, for example, accessibility and interpretation?
- Have you considered peer review groups where similar service managers can review and compare the Commissioning for Carers Principles outcomes together to ensure consistency?
- Implementation/piloting of the Commissioning for Carers Principles will generate a whole new set of data for your service and strategic leads. You now need to make sense of it to inform your subsequent commissioning intentions. Have you considered including the [Adult Quality of Life Survey](#) to measure the impact of services on carers?

Good Practice examples:

- Torbay and South Devon Healthcare NHS Trust Supporting carers in making lifestyle behaviour changes-Evaluated 74% of carers achieve their goals within six sessions of working with a Health Trainer, demonstrating the efficiency and effectiveness of brief interventions.
http://www.nhs.uk/media/2535957/carers_case_study_-_torbay_health_trainers_final.pdf

6.5 Principle 5 - Support for carers depends on partnership working

Carers' needs span health and social care so, perhaps unsurprisingly, partnership working was identified as key to providing joined up seamless services and continuity of care. This can be supported through the NHS working with local authorities, voluntary organisations and local communities to support carers. The use of Joint Strategic Needs Assessments for partnership agreements can support this.

(Select one colour only. Rate where red lowest-----and green highest)

How assured are you about your partnership arrangements i.e. when a person is discharged from hospital to community services, how is their carer linked into support services?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

What could improve your rating? -----

How do you rate your partnership arrangements with regard to carers' services?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

What could improve your rating? -----

How assured are you that you involve carers as partners in your commissioning decision process?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

What could improve your rating? -----

A core component of whole systems integrated care is the concept of outcomes commissioning. In the planning guidance the £3.8bn Better Care Fund includes £130m of NHS funding for carers' breaks. Local plans should set out the level of resource that will be dedicated to carer-specific support, including carers' breaks, and identify how the chosen methods for supporting carers will help to meet key outcomes.

Ask yourself...

OFFICIAL

- Have you mapped your existing services to identify the cross over and overlap to identify who can deliver and support carers most effectively?
- Have you considered commissioning in partnership with the voluntary and community sector?
- Have you considered jointly commissioning carers services with others for example other CCG's or local authorities/ social services?
- Have you considered the impact of the Care Act on your commissioned services?
- Does your business case template demonstrate/encourage partnership working and capture the diversity of carers?
- Have you considered joint commissioning and joint funding of services with carers centres? If so, have you ensured that a partnership agreement can be tracked to ensure it is being met by frontline services?
- As a system leader do you participate in the annual Carers Week in partnership with others?

Good Practice examples:

- Torbay-A joint health and social care approach on identification and support to carers of people with dementia, and the effectiveness of early intervention in primary care - Evaluated using GHQ 12 self-assessments by Manchester University's Personal Social Services Research Unit (PSSRU).
http://www.nhs.uk/media/2535952/carers_case_study_torbay_dementia_final.pdf
- Halton Borough Council and Halton Clinical Commissioning Group (CCG) are working together to provide a co-ordinated approach - 17 practices kite marked as "Community Wellbeing Practices" Evaluation using the Using the WHO 5 index.
http://www.nhs.uk/media/2563117/carers_case_study_-_halton_health_wellbeing.pdf
- Torbay and South Devon-Helping carers of substance misusers- evaluation 12-item General Health Questionnaire and one-to-one questionnaires.
http://www.nhs.uk/media/2563090/carers_torbay_substance_misuse.pdf

6.6 Principle 6 - Leadership for carers at all levels

Feedback from the evidence summits was that leadership for carers at all levels is essential as it enables a shift in thinking, organisational cultural change and accountability in the way carers services are commissioned and increases the identification and support for carers (see [NHS IQ e-book](#)). The carers' agenda has to be linked to the organisations vision as core business. Successful system transformation involves engaging all local partners and stakeholders in "the case for change" including a shared sense of local challenges and intended solutions.²⁴

(Select one colour only. Rate where red lowest-----and green highest)

How assured are you that there is leadership for carers at all levels in your organisation?

□	□	□
---	---	---

How could you improve your rating? -----
.....

How assured are you that there is leadership for carers at all levels for all services you commission?

□	□	□
---	---	---

How could you improve your rating? -----
.....

How assured are you that the services you commission considers factors such as access or quality for carers?

□	□	□
---	---	---

How could you improve your rating? -----
.....

How assured are you about leadership support to improve carers experience of NHS services and access to support?

□	□	□
---	---	---

How could you improve your rating? -----
.....

Ask yourself...

- Does your leadership support carer specific services?
- Do you have carer representation at board level and in what capacity? If not, could this opportunity be created or expanded?
- Do you have leadership support to commission carer specific training?
- Have you engaged with your [RCGP GP Champion for Carers](#) if there is one in your area?
- Is consideration of the health and wellbeing of carers visible in everything you do?
- Do you have a carer champion in your organisation?
- Do you have a policy around supporting your staff who are carers?
- Do you specify champions for carers in service specifications?
- Do you have a designated person to represent and involve young carers/young adult carers?
- How do you overcome barriers in supporting carers due to confidentiality issues?
- How do you deal with the confidentiality challenges in supporting carers?

Good Practice examples:

- Surrey-Wide carers and NHS providers network taking forward Surrey carers strategy and Multi Agency Young Carers Strategy.
http://www.nhs.uk/media/2573748/carers_case_study_-_surrey_ccg.pdf
- Herts Valleys CCG in supporting carers. A Leader in Primary With Carers' champions (one in each of 70 practices) and with Clinical lead (carers) in Integrated Discharge Team.
http://www.nhs.uk/media/2579972/carers_case_study_-_herts_valley_ccg.pdf
- Torbay and Southern Devon Health and Care NHS Trust Early identification of carers by community staff 2013-14 CQUIN (Commissioning for Quality and Innovation) target of reaching 50% of community nursing staff across the whole Torbay (urban) and Southern Devon (rural) patch.
<http://www.nhs.uk/improvement-programmes/experience-of-care/commitment-for-carers/case-studies/identification-and-recognition.aspx>

6.7 Principle 7 - Train staff to identify and support carers

A key theme which emerged from the regional evidence summit events was the provision of education and training for staff, which was thought to provide the following when implemented;

- Recognition & identification of carers
- GPs & all healthcare professionals increased awareness of carers issues
- Carers awareness of their role as experts
- Improved referral/signposting to appropriate services
- Recognition for the establishment of a single point of contact/access

[\(NHS IQ e-book\)](#)

(Select one colour only. Rate where red lowest-----and green highest)

What assurance do you have that staff have training and are continually updated with regards to the role of carers?

□	□	□
---	---	---

What could you do to improve your rating? -----

How assured are you that training and awareness around carers' issues is embedded in all services you commission?

□	□	□
---	---	---

What could you do to improve your rating? -----

How do you rate your current education and training for health and care professionals in relation to carers?

□	□	□
---	---	---

What could you do to improve your rating? -----

Ask yourself...

- Do you know if your local education and training board are including carer awareness training in their programmes?

OFFICIAL

- How have you included carers in your staff training?
- How have you ensured that training around carer awareness is embedded as part of an assurance framework?
- Do you have the leadership support to commission carer specific training?
- Are staff made aware of the difference that asking the right questions can make? For example, “do you look after someone” instead of “are you a carer”?
- Does your staff training include information on confidentiality?
- Are all staff of commissioned services aware of young carers and young adult carers and have the training to identify them as early as possible?
- Do you have a policy around supporting carers who work for you?

Good Practice examples:

- Northumbria Healthcare NHS Foundation Trust-Education programme for medical students –Palliative care and old age psychiatry research on carers experiences put into practice evaluated by University of Plymouth and CIRCLE University of Leeds
http://www.nhs.uk/media/2535888/carers_case_study_-_learning_from_carers_northumbria_nhsft.pdf
- Salford-Carers Express-fast track carer awareness training for GP’s and use of a yellow key logo easily recognisable and Dementia friendly
http://www.nhs.uk/media/2535962/carers_express_final.pdf

6.8 Principle 8 - Prioritise carers' health and wellbeing

The GP Patient Survey in 2013 highlighted the impact of caring on carer health – whilst 51% of non-carers had a long-standing health condition, this rose to 60% of all carers and 70% of carers caring for 50 or more hours a week. The survey also highlighted higher levels of arthritis, high blood pressure, long-term back problems, diabetes, mobility problems, anxiety and depression amongst carers.²⁵ Caring responsibilities can have an adverse impact on the physical and mental health, education and employment potential of those who care. This 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.²⁶

(Select one colour only. Rate where red lowest-----and green highest)

How assured are you that all identified carers of any age in your locality have their health and wellbeing monitored?

□	□	□
---	---	---

What could you do to improve the rating? -----

How assured are you that all identified carers in your locality are receiving Carers' Assessments?

□	□	□
---	---	---

What could you do to improve the rating? -----

How assured are you that your plans for the Better Care Fund have the right level of funding to support carers in your locality?

□	□	□
---	---	---

What could you do to improve the rating? -----

Ask yourself...

OFFICIAL

- Do you have an assurance framework for the services you commission to ensure carers have a care plan?
- Do you invest in self-care to support patients and their carers to understand and manage their conditions better?
- Do you have an assurance framework to ensure carers are offered training in managing medication, moving and handling etc.?
- Are your commissioned services linking with [your local school nursing service](#) as school nurses are being trained in supporting young carers but will now be commissioned by local authorities through public health?
- Are your commissioned services linking with local carer support services for carers of any age?
- How do you address the physical and mental health needs of young carers and young adult carers through services for them and the person that they care for?
- Do you offer self-care support programmes such as the Expert Patient Programme derivative?
- Do you know how skilled, knowledgeable and confident carers are to manage their health and wellbeing and the health and wellbeing of the person they care for? (Carers Patient Activation Measure (Carers PAM)? In development by NHS England.
- What do you have in place to reduce future emergency admissions? For example reducing the number of days cared-for individuals take up a hospital bed).
- What do you do to ensure carers' physical health, mental health and wellbeing is maintained?
- Do you know if carers are offered a flu jab?
- Is Improved Access to Psychological Therapy (IAPT) available to carers on line and over the phone?
- Do you promote the use of [the Triangle of Care](#) in physical health services?
- Do you provide holistic whole family centred services for carers?
- Have you considered commissioning carers respite breaks? For example; "There is evidence to suggest that a significant number of admissions are due to problems associated with the carer rather than the person admitted. One study found that problems associated with the carer contributed to readmission in 62% of cases. Carers of people readmitted were more likely than other carers to:
 - be experiencing ill-health, fatigue and interrupted sleep;
 - be conducting at least one intimate task;
 - generally feel frustrated.²⁷
- Are you using carers' breaks effectively?

- Are you assured that you can provide person centred support to carers, which may not routinely be provided by the NHS so they can continue in their caring role, for example to provide support at home for everyday tasks for the carer, housework to enable the carer to continue caring for a 'loved one'? This was a learning point offered by carers during the introduction of Personal Health Budgets in the NHS.

Good practice examples:

- "Looking after Me", Self-Management course for carers – Kirklees. This is an evidence based self-management education course for adults who care for someone living with a long-term health condition or disability.
http://www.nhs.uk/media/2573743/carers_case_study_-_kirklees_self_management.pdf
- NHS Devon County Council and Devon Carers-Health and wellbeing checks part of the joint Strategic needs assessment, evaluated by University of Plymouth and CIRCLE University of Leeds.
http://www.nhs.uk/media/2535883/carers_case_study_-_health_and_wellbeing_checks_in_devon.pdf
- Northumberland carers wellbeing checks- The development prompted a new CQUIN (Commissioning for Quality and Innovation) target for community nursing.
http://www.nhs.uk/media/2563036/carers_northumberland_carers_checks.pdf

6.9 Principle 9 - Invest in carers to sustain and save

Carers make a critical and underappreciated contribution not only to loved ones, neighbours and friends, but to the very sustainability of the NHS. However, too often carers do not receive the recognition and support that they need and deserve. Investing in carers to help them provide better care and to stay well themselves contributes to better lives for those needing care and more effective use of NHS resources. For example, effective support for carers may reduce unplanned admissions for carers and the people for whom they care for and may in certain circumstances help save money²⁸.

(Select one colour only. Rate where red lowest-----and green highest)

How assured are you that your business case template and criteria for carers' services focus on commissioning for investment and value?

□	□	□
---	---	---

What could you do to improve the rating? -----

How assured are you that that resources for carers have been appropriately allocated as part of the Better Care Fund?

□	□	□
---	---	---

What could you do to improve the rating? -----

Ask yourself...

- Can you start small then increase investment should this provide value for money?
- Are you aware of duties in the [Care Act 2014](#) and the [Children and Families Act 2014](#) to identify, assess and support carers and co-operate with the local authority?
- Is there an assurance framework in your contracts?
- Have you considered combining resources by co-ordinating services through a central consortium?
- Have you considered co-production around key outcomes?
- Have you considered who can deliver the service most efficiently by mapping the services to find crossover and overlap?

- Have you considered carers to be included in Commissioning for Quality and Innovation (CQUINS) payment schemes?
- Are you confident that you have identified the interventions/support that your local populations require?
- Have you considered undertaking or commissioning a carer Social Return on Investment project?

Cost effective interventions:

What the literature is telling us:

- Evidence from Clifford et al 2011 showed how Carers Centre annual impact of the benefits evaluated exceeded the total annual funding across the five Carers' Centres evaluated by at least £68 million.²⁹
- The evidence from Knapp et al 2013 showed that START (STrategies for RelatTives)) made improvement to health related quality of life for Dementia carers demonstrating 99% of interventions being cost effective.³⁰
- Evidence from Graff et al. 2008 showed Occupational therapy-coping behaviours and supervision treatments were 36% more successful at 3 months.³¹
- Evidence from Medical Advisory Secretariat 2008 showed techniques and patient directed exercise programmes were found to be effective in supporting the well-being of unpaid carers of seniors with dementia living in the community.³²

Good Practice examples:

- 'Supporting Carers: a social impact evaluation' - RCGP has worked with Baker Tilly to identify the social return on investment which can be made when CCGs invest in services which support carers. The study shows that this could equate to a saving of almost £4 for every £1 invested. <http://www.rcgp.org.uk/clinical-and-research/clinical-resources/carers-support.aspx>
- Bristol and South Gloucestershire-Identification and Recognition of carers needs-Evaluated Social Return on Investment. http://www.nhs.uk/media/2535893/carers_case_study_bristol_sgloucesters_hire_carers_support_centre.pdf
- NHS Bristol Clinical Commissioning Group and Bristol City Council Combined budgets for carers breaks and developed a CQUIN (Commissioning for Quality and Innovation) Evaluated by the University of West of England. http://www.nhs.uk/media/2543400/carers_breaks_in_bristol.pdf

OFFICIAL

- Carers Trust Cambridgeshire-“Better Health Network” to create a single point of access to third sector help with health and wellbeing. “virtually integrate” health and social care services into more joined up support for carers.

http://www.nhs.uk/media/2535972/carers_cambridgeshire_final.pdf

6.10 Principle 10 - Support carers to access local resources

Feedback from carers highlighted the following as some of the key changes they would value most:

- Ensure information is shared with me and other professionals
- Signpost information for me and help link professionals together

These were identified as being important to enable carers to maintain their own health and wellbeing and continue to support the person they look after with confidence³³.

(Select one colour only. Rate where red lowest-----and green highest)

How assured are you that providers routinely signpost to carer services, websites and professionals providing support as appropriate?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

What could you do to improve your rating? -----

How assured are you that young carers supporting someone with a stigmatised condition (mental ill health or substance misuse) have access to information and specialised support?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

What could you do to improve your rating? -----

Ask Yourself...

- Do you have relevant and appropriate services for all carers?
- Do your commissioned services promote the uptake of Carers Assessments?
- How do you promote services which are available?
- Have you considered commissioning a guide to local and national services? Are you aware of the [RCGP Caring for Carers Hub](#)?
- Is this built into current contract monitoring processes as a local KPI? For example all carers offered signposting service, additional information, percentage of carers with an information prescription.

Good Practice examples

- Lincolnshire Caring at the end of life- An evaluation by the University of Lincoln is currently underway, which will inform the commissioning process for a carers' hub in 2015. Early findings will be fed into the Lincolnshire County Council commissioning process from Sept/Oct 2014.
http://www.nhs.uk/media/2563009/carers_lincolnshire.pdf
- Somerset Partnership NHS Trust – A Trust wide approach to meet the needs for mental Health carers- using the Triangle of Care.
http://www.nhs.uk/media/2535977/carers_case_study_-_somerset_partnership.pdf

References:

- ¹ NHS Choices. (2014) *Understanding Carers (online)* Available from: <http://www.nhs.uk/CarersDirect/understanding-carers/Pages/understanding-carers.aspx> (Last accessed 11 March 2014).
- ² NHS England Five Year Forward View, Oct 2014
- ³ Office for National Statistics. (2013) *2011 Census Analysis: Unpaid Care in England and Wales, 2011 and comparison with 2001 (online)* Available from: http://www.ons.gov.uk/ons/dcp171766_300039.pdf (Last accessed 6 February 2014).
- ⁴ Office for National Statistics. (2013) *2011 Census Analysis: Unpaid Care in England and Wales, 2011 and comparison with 2001 (online)* Available from: http://www.ons.gov.uk/ons/dcp171766_300039.pdf (Last accessed 6 February 2014).
- ⁵ Office for National Statistics. (2013) *2011 Census Analysis: Unpaid Care in England and Wales, 2011 and comparison with 2001 (online)* Available from: http://www.ons.gov.uk/ons/dcp171766_300039.pdf (Last accessed 6 February 2014).
- ⁶ Office for National Statistics. (2013) *2011 Census Analysis: Unpaid Care in England and Wales, 2011 and comparison with 2001 (online)* Available from: http://www.ons.gov.uk/ons/dcp171766_300039.pdf (Last accessed 6 February 2014).
- ⁷ Carers UK. (2004) *In Poor Health: the impact of caring on health (online)* Available from: http://www.carersuk.org/media/k2/attachments/In_Poor_Health_The_impact_of_caring_on_health.pdf (Last accessed 6 February 2014).
- ⁸ Department of Health. (2012) *Assessment, eligibility and portability for care users and carers (online)* Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136450/IA-Annex-C-assessment-and-eligibility.pdf (Last accessed 6 February 2014).
- ⁹ Carers UK. (2013) *The State of Caring 2013 (online)* Available from: http://www.carersuk.org/media/k2/attachments/State_of_caring_report_PDF_version.pdf (Last accessed 6 February 2014).

¹⁰Haley, W et al (2010), 'Caregiving Strain and Estimated Risk for Stroke and Coronary Heart Disease Among Spouse Caregivers'. *Stroke*, 41:331-336

¹¹ Carers Week. (2012) *In Sickness and In Health* (online) Available from: http://www.carersuk.org/media/k2/attachments/In_Sickness_and_in_Health_FINAL.pdf (Last accessed 6 February 2014).

¹² University of Leeds and Circle. (2011) *New Approaches to Supporting Carers Health and Well-Being: evidence from the National Carers's Strategy Demonstrator Sites Programme* (online) Available from: <http://www.sociology.leeds.ac.uk/assets/files/research/circle/151111-6121-circle-newapproaches-complete-report-web.pdf> (Last accessed 6 February 2014).

¹³ Schonegevel, L. (2013) *Macmillan Briefing on Carers Issues* (online) Available from: <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/MPs/Commons2ndReadingBriefing.pdf> (Last accessed 6 February 2014).

¹⁴ NHS England & NHS Improving Quality. (2014) *Commitment for Carers: Report of the findings and outcomes*.

¹⁵ <http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/provision-of-unpaid-care-in-england-and-wales--2011/sty-unpaid-care.html>

¹⁶ <http://www.carersuk.org/for-professionals/policy/expert-comment/4604-sandwich-generation-concern-is-growing> Last accessed 25 November 2014

¹⁷ http://www.childrenssociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-carers_final.pdf

¹⁸ Schonegevel, L. (2013) *Macmillan Briefing on Carers Issues* (online) Available from: <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/MPs/Commons2ndReadingBriefing.pdf>

¹⁹State of Caring 2014; <http://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2014>

²⁰ Valuing Carers, Carers UK and Dr Lisa Buckner, University of Leeds

²¹ NHS England Commitment to Carers, April 2014

²² <https://jointlyapp.com/#welcome>

²³ <http://www.hertsdirect.org/mm/15520570/15744533/adultcareitem620140507.doc>
and community.wellbeing@hertfordshire.gov.uk

²⁴ <http://www.england.nhs.uk/ourwork/part-rel/transformation-fund/bcf-plan/>

²⁵ Policy Briefing, May 2014, Facts about carers; <http://www.carersuk.org/>

²⁶ [Department of Health](#). (2012) *Assessment, eligibility and portability for care users and carers online*.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136450/IA-Annex-C-assessment-and-eligibility.pdf

²⁷ Williams, E, Fitton, F (1991), 'Survey of carers of elderly patients discharged from hospital'. *British Journal of General Practice*, 41, 105-108.

²⁸ *Creating new value with patients, carers and communities*, KPMG International (2014)

²⁹ Clifford, J., Theobald, C., Mason S. (2011) *The Princess Royal Trust for Carers: Social Impact Evaluation using Social Return on Investment*, London, The Princess Royal Trust for Carers.

³⁰ Knapp M, King D, Romeo R, Schehl B, Barber J, Griffin M, Rapaport P, Livingston D, Mummery C, Walker Z, Hoe J, Sampson EL, Cooper C, Livingston G. (2013) Cost effectiveness of a manual based coping strategy programme in promoting the mental health of family carers of people with dementia (the START (STrAtegies for RelaTives) study): a pragmatic randomised controlled trial. *BMJ*. 2013 Oct 25;347:f6342

³¹ Graff MJ, Adang EM, Vernooij-Dassen MJ, Dekker J, Jönsson L, Thijssen M, Hoefnagels WH, Rikkert MG. (2008) Community occupational therapy for older patients with dementia and their care givers: cost effectiveness study. *BMJ*. 2008 Jan 19;336(7636):134-8.

³² Medical Advisory Secretariat (2008) Caregiver- and patient-directed interventions for dementia: an evidence-based analysis. Ont Health Technol Assess Ser. 2008;8(4):1-98. Epub 2008 Oct 1.

³³ NHS England Commitment to Carers, April 2014