



An integrated approach to identifying and assessing Carer health and wellbeing









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Contact Details for	Dave Ross
further information	Patient Experience Team
	Room 5W33
	Quarry House, Leeds
	LS2 7UE
	LOZ 7 OL
	0113 825 5579

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1 Introduction

1.1 The purpose of this paper

This paper builds on the work started by the NHS England *Commitment to Carers* that was published in May 2014, and which sought to give the five and a half million Carers in England the recognition and support they need to provide invaluable care for loved ones.

In December 2014, NHS England and the Royal College of General Practitioners published 'Commissioning for Carers: Principles and resources to support effective commissioning for adult and young carers', to help Clinical Commissioning Groups (CCGs) better identify and help Carers to stay well and to deliver the best outcomes for Carers.

Copies of the *Commitment to Carers* and *Commissioning for Carers* can be accessed at https://www.england.nhs.uk/ourwork/pe/commitment-to-carers/ .

This paper addresses changes to the way in which Carer health and wellbeing need is identified, assessed, and supported, as a result of changes introduced by the Care Act 2014 and the Children and Families Act 2014. It is, essentially, a resource to help promote working together between Adult social care services, NHS commissioners and providers, and third sector organisations that support Carers, of all ages, with a specific focus on developing an integrated approach to the identification, assessment and support of Carers and their families across health and social care. To support this joint working, a template Memorandum of Understanding, to be discussed and agreed locally, is included at Appendix One.

A secondary purpose of this paper is to provide clarity and ensure consistency around the language of care and caring. We understand that, in some cases, different sectors of care are not clear about their duties under the relevant legislation, that the duties of co-operation between agencies are not clearly understood, and that there are variations in understanding of some of the terms used.

An additional purpose of this paper is to identify positive practice in supporting Carers, with a particular focus on Carers from vulnerable communities or at key transition points, in order to reduce health inequalities.

The Better Care Fund (BCF) was launched in 2014 and aims to transform local health and social care services so that they work together to provide better joined up care and support, through CCGs and local authorities agreeing joint plans and agreeing to pool elements of their budgets.

Local Health and Wellbeing Boards are responsible for overseeing agreement of the joint plan and for ensuring that funds are used in accordance with the agreed plan. There is a requirement that plans outline the support that would be made available to Carers, reflecting the retention of £130m to fund Carers breaks in 2016/17.

Given the above responsibilities, it is suggested that all partners on the local Health and Wellbeing Board sign the Memorandum of Understanding at Appendix One in order to demonstrate commitment to the duties of co-operation and promotion of wellbeing, as well as the wider commitment to identifying, recognising, assessing and supporting Carers.

It is recognised that the template Memorandum of Understanding may need to be varied to reflect local circumstances and policies. The important thing, here, is that any such local variation should be discussed and agreed to by all parties on the Health and Wellbeing Board.

Nothing in this paper seeks to amend or replace statutory guidance or accepted best practice. Statutory guidance, *Care and Support Statutory Guidance (DH, 2014)*, on implementation of the Care Act 2014 can be accessed at:

https://www.gov.uk/guidance/care-and-support-statutory-guidance

A template Memorandum of Understanding for supporting Young Carers and their families can be accessed at:

http://adcs.org.uk/early-help/article/no-wrong-doors-working-together-to-support-young-carers-and-their-families

Established best practice and examples of positive practice are included in Appendix Two to this document.

1.2 Acknowledgements

The development of this paper was informed by the invaluable contributions of members of ADASS (the Association of Directors of Adult Social Services) and its regional Carers Policy Network meetings, the support and advice of the Department of Health and NHS England, the Standing Commission on Carers, NHS England regional nursing staff, members of individual clinical commissioning groups, and the many national and local carer support organisations we have met with and spoken to.

We also wish to acknowledge the individual and collective contributions made by Young Carers and Carers from vulnerable communities.

2 The new framework for Carer health and wellbeing

2.1 Understanding the duty of co-operation

The Care Act 2014 introduces a number of reforms to the way that care and support for adults with care needs are met. It requires local authorities to adopt a whole system, whole council, whole-family approach, co-ordinating services and support around the person and their family and considering the impact of the care needs of an adult on their family, including children.

In several places, the Act makes provision for all Carers, including Young Carers and Older Carers. This "whole system" approach bestows a duty of co-operation on local authorities and all agencies involved in public care.

What is the duty of co-operation?

The Care Act 2014 now makes integration, co-operation and partnership a legal requirement on local authorities and on all agencies involved in public care, including the NHS, independent or private sector organisations, some housing functions, and the Care Quality Commission (CQC).

Section 6 of the Act provides for a general duty to co-operate. Section 7 of the Act provides for co-operation in specific cases and includes caveats for specific cases when co-operation is not possible.

Further, Section 15.22 of the statutory guidance provides for "the local authority...consider what degree of co-operation is required and what mechanisms it may have in place to ensure mutual co-operation (for example, via contractual means)".

Who has the duty to co-operate?

Relevant partners of a local authority include any other local authority with which they agree it would be appropriate to co-operate and the following agencies or bodies who operate within the local authority's area, including:

- NHS England
- Clinical Commissioning Groups
- · NHS trusts and NHS Foundation Trusts
- Any NHS-funded service
- · Job centres

- Justice the Police, prisons and probation services
- Housing officers who exercise the local authority functions in relation to housing
 for adults with needs of care and support, or local authority functions in respect of
 Carers and, in some cases, private registered providers of social housing
- Education services

Source: Care and Support Statutory Guidance, Chapter 15

The 2015/16 Planning Guidance for the NHS, *Five Year Forward View into Action*, set out how the NHS will seek to implement its duties under the above acts, including a clear expectation that, "CCGs alongside local authorities...draw up plans to identify and support carers and, in particular, working with voluntary sector organisations and GP practices, to identify young carers and carers who themselves are over 85, and provide better support".

Further, "In developing plans, CCGs should be mindful of the significant changes to local authority powers and duties from April 2015 under the Care Act 2013 [sic]. Plans should focus on supporting young carers and working carers through the provision of accessible services, and services for carers from vulnerable groups".

Copies of the 2015/16 Planning Guidance for the NHS can be accessed at:

https://www.england.nhs.uk/ourwork/futurenhs/deliver-forward-view/forward-view/

2. 2 Understanding the duty to promote wellbeing

The general duty of a local authority towards individuals, under Section 1 of the Care Act 2014 is "to promote that individual's well-being". Local authorities must promote wellbeing when carrying out any of their care and support functions in respect of a person, and that person should be enabled to participate as fully as possible in decisions at every stage in their care.

What is "wellbeing"?

Wellbeing is a broad concept and it is described as relating to the following areas in particular:

- personal dignity, including treatment of the individual with respect
- physical and mental health and emotional wellbeing
- protection from abuse and neglect

- control by the individual over day-to-day life (including control over care and support provided and the way it is provided)
- participation in work, education, training or recreation
- · social and economic wellbeing
- domestic, family and personal relationships
- · suitability of living accommodation
- the individual's contribution to society

Source: Care and Support Statutory Guidance, Chapter 1

There is no hierarchy to these areas, and all should be considered of equal importance when considering "wellbeing" in the round, for the individual concerned.

Further, wellbeing cannot be achieved simply through crisis management; it must include a focus on delaying and preventing care and support needs from developing and escalating, and on supporting people to live as independently as possible for as long as possible.

It is recognised that social care and voluntary sector care practitioners may not always be qualified to clinically assess a carer's physical or mental health. Where a health need is identified as part of the assessment, the carer should be referred back to their GP so that this health need may be addressed.

2. 3 Understanding the duties to address the needs of Young Carers, Parent Carers and to adopt a "whole family approach"

Both the Care Act 2014 and the Children and Families Act 2014 address the needs of Young Carers clearly and directly. The Children and Families Act 2014 builds on the Children Act 1989 to amplify the rights to improve how Young Carers and their families are identified and supported, and extends the right to an assessment of their support needs to all Young Carers under the age of 18 regardless of who they care for, what type of care they provide or how often they provide it. Thus, the principle of the whole family approach applies across all age groups and across all categories of care.

This change also introduces a requirement to make an assessment on the appearance of need. The new provision works alongside measures in the Care Act 2014 (Sections 60-64) to enable a "whole-family approach" to assessment and support, for example in addressing the inter-related needs of Young Carers and their families.

We have heard that many Young Carers take on their role because of multiple care needs in the family and that many Young Carers find themselves with a long-term career in care within their family. Equally, it is now becoming increasingly common to find multiple caring in families, with major implications for some family members.

The intention of the whole family approach is for local authorities and their partner agencies to take a holistic view of the person's needs, in the context of their wider support network. The approach must consider both how the individual Carer or their support network or the wider community can contribute towards meeting the outcomes they want to achieve (see above), and whether or how the needs for care and support impact on family members or others in their support network.

There is a particular need for NHS bodies and the local authority to work closely when planning to support the discharge of patients from hospital and this is covered by Schedule 3 of the Care Act 2014.

2. 4 Delegation of authority for carers' needs assessments

Section 79 of the Care Act 2014 provides for local authorities to delegate some, but not all, of their care and support functions to other parties. This power to delegate is intended to allow flexibility for local approaches to be developed in delivering care and support, and to allow local authorities to work more efficiently and innovatively, and provide better quality care and support to local populations.

However, as with all care and support, individual wellbeing should be central to any decision to delegate a function.

Delegation does not absolve the local authority of its legal responsibilities. When a local authority delegates any of its functions, it retains ultimate responsibility for how the function is carried out.

The Care Act 2014 is clear that anything done (or not done) by the third party in carrying out the function, is to be treated as if it has been done (or not done) by the local authority itself. This is a core principle of allowing delegation of care and support functions.

Where a local authority delegates its responsibility for Carers' needs assessments, it needs to assure itself that these assessments are compliant with the Care Act 2014.

3 An integrated approach to the identification, assessment and support of Carer health and wellbeing needs

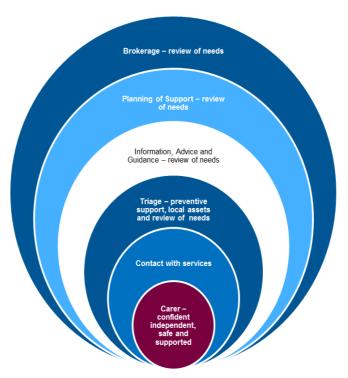
3. 1 The aim of the approach

The aim of this work was to develop an integrated approach to the identification, assessment and support of Carers' health and wellbeing needs across health and social care to:

- a. maintain the independence, physical health and emotional wellbeing of Carers and their families
- b. empower and support Carers to manage their caring roles and have a life outside of caring
- c. ensure Carers receive the right support, at the right time, in the right place
- d. respect the Carer's decision about how much care they will provide and respect the Carer's decision about not providing care at all

The integrated approach sits on a number of supporting principles which are discussed more fully below and which will be used to support and promote the implementation of a combined process across health and social care.

The proposed integrated approach for identifying and assessing carers' and wellbeing needs



3.2 The approach explained

The central aim is to keep the Carer at the centre, or core, of the "onion". This preserves the Carer's independence, their family and social network relationships, and their ability to undertake their caring role. The Carer's primary care team has a crucial role in initiating the discussion about the Carer's support needs and in supporting and maintaining Carer health and wellbeing. The primary care team also has a crucial role in identifying Carers.

The integrated approach recognises that, under the Care Act 2014, Carers have the right to request a formal Carer's assessment of their own needs at any time.

When a registered Carer has any contact with the NHS they are to be asked the core questions to identify whether or not they feel they are in need of additional support, either in order to continue their caring role or to continue contributing to their family and social networks.

Suggested core and supplementary questions are included below. It is recognised that some care settings will need to ask different questions, or phrase questions differently, according to the communication and information needs of the individual carer presenting to that setting.

The inclusion of these questions in this document is to encourage local debate about the range of questions that could be used to initiate a discussion with the Carer of their changing support needs.

Suggested core questions

Throughout our engagement process, it was suggested that the following could provide the basis for a key question to initiate a discussion about a Carer's changing needs:

 Do you look after someone who couldn't manage without your help and support?

This should then be followed by one or more supplementary questions, for example:

- As a result of you being here having (medical) treatment would you be able to continue that care?
- Will you need any extra support because of your own health needs/medical treatment which we are discussing today? (if the answer to this question is "yes" the Carer should be asked what support they need)
- Are you willing/able to continue your caring role?

There may also be an opportunity for services to identify Child/Young Carers by asking along the following lines:

- Are there any children in the household?
- Will any of these children be involved in caring?

Where the Carer identifies they are in need of support, or may need support in the future, the healthcare practitioner should seek to establish what needs the Carer may have as it may be possible to meet these needs during the consultation. Where this is not possible, the Carer should be asked if they are aware of the local Carer support organisation and, if not, referred to the local Carers support organisation. If social care or carer support practitioners are identifying a health need as part of their Carers assessment they should have the ability to refer the Carer back to their GP for health support.

In some areas, NHS primary care services employ care navigators, or other Carer link/support workers, to offer carers advice and information about accessing local support, and, in some cases, to arrange this support on behalf of the Carer. In these cases, it would be useful to ensure primary care and local Carer support work closely to provide the Carer with a seamless service and avoid unnecessary duplication.

The Carers support organisation will then discuss the Carer's situation, including their ability to provide the patient with the required level of care, the wellbeing needs of the family, to assess the level of need and work with the Carer to meet these. This could include referral to other local support, carer support training, preventive services, or referral into the formal needs assessment process. The focus is on meeting needs as quickly as possible to prevent them from escalating and becoming more complex.

For older Carers, many of whom have their own health problems, this discussion could include continuing healthcare arrangements, how this may impact on the Carer's capacity to care, and planning to mitigate against possible failure of the continuing healthcare provider, to ensure that a vulnerable couple is not left without support. It may be useful to complete an initial assessment of support needs and a risk assessment within this discussion.

Where a Carer is offered, or requests, a formal needs assessment, the primary care team may wish to consider what further information, advice and guidance (including advocacy) the Carer requires, at this stage, in order to ensure that the Carer is fully informed about the needs assessment process and how they can prepare for this. In some cases, this may require arranging for an advocate to assist the carer.

In other cases, local Carer support organisations have received delegated authority from the local authority to provide a seamless service for Carers and work closely with the primary care team.

Where a Carer has evidence of support needs and meets the eligibility criteria as set out in the Care Act 2014, this will be picked up during support planning, at which point a more thorough discussion will take place about the ability of the local care support market to meet the identified needs of the Carer, and where additional services may have to be bought in or commissioned. This provides an opportunity for Carers to identify previously unmet need in an area.

A Carer's financial situation may be financially assessed in relation to services provided directly to the carer if a local authority has decided to charge carers. Where a local authority arranges care and support to meet a person's needs, it may charge the adult, except where the local authority is required to arrange care and support free of charge.

The new framework is intended to make charging fairer and more clearly understood by everyone. The overarching principle is that people should only be required to pay what they can afford. People will be entitled to financial support based on a means-test and some will be entitled to free care.

The principles are that the approach to charging for care and support needs should:

- ensure that people are not charged more than it is reasonably practicable for them to pay
- be comprehensive, to reduce variation in the way people are assessed and charged
- be clear and transparent, so people know what they will be charged
- promote wellbeing, social inclusion, and support the vision of personalisation, independence, choice and control
- support carers to look after their own health and wellbeing, and to care effectively and safely
- be person-focused, reflecting the variety of care and caring journeys and the variety of options available to meet their needs
- apply the charging rules equally so those with similar needs or services are treated the same and minimise anomalies between different care settings
- encourage and enable those who wish to stay in or take up employment,

education or training or plan for the future costs of meeting their needs to do so, and

be sustainable for local authorities in the long-term.

Source: Care and Support Statutory Guidance, Chapter 1

In practice, the expectation is that local authorities should apply a 'light-touch' to assessing whether or not to charge for carer support services, "a local authority should ensure that any charges do not negatively impact on a carer's ability to look after their own health and wellbeing and to care effectively and safely... excessive charges are likely to lead to carers refusing support, which in turn will lead to carer breakdown and local authorities having to meet more eligible needs of people currently cared for voluntarily." (*Care and Support Statutory Guidance*, sections 8.50 and 8.51).

The needs of the Carer and their family will be reviewed at regular stated intervals, or when a key transition point is reached, to see what new or emerging needs have developed and to identify additional support may be required. This will be particularly important at key transition points (see below) or when the Carer is approaching the end of their caring role.

3. 3 Supporting Principles

The integrated approach to identifying and assessing Carer health and wellbeing needs rests on a number of supporting principles. These principles are also included in the template Memorandum of Understanding at Appendix One to this document.

Each of these principles covers a number of practical points and each of these practical points features examples of positive practice, in order to encourage and enthuse other practitioners and commissioners to replicate or build on success. These examples of positive practice are summarised in Appendix Two.

In developing a local Memorandum of Understanding, it may prove necessary to develop local supporting principles. Again, this should be based on local discussion and agreement.

3.3. 1 Principle 1 – We will support the identification, recognition and registration of Carers in primary care

The role of the primary care team as the one to which all Carers have access is recognised as being paramount in supporting Carers and maintaining the capacity of Carer to care, if they so choose.

There is a need to improve the registration and assessment of Carers, including Young Carers, in primary care so that their needs can be identified more quickly and before their health and wellbeing deteriorates.

3.3. 2 Principle 2 - Carers will have their support needs assessed and will receive an integrated package of support in order to maintain and/or improve their physical and mental health.

Carers have a dual role as both providers of care for the cared for and as clients of services as a result of the caregiving role which affects their own health and wellbeing. Thus, primary care has a unique opportunity to make a telling contribution to improving the lives of Carers.

Primary care teams are already seeking to support carers in a number of practical ways, including offering Carers flexible appointment times, longer appointments, offering Carers appointments on Sundays, and referrals to a range of local services through Carer/social prescribing schemes.

There is also a need for local agencies to work together in developing integrated support to meet the identified and emerging needs of Carers.

3.3.3 Principle 3 - Carers will be empowered to make choices about their caring role and access appropriate services and support for them and for the person they look after

Carers need to be aware of their entitlement to request to an assessment of their needs in their own right, independent from any assessment of the person for whom they care.

Carers' main support needs may be support with their own health or with information and education to help them provide skilled caregiving and support for the cared for, either of which may be best addressed directly by healthcare practitioners at the time.

Many areas produce directories of Carer support services and some of these are comprehensive. Depending on identified need, referral to the local Carer support organisation may be the best way to ensure that carers receive the support they

need when they need it. Carers will be supported to exercise choice and make well-informed decisions about the support options available to them.

It is acknowledged that Carers are free to choose not to care, or to decide on the amount of care they will provide. Whatever decision a Carer makes should be respected by the staff with whom they come into contact.

The wellbeing needs of the Carer's family will be taken into account when identifying suitable support. The Carer will be supported to plan for life beyond caring, including where the Carer wishes to reduce the amount of care they provide, or where they are no longer able, or no longer wish, to continue their caring role.

3.3. 4 Principle 4 - The staff of partners to this agreement will be aware of the needs of Carers and of their value to our communities

NHS staff would benefit from Carer awareness training. Provision of Carer awareness training in health and social care induction and ongoing professional development programmes is desirable. This training should be offered by integrated health and social care teams to ensure consistency of approach.

Care staff will recognise signs of distress and diminished capacity that may affect the ability or willingness of Carers to continue caring, so that they can ask the Carer if they are in need of support. Care staff will also be aware of local Carer support organisations so that the Carer can be sign-posted. In some cases, care staff may be able to make the referral on behalf of the carer.

Where social care practitioners are identifying a health need as part of their Carers assessment they should have the ability to refer the carer back to their GP for health support.

The aim of this principle is for care staff to work holistically with the Carer and cared for and be aware of Carers' needs from diagnosis, discharge planning and reviews. Staff could provide the carer with information and/or refer early to support to try to avoid a crisis situation or a breakdown in the Carer's health.

3.3. 5 Principle 5 - Carers will be supported by information sharing between health, social care, Carer support organisations and other partners to this agreement.

We understand that the biggest risk to Carers is the failure to share information sensibly. We will work to remove burden of Carers having to repeat information and will reduce the barriers to effective sharing of information.

The registration of Carers in General Practice is key to this as being identified as a Carer will generate a READ code on the Carer's personal medical record and this will accompany that Carer whenever and wherever they use the NHS in England (by being shown on the Summary Care Record). Within integrated services, social care staff will have access to the Summary Care Record.

Service specifications for many Carer support services, including those that have been delegated to undertake needs assessments on behalf of the local authority, provide for data-sharing and processing arrangements that comply with information governance and data protection requirements. Examples of these are included in Appendix Two.

Improved sharing of information will help to identify vulnerable Carers earlier, improve the identification of Carers and the assessment of their support needs, and could improve the responsiveness of support to the changing needs of Carers. However, it is important to check that the Carer consents to this information being shared and has the capacity to give informed consent.

3.3. 6 Principle 6 - Carers will be respected and listened to as expert care partners, and will be actively involved in care planning, shared decision-making and reviewing services.

Carers will be actively involved in the planning of care for the cared for. Carers will have their views taken into account when planning care in advance. Carers will be fully engaged in the planning, redesign and shaping of services.

It is acknowledged that whilst Carers will be expert in the preferences, context and disease history of the patient, they will often not be expert in the disease(s), its course and management and how to deal with emerging caregiving challenges. Carers may, therefore, still need support from healthcare practitioners to empower them to fully fulfil their role as expert partners.

Services will be continuously monitored and reviewed, with Carer inputs, in order to demonstrate where desired health outcomes are being achieved and to identify those areas in need of improvement.

3.3. 7 Principle 7 - The support needs of Carers who are more vulnerable or at key transition points are identified early.

The use of risk stratification tools will allow for predicative modelling through which to develop the necessary preventive and other support resources to meet the needs of vulnerable Carers or those Carers approaching key transition points, including:

Young Carers as they leave primary school and approach secondary school

- and, again, as they leave secondary school to go on to further education
- Young Carers as they move from adolescence to adulthood
- Parents as Carers, particularly parents of children with physical or learning disabilities as they leave the family home or as they become eligible for adult services
- Carers of people with substance misuse problems
- Carers aged over 75
- LGBT Carers
- Carers from BAME (Black, Asian and Minority Ethnic) communities
- Carers with multiple caring roles (e.g., Carers of partners and additional older or other relatives requiring care and support)
- Recognition of additional support needs of bereaved Carers.

3. 4 Benefits of the integrated approach

There are a number of important benefits, and possible benefits, to this approach:

- the focus is on supporting the independence of Carer and the wellbeing of the
 Carer and their families
- the needs of Carer and their families are identified as, or before, they arise
- the Carer can be fast-tracked to preventive and low-level support, including wellbeing checks
- safeguarding issues can be highlighted more quickly
- there is likely to be a reduction in Carer/family crisis and breakdown
- the Carer's right to opt for a formal Carer's assessment, where the eligibility
 Criteria are met, is clearly identified
- the approach avoids unnecessary referral to more complex services and will reduce unnecessary demand on these more complex (and more costly!) services
- the identification, assessment and provision of support for Carers from vulnerable groups will help to reduce health inequalities
- the approach will encourage social cohesion through identification and use of other local assets available to support the Carer
- the support needs of the Carer are continually reviewed
- the Carer is supported at key transition points, including any escalation or change in needs, in particular as they approach the end of their caring role.

3. 5 Thinking Carer across the local health and social care system

In order to ensure that Carers receive the right support at the right time and in the right place, Carers demonstrating eligible needs should be referred to the local Carer support organisation to have their immediate wellbeing needs addressed.

Where a Carer indicates they have a physical or mental health need during an interaction with the NHS, this health need should be addressed as soon as possible, after which the healthcare practitioner should initiate a discussion about the Carer's wider support needs and refer to the local Carer support organisation.

Partnership working and co-operation is key to providing a joined up seamless services. This will include joint working between the local authority, the NHS, voluntary organisations, education, public health, housing and local communities to support Carers.

Central to this joint working will be the development of local data and information sharing processes between agencies, so that information follows the Carer across their own care and support pathway without them constantly having to re-tell their story. Practical examples of how this can be achieved are included in Appendix Two.

The needs of Carers should also be recognised by commissioners and planned for. Work through the local Health and Wellbeing Board and the Joint Strategic Needs Assessment will include identification of the needs of Carers, including young Carers and young adult Carers in the local area; this identification will be crucial in avoiding crisis breakdowns.

The local Joint Health and Wellbeing Strategy will include shared strategies for meeting these identified needs, setting out arrangements for working together and the actions that each partner will take individually and collectively.

Local partners should set out their arrangements for periodic audit and the provision of assurance to the Council, Health and Wellbeing Board, Clinical Commissioning Group, and the public, on how the memorandum of understanding is being implemented. Feedback from Carers, their representatives and the cared for should be an essential element of these audits.

There is an opportunity to include Carers and service users as "experts by experience" in these audits - if Carers are to be genuine partners in strategic development, they have to understand how, why and when things can go wrong in order to achieve the ambition of co-designing the future.

Examples of where local partners have adopted an integrated approach to supporting Carers across a district can be found at:

http://www.coastalwestsussexccg.nhs.uk/our-commitment-to-carers

http://www.hertsdirect.org/docs/pdf/c/carstrat2015.pdf

www.surreynhscarersprescription.org.uk

http://www.wandsworthccg.nhs.uk/localservices/Pages/Carers-Support.aspx

4. Moving forward with our Commitment to Carers

NHS England will continue to work with its partners in CCGs, NHS providers, local Authorities, and the third sector, in order to deliver on the Commitment to Carers.

In 2016/17 we are proposing further work to demonstrate how an integrated approach to the identification and assessment of Carer health and wellbeing need is making a difference to their lives of Carers and their families.

This will include the development of an outcomes framework to identify where an integrated approach is making a difference a difference, work to develop positive practice to help Primary Care identify and support Carers, work to include Carer support within new models of care, and targeted work with vulnerable groups to identify challenges they may face in accessing Carer support.

Appendix One: Template Memorandum of Understanding

Memorandum of Understanding between

[insert partner organisations on the local Health and wellbeing Board]

OR

[insert name of Director of Adult Social Care] and [insert name of Commissioning Lead for local Clinical commissioning group] - :

Supporting an integrated approach to the identification and assessment of Carers' health and wellbeing needs

1. Introduction

This Memorandum of Understanding (MOU) sets out the agreed approach to supporting the implementation of an integrated approach to the identification and assessment of Carers' health and wellbeing needs across [insert name of district].

- a. The local authorities [insert name of local authority/authorities]; and
- b. The following commissioners and providers of NHS-funded care:
- [Insert name of CCG(s)]
- [List all acute NHS Trusts and FT's in area, including tertiary & specialist]
- [insert name of Director of Public Health]
- [Insert name of ambulance trust(s)]
- [Insert name of independent sector providers]
- [Insert name of mental health trusts if applicable]
- [Insert name of community providers if applicable]
- [Insert name of voluntary sector care providers if applicable]
- c. The local Carer support organisation(s) [insert name(s)]
- d. Other local partners:
- [insert names of relevant local partner organisations]

2. Our vision for Carers

[insert name of district/borough] is a place where Carers are recognised, supported and valued, both in their caring role, and as individuals.

3. Working together to support Carers

Partners agree to co-operate with each other, to promote the wellbeing of individual Carers, and to adopt a whole family approach in their work to support local Carers of all ages, in order to:

- a. maintain the independence and physical and mental health of Carers and their families
- b. empower and support Carers to manage their caring roles and have a life outside of caring
- c. ensure that Carers receive the right support, at the right time, in the right place
- d. respect Carers' decisions about how much care they will provide and respect Carers' decisions about not providing care at all

4. Key principles

The integrated approach to identifying, assessing and supporting Carers' health and wellbeing needs rests on a number of supporting principles. Each of these principles covers a number of practical points and each of these practical points features examples of positive practice, in order to encourage other practitioners and commissioners to replicate or build on success.

These examples of positive practice are summarised in Appendix Two.

Partners to the Memorandum of Understanding agree that:

- 4.1 Principle 1 We will support the identification, recognition and registration of Carers in primary care.
- 4.2 Principle 2 Carers will have their support needs assessed and will receive an integrated package of support in order to maintain and/or improve their physical and mental health.
- 4.3 Principle 3 Carers will be empowered to make choices about their caring role and access appropriate services and support for them and the person they look after.
- 4.4 Principle 4 The staff of partners to this agreement will be aware of the needs of Carers and of their value to our communities.

- 4.5 Principle 5 Carers will be supported by information sharing between health, social care, Carer support organisations and other partners to this agreement.
- 4.6 Principle 6 Carers will be respected and listened to as expert care partners, and will be actively involved in care planning, shared decision-making and reviewing services.
- 4.7 Principle 7 The support needs of Carers who are more vulnerable or at key transition points will be identified early.

5. Moving forwards

Actions arising from this agreement will form part of our commissioning plan for Carers and of a more detailed action plan.

We will put in place arrangements for periodic audit and the provision of reasonable assurance to the Council, Health and Wellbeing Board, Clinical Commissioning Group, and the public, on how this memorandum of understanding is being implemented and how our work is making a difference to carers. Feedback from Carers, their representatives, and the cared for, will be an essential element of these audits.

We will involve Carers, in recognition that they are 'experts by experience', in monitoring and reviewing services, and when seeking to redesign, commission or procure Carer support services.

We will put programmes for learning and development in place to raise the awareness and understanding of the needs of Carers and their families, and of local Carer support services.

We will design training and support for those undertaking Carers needs assessments to have the necessary knowledge and skills. This will include ensuring that practitioners in the local authority and partner agencies are aware of the specific requirements concerning Carers of the Care Act 2014 and amendments to the Children and Families Act 2014 and accompanying Guidance and Regulations.

6. Thinking Carer across the system

By supporting carers we are also supporting the cared for. No one should have to care alone.

In order to ensure that carers receive the right support, at the right time, and in the right place, a Carer who indicates that they require additional support or that their capacity or willingness to continue caring is diminished, should be referred to the local Carer support organisation to have their immediate needs addressed.

Where a Carer indicates they have a health need during an interaction with the NHS, this health need should be addressed as soon as possible, after which the healthcare practitioner should initiate a discussion about the Carer's wider support needs and refer to the local Carer support organisation.

Partnership working and co-operation is key to providing a joined up, seamless service. This will include joint working between the local authority, the NHS, voluntary organisations, education, public health, housing and local communities to support Carers.

Central to this joint working will be the development of local data and information sharing processes between agencies, so that information follows the Carer across their own care and support pathway without them constantly having to re-tell their story. Practical examples of how this can be achieved are included in Appendix Two.

The needs of Carers should also be recognised by commissioners and planned for. Work through the local Health and Wellbeing Board, the Better Care Fund Board, and the Joint Strategic Needs Assessment, will include identification of the needs of Carers, including Young Carers and Young Adult Carers in the local area; this identification will be crucial in avoiding crisis breakdowns.

The local Joint Health and Wellbeing Strategy will include shared strategies for meeting these identified needs, setting out arrangements for working together and the actions that each partner will take individually and collectively.

This memorandum of understanding will be subjected to an annual review.

7. Signatories

Name and title	Organisation	Signature

Appendix Two: Resources to support core principles

Principle 1 - We will support the identification, recognition and registration of Carers in primary care.

The role of the primary care team as the one to which all Carers have access is recognised as being paramount in supporting Carers and maintaining the capacity of Carer to care, if they so choose. There is a need to improve the registration and assessment of Carers, including Young Carers, in primary care so that their needs can be identified more quickly and before their health and wellbeing deteriorates.

Some CCGs run Carer accreditation schemes for practices, to promote innovation and recognise good practice in supporting Carers	http://carersinwiltshire.co.uk/our-services/gp-support/
Some Carer support services work closely with GPs in identifying and registering Carers	http://www.carersleeds.org.uk/
The Carers Trust provides useful advice for primary care staff on practical ways in which carers can be identified in primary care	http://www.carerssupportcentre.org.uk/professionals- 2/resources-for-gp-practices/how-to-identify-carers/
Derbyshire Carers Association has developed a carers pledge which promotes the identification of Carers within primary care	http://www.derbyshirecarers.co.uk/carers-pledge
Carers Support Centre Bristol and South Gloucestershire has a dedicated team which supports practices across the district to identify, inform and support all Carers	http://www.carerssupportcentre.org.uk/professionals-2/gp-practices/practice-managers-carer-leads/

Principle 2 – Carers will have their support needs assessed and will receive an integrated package of support in order to maintain and/or improve their physical and mental health.

Carers have a dual role as both providers of care for the cared for and as clients of services as a result of the caregiving role which affects their own health and wellbeing. Thus, primary care has a unique opportunity to make a telling contribution to improving the lives of Carers.

Primary care teams are already seeking to support carers in a number of practical ways, including offering Carers flexible appointment times, longer appointments, and referrals to a range of local services through Carer/social prescribing schemes.

There is also a need for local agencies to work together in developing integrated support to meet the identified and emerging needs of Carers.

There is an opportunity to build on best practice and use	http://www.healthpromotiondevon.nhs.uk/projects/carers-wellbeing
annual Carer health checks as an opportunity to identify	
Carer needs at a key entry point to the needs assessment	http://www.devoncarers.org.uk/devon-carers
pathway. This service also provides an online booking	
service for carers	
In some areas, GP surgeries have designated Carers Leads	http://carersinwiltshire.co.uk/our-services/gp-support/
and run dedicated Carers clinics, to identify and check the	
needs of carers	
In other areas, and where the Carer agrees, the provision of	https://mycitizenportal.oxfordshire.gov.uk/web/portal/pages/help/other
an online assessment/self-assessment form allows for	
primary care to link more easily with the rest of the needs	http://mychoicemycare.org.uk/i-need-help-with/being-a-carer/carers-
assessment process	assessments.aspx

In some areas, GPs are offering Carers-only appointments on Sundays	https://www.manchestercommunitycentral.org/news/carers-accessing-sunday-gp-appointments
It is also possible to recognise, support and value Carers through the use of Carers passports. In some cases these can	http://www.carersinherts.org.uk/how-we-can-help/carer- services/carers-discount-passport
offer Carer discounts on a range of services	
Some GPs are prescribing Carer breaks, as part of a wider Carer prescription scheme. Guidance for GPs can also be accessed by clicking on this link	http://www.actionforcarers.org.uk/professionals/general- practitioners/surrey-gp-carers-prescription/
In some areas, practice staff can access a wide range of resources to help them support Carers	http://www.carersinherts.org.uk/help-us-help-carers/carers-health-information-for-gps/downloads
All Carers should be given information, appropriate to their needs, about local Carer support services and the rights of Carers to an assessment, including right to request an advocate. In Hackney, the local authority has worked with partner agencies to ensure that local Carers receive advice, information and guidance that meets their individual needs and circumstances	www.hackney.gov.uk/Assets/Documents/carers-information-pack.pdf
Some Carer support organisations have been commissioned to work specifically within general practice, in order to provide integrated support for Carers. In other areas, primary care teams and Carers organisations work in partnership to support carers	http://www.supportforcarers.org/what-we-offer/gp-or-professional http://www.leedsnorthccg.nhs.uk/our-priorities/supporting-carers/

North Somerset CCG, Avon and Wiltshire Mental Health
Partnership NHS Trust and charity Second Step are working in
partnership, "Positive Step in North Somerset", to provide
psychological therapies for people with a range of issues
including anxiety or panic, trauma, obsessions and depression.
Carers receive tailored help thanks to a thriving talking therapies
programme aimed at helping them find the strength to carry on.
The psychological therapies (IAPT) service for Positive Step in
North Somerset has helped more than 500 carers with therapy
and support since launching three years ago

https://www.england.nhs.uk/mentalhealth/case-studies/positive-step/

Principle 3 - Carers are empowered to make choices about their caring role and access appropriate services and support for them and the person they look after.

Carers need to be aware of their entitlement to request to an assessment of their needs in their own right, independent from any assessment of the person for whom they care. Carers' main support needs may be support with their own health or with information and education to help them provide skilled caregiving and support for the cared for, either of which may be best addressed directly by healthcare practitioners at the time. Many areas produce directories of Carer support services and some of these are comprehensive. Depending on identified need, referral to the local Carer support organisation may be the best way to ensure that carers receive the support they need when they need it. Carers will be supported to exercise choice and make well-informed decisions about the support options available to them.

It is acknowledged that Carers are free to choose not to care, or to decide on the amount of care they will provide. Whatever decision a Carer makes should be respected by the staff with whom they come into contact.

The wellbeing needs of the Carer's family will be taken into account when identifying suitable support. The Carer will be supported to plan for life beyond caring, including where the Carer wishes to reduce the amount of care they provide, or where they are no longer able, or no longer wish, to continue their caring role.

Some Carer support organisations provide comprehensive information about Carers' rights	https://www.carersuk.org/help-and-advice/get-resources/carers-rights-guide
Some Carer support organisations also	https://www.sutton.gov.uk/info/200335/at_home/1076/staying_in_your_own_home/4
provide training on the choice and safe use of equipment to help support the cared for or on safe manual handling of the cared for	http://www.birminghamcarershub.org.uk/free-safe-moving-handling-training/

Carers have told us they would also welcome more information and training on the safe prescribing of medication, and for clearer information about the patient's condition(s), its development and the prognosis	http://www.sja.org.uk/sja/what-we-do/community-projects/carers-support-programme.aspx
Carers have asked for clear information on how to access support out of hours and in emergencies	http://www.doncastercarersservice.org.uk/carers_emergency_contact_scheme/ http://www.kentcarersemergencycard.org.uk/
There are a variety of carers emergency contact schemes in operation, some run by Carer support organisations, others run in partnership with the local authority	http://www.carerssupportcentre.org.uk/free-message-in-a-bottle-service/ http://www.yorkcarerscentre.co.uk/adult-carers/carers-emergency-card/
Some Carer support organisations run courses to help carers care with confidence, addressing themes ranging from handling emotions, looking after the Carer's own health, and dealing	http://www.sunderlandcarers.co.uk/caringwithconfidenceprogramme.html http://www.yorkcarerscentre.co.uk/
effectively with professionals and service providers	
Some organisations provide advice and support to carers who wish to return to work after their caring role has ended	https://www.carers.org/help-directory/after-caring

Principle 4 - All health and social care staff will be aware of the needs of carers and of their value to our communities.

Care staff would benefit from Carer awareness training. Provision of Carer awareness training in health and social care induction and ongoing professional development programmes is desirable.

Care staff will recognise signs of distress and diminished capacity that may affect the ability or willingness of Carers to continue caring, so that they can ask the Carer if they are in need of support. Care staff will also be aware of local Carer support organisations so that the Carer can be sign-posted. In some cases, care staff may be able to make the referral on behalf of the carer. Where social care practitioners are identifying a health need as part of their Carers assessment they should have the ability to refer the carer back to their GP for health support.

The aim of this principle is for care staff to work holistically with the Carer and cared for and be aware of Carers' needs from diagnosis, discharge planning and reviews. Staff could provide the carer with information and/or refer early to support to try to avoid a crisis situation or a breakdown in the Carer's health.

Some NHS organisations recognise Carers within their corporate	http://www.gloshospitals.nhs.uk/en/Wards-and-
induction programmes	Departments/Other-Departments/Education-Learning-and-
	Development/Induction/?id=6151
	http://southtees.nhs.uk/patients-visitors/carers-supporting-your-needs-and-rights/
Some Carer support organisations employ hospital liaison	http://www.carerssupportcentre.com/north-
workers to raise awareness of issues affecting Carers across	lincolnshire/information-for-healthcare-pro
local hospitals and other health services	

Some Carer support organisations run Carer awareness training for professional health and social care staff, with a number	https://www.carersuk.org/for-professionals/training/e-learning
segmenting this training to address the particular needs of Adult	http://www.carerssupportcentre.org.uk/professionals-2/carers-
Carers, Young Adult Carers and Young Carers	awareness-training/
Some organisations provide this training online	http://www.ycctraining.co.uk/
Some Carers organisations provide information on the signs of	https://www.carers.org/help-directory/managing-stress
Carer stress	
Some Carer support organisations have produced DVDs and video clips as a more flexible approach to raising awareness with health and social care agencies of the issues affecting Carer health and wellbeing	http://www.sunderlandcarers.co.uk/dvd.html

Principle 5 - Carers will be supported by information sharing between health, social care and Carer support organisations.

We understand that the biggest risk to Carers is the failure to share information sensibly. We will work to remove burden of Carers having to repeat information and will reduce the barriers to effective sharing of information. Improved sharing of information will help to identify vulnerable Carers earlier, improve the identification of Carers and the assessment of their support needs, and could improve the responsiveness of support to the changing needs of Carers.

The registration of Carers in General Practice is key to this as being identified as a Carer will generate a READ code on the Carer's personal medical record and this will accompany that Carer whenever and wherever they use the NHS (by being shown on the Summary Care Record). Within integrated services, social care staff will have access to the Summary Care Record.

Service specifications for many Carer support services, including those that have been delegated to undertake needs assessments on behalf of the local authority, provide for data-sharing and processing arrangements that comply with information governance and data protection requirements.

In some cases, data exchange and sharing between agencies is covered as part of the contract or SLA	https://democracy.wandsworth.gov.uk/documents/s34738/14-565%20Integrated%20Carer%20Support%20Services%20-%20Appendix%20A.pdf
In other cases, data processing contracts have been agreed to share information about Carers, and their support needs, between agencies	Available on request from Jane Weller, Commissioning and Contract Manager, Liverpool City Council jane.weller@liverpool.gov.uk
A Shared Care Record has been developed in Salford, under the	http://www.salfordtogether.com/wp-
Integrated Care Programme to support personalised care	content/uploads/2016/04/Salford-Shared-Care-Record-
planning between health, mental health and social care	<u>Screenshots.pdf</u>

Principle 6 - Carers will be respected and listened to as expert care partners, and will be actively involved in care planning, shared decision-making and reviewing services.

Carers will be actively involved in the planning of care for the cared for. Carers will have their views taken into account when planning care in advance. Carers will be fully engaged in the planning, redesign and shaping of services. It is acknowledged that whilst Carers will be expert in the preferences, context and disease history of the patient, they will often not be expert in the disease(s), its course and management and how to deal with emerging caregiving challenges. Carers may, therefore, still need support from healthcare practitioners to empower them to fully fulfil their role as expert partners.

Services will be continuously monitored and reviewed, with Carer inputs, in order to demonstrate where desired health outcomes are being achieved and to identify those areas in need of improvement.

Involving Carers in the planning of care can have significant benefits for the cared for	http://www.sabp.nhs.uk/advice/care-planning
The contribution of Carers in advance care planning is cited as good practice	http://www.ncpc.org.uk/freedownloads
	http://www.gloucestershireccg.nhs.uk/your-
	services/eolc/advanced-care-planning/
The involvement of Carers in personal care planning is also recognised as being beneficial	https://professionals.carers.org/involving-carers-planning
Carers are also involved in advance care planning and shared	https://www.england.nhs.uk/ourwork/pe/sdm/tools-sdm/pda/
decision-making. The provision of patient decision aids (or	
PDAs) may support the involvement of Carers in this process	http://www.harrogateandruraldistrictccg.nhs.uk/reports-and-
	publications/shared-decision-making/

Carers will be fully engaged in the planning of services. Some areas have reviewed their care market around the needs of carers, in order to promote individual choice and control, and the personalisation/ tailoring of services to meet individual Carer circumstances and preferences	www.hertsdirect.org/hertsmpe
Many NHS trusts have their own strategies for involving Carers	http://www.5boroughspartnership.nhs.uk/basepage.aspx?ID=5697
in the planning, delivery and evaluation of its mental health	
services	http://www.nsft.nhs.uk/Get-involved/Pages/Service-user-and-
	<u>carer-involvement.aspx</u>
	http://www.sssft.nhs.uk/service-users-carers/our-service-user-
	and-carer-charter

Principle 7 - The support needs of Carers who are more vulnerable or at key transition points are identified early.

The use of risk stratification and carer recognition tools will allow for predicative modelling through which to develop the necessary preventive and other support resources to meet the needs of Carers approaching key transition points. The aim of this principles of to protect and support vulnerable Carers and to reduce health inequalities. It is important that commissioners ensure that this data is collected, handled and managed through arrangements that comply with information governance and data protection requirements.

Carers within the following groups face the same challenges and difficulties as all Carers, but often face additional problems in accessing or using support.

NHS Salford CCG and Salford Council use a risk stratification tool to help identify Carers who may need a bit of extra help to live their lives

www.salfordccg.nhs.uk/vulnerable-standards

Action for Carers Surrey has worked closely with local CCGs in developing a Carers recognition tool to determine the level of stress on Carers and can be used to prioritise need and support plans for the Carer. It has been designed to help to support and inform clinical decisions around the role of the Carer

http://www.actionforcarers.org.uk/professionals/general-practitioners/forms-information-and-other-downloads-gps/

Carers aged over 75 – NHS England, Age UK, Public Health England, and other partners, have produced a healthy ageing guide, and a sister publication, "a practical guide to Healthy Caring"

https://www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-2/healthy-ageing/

https://www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-2/healthy-caring/

Young Carers as they leave primary school and approach secondary school, as they leave secondary school to go on to	http://www.scie.org.uk/care-act-2014/transition-from-childhood-to-adulthood/young-carer-transition-in-practice/transition-in-care-
further education, and as they move from adolescence to adulthood	act-children-and-families-act.asp
The National Carer Family Network promotes the rights and views of those caring for a person with a learning disability	http://www.familycarers.org.uk/
Connexions Dudley provides a transition guide for parents/Carers of teenagers with learning difficulties and/or disabilities	http://www.connexionsdudley.org/about-2/resources- publications/
The Children's Society Young Carers in Focus programme and Carers Trust run the Young Carers in Schools scheme to improve the identification and support of young carers in schools	http://www.youngcarer.com/resources/young-carers-schools
Parents as Carers, particularly parents of children with physical or learning disabilities as they leave the family home or as they become eligible for adult services. A directory of local parent carer groups can be accessed at this link	http://www.cafamily.org.uk/what-we-do/parent-carer- participation/what-is-a-parent-carer-forum/
The National Network of Parent Carer Forums exists to develop good practice and effective participation for parent Carers	http://www.nnpcf.org.uk/

Leicestershire County Council runs a 'take a break' scheme for parent carers of disabled children	http://llrchildcare.proceduresonline.com/chapters/p_take_break.html
Lesbian, Gay, Bisexual and Trans (LGBT) Carers	http://www.ageuk.org.uk/health-wellbeing/relationships-and-family/lgbt-information-and-advice/lesbian-gay-bisexual-or-
Age UK has produced a number of guides for older Carers who identify themselves as being Lesbian, Gay, Bisexual or	transgender-in-later-life/
Trans	http://www.ourgateshead.org/news/lgbt-carer-support-group
A number of LGBT Carer support groups exist to inform and advise LGBT Carers about the support available to them and to work with commissioners in representing the views and	http://www.thecarerscentre.org/our-services/adult-carers/reachingout/
interests of LGBT Carers	http://lgbt.foundation/information-advice/Carers/
Carers from Gypsy, Roma and Traveller communities	http://www.carerssupport.org.uk/all-carers/travellers/grt-health-and-
Carers Support West Sussex and the Sussex Traveller	caring
Advisory Group are working in partnership to identify and support the needs of Carers from these communities	http://www.sussextag.org.uk/
Carers Federation in Nottingham provide training, clinics, help and advice in the community for Gypsy, Roma Travellers	https://www.carersfederation.co.uk/services/the-clinic/gypsy-roma-traveller-health/

Military Carers and Military Young Carers - spouses and children in military families may be caring for a parent/sibling who has returned from combat injured, both physically and/or emotionally, or they may be caring for a parent who has health problems while their other parent is away with the military	
Carers Trust provides a national voice for the needs of Military Carers and Young Military Carers	https://www.carers.org/community/blog/who-are-military-young-carers-and-why-do-we-need-raise-their-profile
In Wiltshire, local partners have been running a pilot online support service to carers of people suffering from severe mental illness (SMI) in the Armed Forces Community over a one-year period. This pilot is currently being evaluated	http://www.fim-trust.org/news/the-forces-in-mind-trust-awards-a-grant-to-wiltshire-mind-to-provide-a-pilot-project-offering-online-support-to-carers-in-the-armed-forces-community/
The Sussex Armed Forces Network works to improve the lives of armed forces communities. This links closely with local Carer support organisations, provides Carer awareness training and employs a Carers and Families Liaison worker	http://www.sussexarmedforcesnetwork.nhs.uk/about/
Carers of people with substance misuse problems - since 1997, Derbyshire County Council has funded Spoda to provide services to address the wide range of complex issues facing Carers of people with substance misuse problems. It was recognised that the shame and stigma associated with substance use meant that Carers do not fit well within generic carer services	www.spoda.org.uk

Carers from BAME (Black, Asian and Minority Ethnic) communities	
Bristol Black Carers supports carers and those whom they care for to access mainstream care and health related public services	http://www.bristolblackcarers.org.uk/
Carers First Nottingham City Carers team has African Caribbean, South Asian and Ethnic Minority Carer Support Workers who can offer culturally appropriate information including, language support for South Asian carers	https://www.carersfederation.co.uk/services/adult-carer-support/adult-carers-nottingham-city/carers-federation-support-workers/
Gateshead Carers Association has published an evaluation of its work to support "hidden" carers	http://www.nemhdu.org.uk/news/2016/1/4/gateshead-carers-association-reaching-hidden-carers-project-evaluation-report
Carers and bereavement	
The death of the person being cared for can often lead to a double bereavement – the loss of a loved one and the loss of the caring role. Many health-related charities and carer support organisations offer bereavement support, with many areas running support groups for bereaved carers	http://www.carersinherts.org.uk/how-we-can-help/carer-services/carers-bereavement-group http://carers-network.co.uk/bereaved-carers-support-group/
Young Carers and bereavement - a number of national and local groups support bereaved children, young people and their families.	http://www.griefencounter.org.uk/ http://www.mosaicfamilysupport.org.uk/parents-and-carers4.asp