Who are our carers and how do they contribute?

1. The caring experience
2. The personal cost of caring
3. Services and redesign
4. Involving carers in commissioning
5. Analysis and planning
6. Procurement and contracting
7. Delivering improvement
8. Primary care commissioning for carers

Commissioning for Carers 2013

Click on the circles above for more information
Carers are one of the most valuable assets within our communities. They are people whose contribution commissioners need to recognise, support and nurture. Yet, they are rarely recognised within service and care pathway redesign. Often proportionately little investment is made in making life easier for them.

Carers are as diverse as society itself. They may be any age and come from any cultural background. Many carers are invisible to the commissioning and care system. This is partly because they do not define themselves as ‘carers’ and dislike the label, believing it detracts from their identity as parents, sons, daughters, partners or friends.

This guide aims to provide a simple yet comprehensive route map towards great commissioning for carers. It provides commissioners with an easy to navigate approach, the essential insights that need to shape commissioning work and signposts to valuable sources of further information and good practice.

This resource is designed for:
- Health commissioners based within Clinical Commissioning Groups (CCGs)
- Specialised service commissioners
- Integrated health and social care commissioning teams
- Local authority commissioners with responsibility for social care
- Health and Wellbeing Boards
- NHS England and its Area Teams
- Regional community support groups
It is important to differentiate between carers and paid care workers. We also talk about ‘young carers’. They are young people under the age of eighteen who carry out significant caring tasks.

A carer is a person of any age - adult or child - who provides unpaid support to a partner, child, relative or friend who couldn’t manage to live independently or whose health or wellbeing would deteriorate without this help. Those receiving this care may need help due to frailty, disability or a serious health condition, mental ill health or substance misuse.

Young carers are children and young people who assume inappropriate responsibilities to look after someone who has an illness, a disability, or is affected by mental ill-health or substance misuse. Young carers often take on practical and/or emotional caring responsibilities that would normally be expected of an adult.
1. Who are our carers and how do they contribute?

Your carers are an army of voluntary ‘providers’ who contribute care worth in excess of £74.9 million every year to support your work and the people you commission for.

- **20,000 carers**
  - 4,000 adults caring more than 50 hours a week (1/3 of this group are over 65)
  - 6-8,000 adults caring more than 20 hours a week
  - 9,000 adult carers 45-64 years
  - 7,000 older carers over 65 years
  - 6,000 carers transitioning in or out of caring every year
  - 96 young carers 18-24 years caring more than 50 hours a week
  - 1,200 young carers 5-10 years
  - 2,000 young carers 11-18 years
  - 800 young carers 18-24 years

Your CCG’s caring community (a population of 200,000 people)
1. Who are our carers and how do they contribute?

What carers do and how they contribute

The most important thing that carers do is to help the person or people they care for to remain independent and live the life they choose. They do this by:

**Doing practical things** that otherwise the health or social care system would need to fund. 1.25 million carers in the UK undertake caring tasks for more than 50 hours per week. Two million care for more than 20 hours. 12% of young carers (18-24) care for more than 50 hours a week.

**Contribution to the economy** 2.9 million carers combine paid employment with caring for a loved one. The caring work carers do equates to £119 billion, which makes carers an unpaid provider ‘asset’ within your CCG that contributes more than your entire budget! So ignore carers at your peril.

**Knowing about the person and his or her health issues;** often co-ordinating and quality assuring his or her care; helping the person to self-care by noticing symptoms that might indicate a deterioration in health, proactively managing his or her care so the person can stay as well as he or she can be.

**Providing love, friendship, reassurance and connection for the person;** emotions that are critical to maintaining health and well being.

The 1.25 million carers who provide care for more than 50 hours each week are a full-time workforce greater than the entire NHS!

The bottom line is that our communities and health system simply could not function without people willing to be carers.
What shapes carers’ contributions?

Although carers do not generally choose to care, most prefer to look after their family members or friends rather than have someone else care for them. The tasks that carers perform depend on a number of factors, including:

1. **Who are our carers and how do they contribute?**

   - **The needs of the person:** a person with mental health problems will have very different care needs to a person with paralysis.
   - **The carer’s circumstances:** if the carer works or has other caring responsibilities, he or she might not have the time to perform some caring tasks. Similarly, if the carer has previous expert nursing experience, he or she might take on tasks that other carers would find too demanding.
   - **The environment:** the range of locally commissioned support services; whether the carer lives close by or in the same home as the person; personal finances - whether the person is eligible for state funded care; the carers’ own financial situation.

---

**Key UK Carer Statistics:**

- 12% of people (2 in 25) are carers. That’s more than 6 million in total.¹
- 49% have been caring for more than five years.²
- A third of those who care for someone over 50 hours a week are over 65.³
- 58% of all carers are female.
- 7,000 aged over 65; 9,000 aged 45-64; over 250,000 aged 18-24; 175,000 young carers recorded in census⁴, with the true figure likely to be nearer a million⁵ with 71% of young carers aged 11-18 and the remainder aged 5-10 years.⁶
- One in five people in their 50s provide unpaid care.⁷
- Two million people move in and out of caring roles every year.⁸
- UK carers make a personal, unpaid investment in the health and well being of the people they care equivalent to £119 billion or £18,473 per year for every carer in the UK.⁹
What carers contribute

1. Who are our carers and how do they contribute?

Click on the tabs below for more information:

- Definition
- Who cares?
1. Who are our carers and how do they contribute?

References

1. 2011 Census and 2009/10 Household Survey
5. ibid 1
7. ibid 2
Many carers gain great personal satisfaction from their caring role and want to continue caring. However, caring comes at great personal cost and takes its toll on the carer. Carers experience negative health, social and financial consequences and these have an additive effect:

1. The personal costs of caring

- Isolation and disconnection from family and social networks
- Mental and physical health and well-being
- Money and life chances

To support carers, commissioners need to invest in supporting carers as a critical asset. By working together with carers in their community, commissioners can maximise carers’ health and well-being and in so doing, also improve the wellbeing of those for whom they care.
Carers have comparatively poor health. This is recognised as a critical public health issue. They are therefore a high risk population whom commissioners should make a priority.

Carers tend to neglect their own health; sometimes for practical reasons - like not being able to leave the home to attend appointments or hospital treatment, and sometimes simply because their sole focus is caring for the person they are looking after. They often do not even notice their own health is deteriorating. Carers may also forget to make or miss routine health appointments like ‘flu vaccinations or check-ups with doctors or dentists.

Caring can also limit carers’ ability to take time out to exercise. Reduced income and lack of cooking skills may contribute to excess weight gain or loss. As many as 20% of adult carers increase their alcohol consumption as a coping strategy.

Emotional impacts such as worry, depression and self-harm have been identified in young carers.

Mental and physical health and well being

40% of carers experience psychological distress or depression, with those caring for people with behavioural problems experiencing the highest levels of distress.

33% of those providing more than 50 hours of care a week report depression and disturbed sleep.

Those providing more than 20 hours of care a week over an extended period have double the risk of psychological distress over a two year period compared to non-carers. Risk increases progressively as the time spent caring each week increases.

44% of carers suffer verbal or emotional abuse; 28% endure physical aggression or violence from the person they care for.

Older carers who report ‘strain’ have a 63% higher likelihood of death in a 4 year period.

Providing high levels of care is associated with a 23% higher risk of stroke.

28% endure physical aggression or violence from the person they care for.

44% of carers suffer verbal or emotional abuse.
Carers’ financial problems correlate directly with their time commitment to caring. In other words, the more they care, the more likely they are to find themselves in financial difficulty.

Despite their desperate need for financial support, less than 50% of carers claim the benefits for which they are eligible - including Carers’ Allowance. One survey found that 81% of carers had been caring for over a year and just under 40% had been caring 5 years before accessing benefits. 50% felt that they had missed out on benefits they were entitled to.

Money and life chances

Carers’ financial problems correlate directly with their time commitment to caring. In other words, the more they care, the more likely they are to find themselves in financial difficulty.

Despite their desperate need for financial support, less than 50% of carers claim the benefits for which they are eligible - including Carers’ Allowance. One survey found that 81% of carers had been caring for over a year and just under 40% had been caring 5 years before accessing benefits. 50% felt that they had missed out on benefits they were entitled to.

Caring can also impact in more subtle ways on financial health. For example, caring may:

- Hinder success and promotion prospects at work
- Impact on young people’s educational achievement and longer term job prospects
- Make it difficult for young adult carers to leave home

20% of carers give up work to care.

Carers retire 8 years earlier than the average retirement age.

In 87% of households with working age carers looking after partners, no-one in the household is in paid employment.

65% of carers live in fuel poverty; 52% cut back on food; 74% have difficulty paying essential utility bills and 55% are in debt as a result of their caring responsibilities.
Being a young carer may have a lifelong impact. Young carers are often mature beyond their years and find it difficult to play or socialise with other young people. They miss out on sporting and leisure activities - because they have no time due to caring responsibilities or because they do not have an adult able to support them.

Young carers report problems maintaining new personal relationships\textsuperscript{13} and higher levels of bullying\textsuperscript{14}. Many former young carers continue to have emotional problems into adulthood and ongoing difficulties establishing relationships\textsuperscript{15}. They may have an over developed sense of responsibility for the health and welfare of others that may act as a barrier to balanced relationships.

22\% of young carers experience educational difficulties\textsuperscript{17}. Difficulties are especially common amongst young carers aged 11-15 and include:

- Increased absences and/or lateness
- Failure to submit homework or coursework, or poor quality work.
- Tiredness, poor concentration and/or lack of attention
- Under attainment and restricted education options.

Young carers need support to regain confidence in their own identity to help them to move forward in their lives beyond their caring role.

Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive to enjoy positive childhoods.\textsuperscript{16}
Isolation and disconnection from family and social networks

Social research has established the causal link between social connection and physical and mental well being\textsuperscript{18}. Caring impacts on all dimensions of social and family relationships. Carers report:

- Adverse effects on their social functioning
- Restricted social activity
- Deterioration of relationships with other family members
- Social isolation

We know that carers’ social support networks shrink over time - and both adult and young carers generally have smaller social networks than other people.

This relative isolation and lack of connectedness puts carers at higher risk of mental and physical illness, including depression. Isolation also takes its toll on carers’ self esteem.
References

15. ibid 13
16. ibid 15
18. http://links.jstor.org/sici?sici=0022-1465%281995%2935%3C80%3ASCAFCO%3E2.0.CO%3B2-S
The caring experience

People must always come before numbers. Individual patients and their treatment are what really matters. Statistics, benchmarks and action plans are tools - not ends in themselves. They should not come before patients and their experiences. This is what must be remembered by all those who design and implement policy for the NHS.

Robert Francis, QC

This powerful citation from The Francis Inquiry highlights how critical improving experience of care is becoming for commissioners. The NHS Commissioning Board’s 2013/14 Planning Framework and The NHS Outcomes Framework both emphasise the importance of improving experience of care and treating patients as customers. Commissioning for improved experience is a big shift for commissioners and means doing commissioning differently and in an experience-led way.

A lot of work has been done over recent years to explore how to commission for improved experience - and some innovative commissioning approaches have been piloted and evaluated.

Every caring experience is different. Yet, we know from qualitative research into carers’ experiences that there are common emotional touch points that commissioners can map and work with to pin point how well services are supporting carers and making a difference to their lives.

The Caring Journey Infographic in this section describes some of those key emotional touch points and clicks through to video clips from www.healthtalkonline.org that provide insight into carers’ stories and a taste of what it is like to walk in carers’ shoes. The Infographic also includes exemplar quotes from discovery interviews undertaken as part of experience-led commissioning programmes.

It is important to remember that these clips and quotations may not represent how all carers feel. However, they have been selected as being representative of the experience of many carers by applying rigorous, qualitative research processes and so they typify the experiences of many of those who use health and social care services.
Commissioners seeking to commission in an experience-led way should remember that it is during times of transition that most people experience the ‘high points’ in their experience (when services get it right and are well designed) or the ‘low points’ (when providers and commissioners have failed to understand how it feels like to be a carer and services do not serve carers well).

This means that focusing commissioning work on improving experience during times of transition is especially important and worthy of attention. Times of transition that commissioners can focus on especially to support carers are:

- Becoming a carer
- Dealing with crisis and urgent care
- Discharge from hospital in-patient care
- Rapid deterioration in the person or carers’ health
- After caring is over

About Healthtalkonline

Healthtalkonline is the only source of patient, user and carer experience that meets the rigorous standards applied by NHS Evidence. Healthtalkonline has also achieved the Department of Health Information Standard; a certification scheme for organisations that produce evidence-based health and care information for the public. Any organisation achieving The Information Standard has undergone a rigorous assessment to check that the information they produce is clear, accurate, balanced, evidence-based and up-to-date.
The caring experience
Click on the relevant sections to find out more

Before caring

Becoming a carer

Crisis care

Hospital care

Community care

Voluntary sector support

Inpatient

Outpatient

Juggling life

Before caring

After caring

Keeping myself well

Primary care

Physical & mental health

Pharmacy

GP

Dentist

Click on the tab below for more information:

The caring experience
The caring experience

Before caring

Before caring some people report that life feels ‘normal’ before becoming a carer. They may not realise that anything is wrong with their loved one; or the death of another family member or sudden illness or accident may thrust them into a caring role.

Others may suspect something is wrong with the person they love. The time proceeding diagnosis and to their becoming a carer may be filled with anxiety and worry about unexplained symptoms - and searching on the Internet to find out what is wrong. Often carers feel a sense of relief when they find out what is wrong and get a diagnosis; even if it is bad news. Most carers receive the news about diagnosis during a medical consultation; a nurse is sometimes present. Diagnosis can also become a shared burden for carers and the person as they may not want to tell other people how unwell the person is:

Click here for a carer’s story.

If the person is older, a terminal diagnosis may feel easier to bear.

For others, the transition to becoming a carer is more gradual and life before caring seems more blurred as their loved one’s condition progresses:

Click here for a carer’s story.

Click here to return to The Caring Experience diagram
Becoming a carer

When caring comes suddenly and unexpectedly, for example after injury, sudden illness, unexpected diagnosis or after the death of a parent, people often go into shock:

Click here for a carer’s story.

When a carer’s role creeps up more gradually over time, he or she may find it easier cope and take on more and more caring responsibilities; to a greater extent than they ever imagined:

Click here for a carer’s story.

Becoming a carer may be associated with feelings of grief for the working life and freedom the carer has given up. Taking on a caring role can also be mixed up with feelings of grief for someone who has died - and for the person whom the carer is supporting - for instance if they have dementia or are terminally ill:

Click here to watch a short video about this.

People respond to caring in many different ways. Some loathe it and rage against it. Some do it because they have to. Some may feel a great sense of pride at being able to care for someone they love; someone who has cared for them in the past:

Click here for a carer’s story.

Some carers get a strong sense of satisfaction from doing the best they can for someone they love. Some feel constantly frustrated. Some are surprised that aspects of caring prove to be enjoyable:

...There are even things that I positively enjoy about it if one can actually say that. I’ve taken great pleasure and joy in, she now allows me to, look after her hair which I, we, have daily sessions with that, usually with lots of laughter on both sides. She thinks I’m turning into some kind of rather eccentric hairdresser! And, so that, there is a lot of satisfaction in that. I do get a great satisfaction when I know that she’s nicely dressed and nicely turned out and is feeling good about herself. I love, I think I’ve said this before, I really have enjoyed, cooking and cooking for her and that sort of thing...
The caring experience
Caring for the person

Carers report feeling worried, anxious and stressed about their responsibilities for the person for whom they care. There is often conflict between the needs of the carer and the person, which leaves carers feeling impatient, guilty, angry, frustrated, isolated and trapped - especially in the beginning:

Click here for a carer’s story

Often people being cared for are unaware of the impact their condition has on their family and friends:

And, apparently, my eldest son took me to [town] to catch a train to London on one of the occasions I was going up for treatment and when he came home, he was in tears and he said to my wife, “I took Dad to the station. I put him on the train and I didn’t know whether I’d ever see him again.” I hadn’t realised how much it must have affected them - but I know that there were occasions when it used to make me very grouchy and bad tempered - when it (atrial fibrillation) was happening - because I felt so helpless.

The dynamic between the carer and the person changes. It is sometimes hard to tell where the person starts and the illness ends. Over time, some carers may find this easier to cope with:

Click here for a carer’s story

Being able to talk about each others’ fears and concerns can bring friends, spouses and the person living with the condition closer together; although spouses and family may want to ‘wrap the person in cotton wool’:

You feel all sorts of things; how long is this going to affect us? We were both frightened for a long time! I sort of over powered him to take care – by saying don’t do that!

Spouses can become very close through caring and experience love on a new emotional level:

Click here for a carer’s story
The caring experience
Caring for the person

Dealing with personal care and incontinence is a particularly difficult burden for carers:

Click here for a carer's story

Young carers often have many questions that trouble them that they may not share with others:

Can I catch it? Will it happen to me too?
What caused it? Why us? Is it my fault?
Can I do anything to make it better?
Will the person that I look after get worse or die?
What should I do in an emergency?

Many carers feel ignored by health professionals.

Carers also tell us they feel 'blinded by science' when they talk to care professionals. They need professionals to speak simple language and carers want to be spoken to as equals - professionals in the care of their loved one:

Click here for a carer's story

Carers do not understand how the NHS and social care system works. It seems very confusing. This gets in the way of them supporting and co-ordinating their loved one's care. Lack of communication between services causes carers many problems. Carers say they feel like 'medical secretaries'. Some spend hours 'phoning and emailing around to find out how to access the care and services their loved one needs:

Click here for a carer's story

Carers may even take it upon themselves to actively manage professionals and bring them together in an attempt to co-ordinate care better:

Click here for a carer's story

Click here to read on
Carers often have to fight for the person - to get what they feel is the right care. This work is characterised by many as a ‘battle’ that carers cope with, alongside dealing with all the emotions, juggling caring and other duties and coming to terms with their loved one’s condition.

Carers’ resourcefulness, personal capability and determination to ‘fight the system’ often determines the level of support they get access to:

Click here for a carer’s story

Carers play a critical role in helping health professionals and others gain an accurate picture of the person’s capabilities and keeping the care team informed about changes in the person’s health status:

Click here for a carer’s story

Click here to return to The Caring Experience diagram
The caring experience
Crisis and Hospital Care

Preventing Crises in Care

Emergency admission into hospital or residential care are often the first indicator for professionals that a carer is no longer coping. Carers of people admitted to hospital report ill health, fatigue and interrupted sleep - and generally feeling frustrated.

By investing in proactive planning in case of emergencies and by supporting carers to keep well and maintain their mental and physical resilience, we may help prevent unplanned hospital admissions:

Click here for a carer’s story

Hospital Care

Experiences of outpatients can feel pointless; especially if there is little that can be done. Seeing different doctors and having to repeat the same information is very wearing for carers and the person:

Click here for a carer’s story

Carers perceive that it is the managers of the service that cause problems with scheduling of appointments rather than the professional staff:

Click here for a carer’s story

“We get appointments sent to us, and then a telephone call saying, “Oh they’ve made a mistake.” So we phone the consultant’s office to find what date he wants to see me because the staff concerned are getting it wrong. We shouldn’t have to do that.”
The caring experience

Inpatient care

Inpatient care teams may not be responsive to the person's needs - even if the carer ensures they are aware; especially where people have a limited ability to communicate themselves what is wrong:

Click here for a carer's story

Simple things like failing to respond to the person’s preferences for clothing indicates to some carers that hospital staff care less about the person and more about making life convenient for themselves. That infuriates them:

Click here for a carer's story

Early discharge causes carers anxiety and upset - especially if the person is in pain. They need support from the medical team to help them to know what to do in an emergency:

Click here for a carer's story

Click here to return to The Caring Experience diagram
Primary care plays a critical role, supporting carers with information. People are not precious about who provides them with information. They just want someone to talk through their concerns:

Interviewer: With whom would you have liked to sit down with and talk?

“Anyone to be honest! We would have liked to have known (the diagnosis was atrial fibrillation) when we came out of the hospital. I knew there was something different as when he was on the monitor I could see his heartbeat wasn’t right. But they discharged us without saying anything. Our GP rang a week later and said he’d had a letter from the hospital, saying you have to go on warfarin. But still no explanation! We found out at the hospital eventually that it was AE.”
The GP surgery is often the first point of contact for carers.

GPs play a critical role in putting together the right care package:

Click here for a carer’s story

Carers sometimes feel they are not involved by general practice teams because of issues surrounding recognition of carers and patient confidentiality:

“I quite often go in with my mother when she goes to the doctor, but they still don’t recognise the fact that I’m a young carer and still don’t pay attention or give time to that matter.”

“Her GP won’t discuss her condition with me and I feel isolated from the situation, despite being her full time carer.”

GPs also play a vital role in trouble shooting during a crisis.
Pharmacy and medicines

Medication causes problems and worries carers. Many are anxious about the responsibility that they take on when administering medication.

“A major worrying task is that most young carers are responsible for giving out medication to the person they care for….They were worried that one mistake could be fatal.”

Pharmacists are a source of help and support around medicines and general life style advice:

“We know a pharmacist and asked him if he had any information at all about a person who is taking warfarin and got atrial fibrillation. He gave me recipes, leaflets on what he could and couldn’t eat; a sheet to put up which had different colours for what amount of what he could eat. And we pinned it up.... We have learnt a lot, but not on the internet; from the pharmacist we know and we are in a cardiovascular club and a group for heart patients, which are very useful.”

Unlike GP surgeries, pharmacies do not currently maintain carer registers, even though many carers will often use the same pharmacy regularly.

Dentistry

Carers struggle to know how to arrange a dentist’s appointment; especially if they care at a distance. Accessing services like dentistry is a challenge.
The caring experience
Voluntary Sector

Carers may not know about the support available from the voluntary sector:

Click here for a carer’s story

The voluntary sector is seen by many as a very important source of information about the person’s condition:

Click here for a carer’s story

The voluntary sector can play a critical role to help people act as advocates for themselves by making sure they know the right questions to ask professionals like GPs:

Click here for a carer’s story

The voluntary sector and other services may not be as responsive to carers who are caring at a distance or who work during the day. There may be regional variations in support from the voluntary sector:

Click here for a carer’s story

Click here to return to The Caring Experience diagram
The caring experience
Community Based Care

Carers have mixed experiences of community based care, including community nursing, social care and home care providers.

Carers are often feel ignored by professionals and unrecognised as partners in care:

“The district nurses come on visits about my mother’s ulcers, but I feel invisible. No one says: ‘How are you coping?’ If you say: ‘This is getting on top of me’ then you get a few words of sympathy. The doctors also treat me like I am invisible, they come in and sort out mother then they just go.”

For other carers, the district nurse team, in particular, becomes a lifeline. The district nurses provide moral support, as well as care:

“Click here for a carer’s story”

Continuity and relationship-based care is important for carers:

“The GP was amazing and so was the district nurse, but they changed too often.”

Caring at a distance
Supporting the co-ordination of care and liaising with social care is a particular challenge for those caring for a friend or relative at a distance:

“Click here for a carer’s story”

Meals on wheels
Meals on wheels services do not always work well. Flexibility is important and to have a contingency plan that deals with people not being at home - especially for people with dementia who may forget the service is coming:

“Click here for a carer’s story”

Click here to return to The Caring Experience diagram
The caring experience

Respite care

Carers’ first experience of respite care may impact on their future confidence in respite care. Some are so put off by their first experience, they never use it again.

Click here for a carer’s story
Click here for a carer’s story

Those who have a good experience of respite that is flexible and tailored to their lives can find it very helpful:

Click here for a carer’s story

At the same time they may also feel guilty about being away from the person, perhaps having fun:

Click here for a carer’s story

Because there is so much to be co-ordinated, some carers do not feel they can have time off and they feel guilty about doing normal things their loved one can no longer do:

Click here for a carer’s story

Getting the right type of respite care for each carer and being flexible to design a solution that works for each family is important.

Click here to return to The Caring Experience diagram

Continuing care

A continuing care plan can transform a carer’s life because it ensures that the person gets the care needed:

Click here for a carer’s story

Accessing equipment

Even where people are entitled to equipment, accessing it is often a battle for carers:

Click here for a carer’s story

Carers of people with motor neurone disease face particular challenges accessing equipment:

Click here for a carer’s story

Click here to return to the index page
People’s experiences of home care are mixed; especially home care for people who are vulnerable like those living with dementia or at the end of life. Direct payment schemes are very complex to manage, including accounting - even if there is help available:

Click here for a carer’s story

Carers have to have the strength to be persistent and fight for the home care they want:

And I put that (the fact they got a carer who was the right fit for their family) entirely down to actually just speaking to this agency consistently and saying, “This is what we want. Either you provide it, or we don’t use you.” And I think that’s the only way. Most of them of course are not used to working in homes where there are other people present, that’s quite an unusual set up for them, so they really struggle to know how to manage with a family. And I feel desperately sorry for people who have these people coming in who are on their own, because their ability to report back on the misdemeanours is not going to be as good as mine is, and they happen all the time. The level, the standard is quite shocking, really. So they’re a mixed blessing. Tricky.
The last 12 months it was 24/7. I cancelled my operation for oesophagus cancer four times. The last time was the day before she died. That was the day I was supposed to be admitted for the op. When she had been buried, four days later I went and had the op...20

It’s a terrible thing to have to say and I regret having to say it but you’ve got to think about yourself from time to time. And I keep reminding carers whenever I see them of the number of instances I’ve had where a perfectly healthy carer who’s stuck it out longer than they should have done, dies.

In one case in particular I remember where a, a carer died in the presence of the person he was caring for and nobody knew. She was still watching the television when several hours later a member of the family came into the house and found that the carer was dead and that the person being cared for was sitting ‘happily’ - in quotes - watching the television. How sad. And they then had to go into a home anyway.21
Carers often neglect their own health. This carer shares why it is so important to keep connected and to take time out to relax so carers can keep caring. He reflects on how the only people who can really understand are other carers:

Click here for a carer’s story

People who are caring often live with no sleep, depression, desperation and anxiety:

Click here for a carer’s story

They may also feel anger. Many say it helps to have someone to talk to and a safe space where they are not judged:

Click here for a carer’s story

Being connected with people with similar experiences of caring; with friends, family and the community - and being needed by other members of their family can help keep carers going:

Click here for a carer’s story

Friends and the local community can be a huge source of support and help:

Click here for a carer’s story
Coping with the demands of employers while also caring can be difficult:

Click here for a carer’s story

People may use flexi-time and holidays to help them to juggle home and work. A common criticism is that services are not organised around the person and their carers, especially if they work:

Click here for a carer’s story

Many carers find they cannot cope and give up work. The benefits system is often unhelpful and mitigates against part time working, which would help carers maintain social contact:

I can’t do a full time job any more - and when you look for help, there isn’t any out there.... Because I was working 32 hours a week, I didn’t get any help (benefits). So now I’m down to 22 hours a week, but they say if you earn over £100 a week you don’t qualify anyway.22

...They’ve decided I don’t qualify for disability benefit. I filed an appeal and now have to wait and until then, I’m living on tiny bits of money which is impossible! All I get is pension credit...23
The caring experience

After caring

For so long, it’s like I’ve been living in a dark tunnel that gets narrower. But now I’ve reached the light at the end, I feel completely blinded by it.

How a person copes with life after caring depends very much on the length and complexity of the caring responsibility and the relationship between the carer and the cared for person.

It also depends on how caring ends; be it death, a move to residential care or a change in the person’s needs due to full or temporary recovery. In many cases, there may be a strong feeling of grief - even if the person has not died:

Click here for a carer’s story

The carer may still feel that he or she needs to be strong for others in the family:

I didn’t want to put my grief on my daughters. One was 26 the other 16. But I am lucky to have good friends.... I think there needs to be more help for young people dealing with grief...

Grief and a sense of loss is present - even if there is also a sense of relief and a feeling that the outcome is for the best:

Click here for a carer’s story

Click here to read on
If caring has defined their life, carers may experience a sense of loss at the ending of their caring role, even if it was not a role they wanted. When caring is over, carers often feel they have lost their purpose in life - and even their sense of identity, which may have been shaped by being a carer for many years.

Time lost from education, employment and the impact of caring on personal and family relationships may leave carers feeling they have limited life choices and they may question what else they are able to do now.

Feelings of emptiness and the sense of a void without the company of the cared for person are common. People can feel an even stronger sense of loneliness and social isolation than before. Many carers have lost touch with their circle of friends and may now lack the confidence to reach out to people after so many years.

This is the time when many carers become ill. They are vulnerable to health issues that have been building up over many years of self neglect, physical strain, lack of sleep and stress and this catches up on them now. Low self-esteem, depression, anxiety, and social isolation may also lead to self-destructive behaviour such as alcohol abuse.

Carers are at high risk at this time and need ongoing support to help them rebuild their lives and move on to the next chapter. GPs can be an important support with this.

I got really ill after my mother died. It all came out – all the health issues I had locked away.26
The caring experience
Moving forward

When carers have moved forward, it may become easier to remember the good times and hang onto the positive things about the person and their caring experience:

**Click here for a carers story**

Focusing on the positive memories of their life with the cared-for person before caring started can really help the carer to move forward:

**Click here for a carers story**

Over time, for some, feelings of guilt at moving forward are replaced with positive memories of and associations with the cared-for person; and comfort for the carers knowing that they have done the best they could:

**Click here for a carers story**

Some former carers find a sense of purpose in helping others who find themselves in their same situation - or in raising money for a charity or cause linked to the condition the person they cared for had. This provides them with a renewed sense of purpose provided by giving something back.
References

5. http://westminsterresearch.wmin.ac.uk/10257/
6. http://www.phc.ox.ac.uk/research/health-experiences
7. Transcribed clip from Carers of people with dementia on www.healthtalkonline.org
9. ibid 1
12. ibid 2
13. ibid 4
14. ibid 4
16. ibid 2
17. ibid 4
18. ibid 1
22. ibid 14
23. ibid 14
24. ibid 4
25. ibid 14
26. ibid 14
The clear direction in public sector commissioning is to work with local communities and the people who use services as equals. Co-designing services goes beyond undertaking a consultation exercise. It transforms engagement into a really meaningful process where carers feel part of commissioning and service redesign decisions - and in effect, write the strategy with commissioners.

We can learn a lot about what matters to carers from national research and surveys. However, there is absolutely no substitute for engaging with local people who use services to understand what is working and what we can improve. Furthermore, local engagement is about ‘how we make improvement happen around here’ as much as it is about ‘what needs to be done’. It is about getting people energised to make change happen - and that can only happen through engagement.

Commissioners often voice two concerns about involving people who use services in commissioning work:

- What if we cannot afford to commission what people say matters?
- How can we be sure that the people we engage with are representative of the collective voice?

The challenge facing the NHS is to become truly patient-centred, where patients participate in designing services and are able to exercise choice as customers, whilst seeking always to ensure that no community or part of a community gets left behind.

NHS Commissioning Board
Involving carers in commissioning

Commissioners who work closely with local people tell us people want services that make a difference to their lives as much as to their health.

Research teaches us that what people value most about services are relationships. We also have many useful insights from national research about what matters to carers (see 'The Caring Experience'). These can act as a benchmark so that commissioners can feel confident that when they engage with local carers and similar issues emerge, what is said in the room is how most people feel.

In the beginning I was worried and doubtful as I didn’t know how we would manage people’s expectations - creating a strategy that was going to be far too expensive for the CCG to implement - but when you look at it, it isn’t going to be as expensive because it is about awareness; about prevention - using what we have got already and joining it all up.
4. Involving carers in commissioning

Reaching carers

As well as working with carers who are known to us, engaging with those who have not yet tapped into carer support is vital if we are going to understand how to improve access. Those leading local engagement work have to be especially resourceful and inventive - because as we have highlighted, carers are often ‘invisible’ to the care system.

Engagement leads also need to invest special attention in engaging young carers and those from a range of ethnic and religious backgrounds where caring may or may not be a more integrated part of everyday family life.

The Department of Health is publishing a Smart Guide to Engaging Carers in June 2013. This will cover this topic in more detail - and describe good practice in engaging carers in commissioning as a specific group.

Important sources of support for commissioners to access existing networks of carers to involve in your engagement work include:

- The voluntary sector (including and not limited to Carers UK, Carers Trust)
- Existing local authority carer ‘consultation’ groups and networks
- Peer support groups for parents of disabled children; people with respiratory, cardiovascular, neurological, dementia or mental health issues and those living with drug and alcohol misuse
- GP practices and their patient participation groups
- Pharmacies
- Care homes who can link you with the families of residents
- Home care service providers
- Schools and colleges
- Citizens Advice Bureau
- Bereavement counselling services

Click on the tabs below for more information:

- Involving carers
- Engagement
- Designing your programme
4. Involving carers in commissioning

Engagement and Commissioning

To encourage commissioners and others to embed good practice in engagement, the NHS has commissioned InHealth Associates to produce an engagement cycle framework. The cycle is reproduced here.

Click here for more information on the Engagement Cycle.

Click on the tabs below for more information:
- Involving carers
- Reaching carers
- Designing your programme
As with many aspects of care that apply across a range of health conditions and in a world where we still tend to commission on a ‘condition specific’ basis in health, we face a design dilemma: do we create an overarching strategy that addresses the needs of all carers? Or, alternatively, do we address carers’ needs as part of the work in every commissioning programme we undertake?

The two approaches are summarised on the infographic here.
4. Involving carers in commissioning

Designing your commissioning programme
The pros and cons of different designs

**Umbrella Approach**

**Pros**
- Enables primary focus on the common aspects of carers experiences
- Facilitates joint commissioning with local authority
- May enable a networked approach to service development and economies of scale

**Cons**
- May make it more difficult to integrate carer services within condition specific care pathways

**Integrated Approach**

**Pros**
- Enables primary focus on the needs of those caring for people with specific conditions
- May improve integration of carer support as part of integrated care pathway design
- May facilitate involvement of people who are cared for in sharing their insights and concerns about those caring for them

**Cons**
- May lead to fragmentation and duplication of carer support services and prevent economies of scale

There is no right or wrong answer. Decide what suits your local situation. Test out your decision and change direction if it is not working for you.

A word on staff engagement

Often when we do commissioning work, we forget that front line staff and clinicians are patients and carers too. As well as bringing a wealth of experience to the table from the jobs they do, remember that many of your staff will be carers. So make sure they have their say in your commissioning work wearing both hats.
References

1Experience Led Commissioning 360 Degree Audit Archive. (2012) GCA Ltd, Abbots Langley
Key facts to frame your commissioning analysis and planning

Around 60% of people will be a carer at some point in their lives.

In a population of 200,000 people, around 12% will be carers. Click here to remind yourself about the make-up of your carer community in more detail.

The financial value of the work that unpaid carers contribute adds up to more than the total NHS budget. Without carers, the care system you manage would collapse.

Carers form a substantial and growing proportion of the population of your area. Over the next 30 years, the number of carers will increase by around 60% as the population ages.

Carers are often invisible to the system as they do not define themselves as carers.

Most carers are over 50 years old. Carers over 65 account for a third of those providing more than 50 hours care a week.

High stress levels, together with social exclusion and financial problems may leave carers vulnerable to depression and anxiety. Harmful coping mechanisms such as self-harm in young carers, alcohol misuse or smoking may exacerbate health problems.

Carers have significant health problems of their own. Around 60% of adults over the age of 65 have at least one long-term condition with 18% living with two or more long term conditions - and carers over 65 are no different.

Carers have higher prevalence of physical illness, particularly stroke and other cardiovascular disease and are more likely to die prematurely.

Many carers live with debt and in poverty. The majority do not claim the benefits that they may be entitled to.

Inappropriate caring roles or long hours of caring are likely to have a detrimental impact on young carers' lives and life chances, including their health and educational achievement. Commissioners have a statutory duty to support them to achieve their potential and to have the same opportunities that other young people enjoy.
Designing your commissioning approach

The first design challenge is to decide whether to put in place one overarching commissioning strategy and plan for carers (the umbrella approach) or whether every relevant commissioning strategy you develop will address carers’ needs as an integral part.

Click here to weigh up the pros and cons of each:
Ask the right questions; start with the end in mind

To complete a robust needs assessment, for each of these critical commissioning questions, you need to understand in depth:

- Who are we commissioning for?
- What assets have we got already in this community to help achieve our desired outcome?
- What currently commissioned services are working well and adding value for carers and their families?
- What services are not adding value that we could decommission?
- What services do we need to improve and change?
- What are the options to deliver that change and improvement?

You can work with a range of partners to build and improve your data set. Make sure you build on data already collated in your locality including:

- Previous carer commissioning strategies undertaken by the Primary Care Trust or Local Authority
- Joint Strategic Needs Assessment
- National and local surveys and other forms of needs assessment undertaken by voluntary sector organisations
- Voluntary sector registers of carers
- Local authority or school registers of young carers
- Statistics for those claiming Carers Allowance and other benefits that signal someone is a carer
- Statistics from Carers Needs Assessment undertaken by social care
- Data about care home residents and those receiving home care from social care or private providers
- Data from other health and care providers e.g. NHS community or acute trusts, pharmacies

It is likely that you will identify many gaps in your data set. Recognise the gaps, put in place strategies to start collecting this data - and continue your work.
Who are we commissioning for?

Carer epidemiology
You can only assess carers’ health needs within your population if you know who they are.

Not being connected with carers and lack of data about the specific health needs of your local carer population - as well as lack of insight into the needs of those whom they care for - is not an impediment to improving outcomes through commissioning. It just means you need to recognise the limitations of your current data set and work with a set of assumptions when planning that may change as your data improve.

You can draw some conclusions about the health status of carers based on what you know about the general health of your community at different age groups e.g. if you know that in your locality, 50% of those over 65 are living with a long term condition, then the chances are, that is also true of carers over 65 as well. This data is easy to access already.

Quantitative data will always be important and you will never have the whole picture. Accept and work with what you have. If having more quantitative data would improve your ability to make decisions, set up processes to collate and collect it. If not, work with your assumptions and learn by doing, improving care and listening to what carers and their families say is working for them as you go.

Using this dataset as a benchmark, map your caring community. Click here to view a benchmark ‘CCG Caring Community’. Based on your population:

- How many carers in each age group would you expect to have?
- How many carers do you know about and have links with?
- How many are claiming carers allowance in your area?
- How many carers are already using the services you provide?
- How many carers do you calculate are invisible to the system just now?

The public health or business analytics team that supports your commissioning will be able to help you complete this mapping exercise, using census data and other sources. Be aware of the limitations on census data. Even the new census data will probably be an underestimate because if people do not define themselves as a carers, they will not complete the relevant section of the census. Put in place a plan to work with the voluntary sector and other providers to improve the quality of your demographic and prevalence data, moving forward.

Click here to go back to the index page

Click on the tabs below for more information:
- Key facts
- Designing your approach
- Assets mapping
- Policy

Carers UK’s Key Facts 2012 provides lots of useful National benchmark data.

Click here to view ‘Facts about Carers 2012’
Assets mapping helps answer the question: what have we got already?

Asset mapping is the process of creating an inventory of the people, businesses, organisations and institutions that create a community. The asset mapping process identifies local resources that have the potential to provide support, programmes, services, funds or in-kind gifts to help achieve quality improvement for people. By understanding the social, material, and financial assets within your community, you can discover local networks of resources that you can target when developing commissioning intentions, to build on a broad base of support and partnership.

Understanding community assets

A community asset is a quality, person or thing that provides an advantage, provides resource or adds value to an organisation or community.

- **Level 1**
  Gifts, skills, and capacities of the individuals living in the community.

- **Level 2**
  Citizens’ organisations/networks through which local people pursue common goals and aspirations.

- **Level 3**
  Institutions present in the community, such as local government, hospitals.

The infographic overleaf provides an overview of the assets you can map and develop within your community to support carers.
Assets mapping:
This assets map is a starter for 10. Develop your own version with all the local support and services already in place mapped for carers.
You need to build the most comprehensive picture you can about currently available services. You will have already started this process with assets mapping.

Find out how carers are using current services; what is working well - what can improve; the capacity and capability of current services that are working well to expand - and what resources it would take to expand that capacity and capability.

Find out also what services are not working well and adding value; and why.

Explore with providers what it would take to exit the market - and how the resources being used to fund those services could be diverted to other work.

Explore with people using any services what it is about those services you are thinking of decommissioning that adds value for them - so that can retain and build that value into future services you commission.

Your local carer community can also tap into national sources of support. Make sure you include those in your assets map too (especially web-based resources). Your local service use review should cover at least:

- Carers’ health checks
- Carers and respite
- Carers and work
- Carers and benefits
- Carers and education
- Lifestyle and health improvement services for carers
- Carers and counselling services (including bereavement)
- Training for carers e.g. medicines management, lifting, communicating with and support people with mental health issues etc.
- Professional and clinical support and advice for carers around managing medicines
- Peer support and social networks for carers
- Information, signposting and advisory services

You also need to find out from all your providers e.g. hospitals, GPs, pharmacies, dentists, opticians and the voluntary sector broadly - not just those who specifically support carers - what they do to support carers; what new initiatives they have planned - and what is stopping them doing more. For example, do pharmacies and GPs have carers flagged in their systems and how do they support them differently as a result of having this register?

Click here for information about a range of resources available at National level from Carers Trust.
Policy check list

Key policy papers you need to understand to frame and plan this work are:

**Adult carers**

- Recognised, valued and supported: Next steps for the Carers' Strategy (2010)
- Caring for our future: reforming care and support' provided two core principles (2012)
- Quality and Outcomes Framework for general practice (Management 9) indicator: ‘The practice has a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment.’
- Everyone Counts: planning for patients in 213/14 (2012)

**Young carers**

- Replace with: Recognised, valued and supported: Next steps for the Carers' Strategy (2010): ‘Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive and to enjoy positive childhoods.’
- Convention on the Rights of a Child. (1989) United Nations: ‘Every child has the right to participate fully in family, cultural and social life. It is an integral part of the role of all health and social care services to uphold this convention.’
- 0-18 years: Guidance for all doctors General Medical Council (2007): ‘Doctors should be aware of the needs and welfare of children and young people when they see patients who are parents or carers, or who are cared for by children or young people.’
- Working together to support young carers and their families: A template for a local memorandum of understanding (MoU) between Statutory Directors for Children’s Services and Adult Services

A more comprehensive overview of this policy context in relation to carers is provided in Supporting carers: an action guide for GPs.

Click here to view this guide.
References

There are endless possibilities and ways to design support for carers; some of the best ideas may not yet have been conceptualised or tested.

Use your commissioning work with carers and the people they care for - and a wide range of providers - to explore all the possibilities and come up with innovative service solutions that build on the assets you already have within your community. Be open to good practice from other areas too. Model good practice that works well.

Reach out to communities that have already succeeded in improving services and ask:

What did you do and how did you make it happen?
What have you learnt?
How would you do things differently to accelerate your progress if you were starting over again?
What can you share to help us accelerate our progress and replicate your good practice approach?

The Good Practice Infographic showcases some exemplars of good practice across the different stages of the carers journey. Click here to see the Good Practice Infographic.

Click here to visit www.carershub.org for many more good practice examples to stimulate your thinking.

Click on the tab below for more information:

- Good practice infographic
- What works?
What we know works

There are a number of changes in behaviour and clinical interventions that we know impact on carers’ well being and a number are backed with research evidence. They include:

**Personal care training for carers:** research has found that providing personal care training for carers resulted in a higher proportion of patients who have had a stroke achieving independence at an earlier stage, and reduced the need for physiotherapy and occupational therapy. There were also significant reductions in carer burden and improvements in mood and quality of life for carers and care recipients. This was also an RCT.

**Listening to and involving carers as partners in care planning:** this obvious and simple change in professional behaviour not only makes carers feel valued and acknowledged. It also improves care quality and reduces cost. Carers know the people they care for better than anyone. Their insight can be extremely useful to health and social care professionals to support care planning and diagnosis of emerging medical or other problems requiring intervention. When carers are involved as equals, they can better support care plan implementation and will own the plan because they helped to shape it. Research into the benefits of involving carers as partners in care has focused on improving well-being. Evaluation of four re-ablement programmes in England found that involving and supporting carers can improve re-ablement of patients.

**Keeping carers connected:** carers perceptions of having access to social support alone are associated with positive mental health outcomes for carers. Putting in place support so that carers can keep connected is vitally important to carers’ resilience and to combat depression and feelings of isolation and frustration.

**Proactive relationship-based care and respite:** studies have shown that providing carers with breaks, emotional support and access to training can significantly delay the need for the person receiving care to go into residential care. It may also prevent emergency admission to hospital. One study tracked people aged over 75 years and found that 20% of those needing care were admitted to hospital because of the breakdown of a single carer on whom the person was mainly dependent. Another study found that issues related to the person’s carer contributed to hospital readmission in 62% of cases, with carers of people admitted to hospital more likely than other carers to be experiencing ill health, fatigue and interrupted sleep; conducting at least one intimate task and generally feeling frustrated. These studies suggest proactively looking after and supporting carers mental and physical well being could reduce health and social care costs and improve outcomes for both carers and those that they care for.

**Emotional support and access to talking therapies e.g. CBT:**

**Health checks for carers**

**Click on the tab below for more information:**

- Services and redesign
- Good practice infographic
Good Practice Exemplars: carer support services

Click on the diagram below for further information

- Identifying carers
- Voluntary Sector
- Supporting carers
- Pharmacy
- General Practice
- Caring at end of life
- Preventing hospitalisation and crisis
- Carer mental and physical wellbeing
- Supporting professionals

Click on the tab below for more information:

- Services and redesign
- What works?
Good Practice Exemplars: carer support services
Identifying carers

Salford Carers Centre Primary Care Liaison Service
The Primary Care Liaison Service works with health and social care professionals from GP surgeries, community health services and Salford Royal Foundation Trust to enable them to identify and support carers and refer them to Salford Carers Centre.

For further information please click here

Support of vulnerable carers through a ‘single point of contact’ (SPOC) service, Gateshead, South Tyneside and Sunderland
The SPOC service is a confidential telephone signposting service for carers of people using drugs or alcohol. The service is delivered by First Contact Clinical, a social enterprise working in Gateshead, South Tyneside and Sunderland. Clients or customers seen by the primary care team are asked if their family or friends would benefit from some advice and support about drug or alcohol use or if they have a caring role themselves. If they say yes, the practice team member telephones SPOC, giving the carer’s name, telephone number and consent to contact.

For further information please click here or email enquiries@firstcontactclinical.co.uk

The Carers’ Resource, Airedale, West Yorkshire
Specialist carer support officers (CSOs) of the Carers’ Resource are directly linked with GP surgeries and hospital wards /departments. They provide comprehensive support for carers and encourage confident and regular carer identification. CSOs are also attached to other multi-disciplinary teams involved in integrated service delivery (e.g. memory clinics, community mental health teams, and child development centres). They:

Input into the training of health and social care professionals

Assist with the induction of staff in partner organisations

Contribute to multi-agency planning and service reviews.

Support hard to reach (hidden) carers

Train carers (informally and formally)

Ensure carers are offered services which promote their dignity, establish them as equal partners

For further information please click here or email director@carersresource.org

Click here to return to The Good Practice diagram
Good Practice Exemplars: carer support services

Supporting professionals

Primary and community care development worker, Worthing and District

This role was funded by West Sussex County Council to:

Raise the profile and awareness of patient/carer issues amongst primary and community care professionals

Work with GP and community teams to improve their support to carers

Ensure that primary care is encouraged and supported to develop systems and protocols that effectively support carers

Increase ‘health awareness’ amongst carers themselves to help reduce demand on GPs and other health care professionals.

The development worker links with over 30 GP practices across Adur, East Arun, Worthing and Chanctonbury. Each practice has a named carers’ lead or link worker who has a responsibility to monitor the practice’s carers register, identify carers and offer a referral to the carers support service, update carers information in the surgery and liaise with the development worker on ongoing carer initiatives e.g. ‘flu vaccinations for carers, or health promotion events. Carers are encouraged to ask a member of the practice staff to identify the carers’ lead for them, or they can look for the person wearing the ‘Are you a carer - ask me!’ badge

For further information please click here

Click here to return to The Good Practice diagram
Good Practice Exemplars: carer support services
Preventing hospitalisation and crisis

Hospital Care
Crossroads Care Coventry and Warwickshire, NHS Coventry and Coventry City Council
When a stroke patient has completed the first part of treatment through a hospital, a meeting is arranged between a Crossroads Care support worker, the patient, the carer and a physiotherapist, to look at the goals and decide upon a rehabilitation plan. The support worker, who has completed intensive training with the physiotherapy department, comes to the patient’s home for a two/three hour period to help with exercises, thus giving the carer respite, during which The Carers Trust can help the carer access other services, such as support groups and activities.

For further information please click here

Bristol and South Gloucestershire Carers’ Centre, NHS South Gloucestershire
A Carers’ Support Worker, based at Frenchay Hospital, supports carers through the hospital pathway and discharge process. Carers are offered emotional and practical support and services run by the Carers’ Centre; training in providing care; emergency planning; and support groups. The Carers’ Centre has worked with hospital staff to improve awareness of carers’ issues and hospital practice. Ninety one families were supported in an 18-month period, saving 300 bed days.

For further information please click here
Good Practice Exemplars: carer support services

General Practice

Highview Medical Centre, Potters Bar

This GP practice won the UK Caring for Carers Award in 2010 for its work. The practice has a carer lead who maintains the carers’ register, keeps the notice board that displays information for carers and young carers up to date and signposts carers to other services and information. When a carer is identified he or she is asked to complete a registration form. The carer’s electronic record is ‘read coded’ so that the carer is identified as soon as his or her record is accessed. Each carer is provided with a welcome pack that contains information including:

A leaflet about Carers in Hertfordshire

A copy of the most recent carer newsletter (Care Waves)

The young carer pack also includes an information sheet and a link to the young carers’ website.

Once identified, carers are allocated a named GP and given priority booking of appointments in recognition that carers can often only attend when they have alternative arrangements in place to look after for the person they are caring for. Carers are offered an annual ‘flu vaccination and health check;

GP are careful to ensure that they specifically think about depression in the check-ups.

Parkfield Medical Practice, Wolverhampton

Monthly GP-led clinic for carers of 15 minute appointments providing general health checks including blood pressure, weight, depression screening, alcohol history and vaccination advice. The clinic appointments are also used for signposting carers to benefits advice, and support from carers’ organizations and to provide information about emergency care planning and eligibility for social services carer assessments.
Good Practice Exemplars: carer support services
Pharmacy

Belfast Carers’ Centre and Boots Wraparound Health Promotion Project

Funded for one year by the Pfizer UK Foundation, this project provides one-to-one information and support to carers aged 65 and over in their own homes. Carers are offered health assessments and tailored support and information on nutrition, exercise, emotional well-being, coping strategies and other health related issues. The service also offers emotional support and signposting to other services such as free health checks at the local Boots chemist.

Carers with health needs are identified and referred to the service by the Carers’ Centre, social work teams, local charities and voluntary groups such as Age UK and the Alzheimer’s Society or through self-referral as a result of leaflets or word of mouth. A Health promotion officer visits the carer at home for an hour once a week for 6 weeks. The project has helped to identify carers in isolated and socially deprived areas and has successfully developed a holistic approach for the support of older carers.

Carers are offered health assessments and tailored support and information on nutrition, exercise, emotional well-being, coping strategies and other health related issues.
Good Practice Exemplars: carer support services
Voluntary Sector

Carer centres and services provided by local and national carers’ charities are a very valuable source of help and support. Organisations such as The Stroke Association, Parkinson’s UK, The Alzheimer’s Society and Mind also provide excellent condition-specific information and more general support for both people and their carers. Through these organisations, carers can access training on topics such as first aid, moving and handling, and stress management; meet other carers in support groups or receive one to one support from trained workers, including counselling. They can also get help with applying for benefits - or even receive respite breaks giving them a much-needed break.

The Carers Trust in its UK network, including 85 young carers’ services. Each Carers’ Centre delivers a wide range of services including:
- Finding hidden carers via outreach in GP surgeries, hospital wards and schools.
- Finding the right information for every carer, whatever their circumstances.
- Making sure carers’ voices are listened to by local decision makers.
- Supporting carers emotionally and practically throughout their caring journey.
- Helping to make caring a positive experience by helping carers to share experiences, ensuring access to breaks, education, training and employment.

Find your nearest Carers’ Centre at www.carers.org

Young Carer Services provide specialist advice and support for carers under the age of 18. A full list of local Young Carer Services is available at www.youngcarer.com.
Support on prescription, Cambridgeshire
In 24 GP practices in Cambridgeshire, GPs issue carers with a free prescription to contact Crossroads Care Cambridgeshire (www.crossroadscarecambridgeshire.org.uk) who will visit the carer and help them access the support they need and want.

If the carer wants a break, it can be booked directly through Crossroads Care (now The Carers Trust) and at no charge to the carer. There are also free support group sessions that carers can join. The cost of the prescriptions is underwritten by commissioners (NHS Cambridgeshire) and is available for carers of any age. GP commissioning groups have supported expansion of the service to all 77 practices in Cambridgeshire. As one GP said:

“Previously, we were required to compile a carers’ register. But what do you do with it? Now we’ve now got a real resource we can attach to it.”

For further information please click here or email care@crossroadscarecambridgeshire.org.uk

Richmond Dementia Café, Richmond-upon-Thames, Surrey
The Carers Trust in partnership with the Alzheimer’s Society, with support from Richmond NHS and the London Borough of Richmond upon Thames, provides carers and people affected by dementia the opportunity to socialise in a friendly and welcoming environment, supported by a skilled staff team. The café is open on the first and third Saturday of each month from 11am – 3.30 pm and provides respite, advice and support, social opportunities and activities to tackle isolation. Transport is provided when needed. Should carers want to take time out for an hour or so, for example to attend support groups, or visit the shops, there is provision to care for 10 people with dementia within the café.

For further information please email richmonduponthames@crossroads.org.uk

CLASP the Carers’ Centre, Leicestershire and Rutland
Counselling is provided entirely by volunteers who are coordinated by a professional counsellor. The coordinator takes referrals, makes the original assessment, matches carers with counsellors and provides supervision and support. CLASP works with several higher education institutions which provide trainee counsellors as volunteers whose work at CLASP counts towards a counselling qualification. Carers are initially offered six sessions, which can be extended if necessary.

For further information please click here
Good Practice Exemplars: carer support services
Supporting carers to successfully juggle life and caring

Swindon Young Carers Standards Award scheme for schools and colleges

"Thank you for coming into my school. I felt alone but your assembly made me realise that I don’t have to do things by myself.

Young carer"

This awards scheme assesses schools and colleges against set standards for support provided to pupils/students who are young carers. The standards, developed in consultation with young carers, aim to ensure that young carers are identified, their needs are individually addressed, relevant provision is put in place and the impact evaluated. Schools and colleges that achieve these standards are given an award (Standard 1 to Standard 4) to recognise their commitment to supporting young carers.

For further information please click here

Carers’ Support (Bexley): Welfare Benefits Advice Service

Carers’ Support Bexley’s welfare benefits advice service is managed by an experienced welfare benefits advisor. When a carer first contacts the Centre, he or she is offered a welfare benefits “check”. If the service identifies that there are benefits that the carer or cared for person can claim, a worker will arrange to meet with the family to complete the forms. The service manager also holds welfare benefits “surgeries” at the offices of other voluntary organisations and gives talks to groups of carers and professionals to raise awareness about entitlements, and carers’ issues in general.

The Centre is registered as an “Alternative Office” with the Department of Work and Pensions (DWP). This means that the service manager can verify documents (rather than sending them to the DWP) and date stamp claim forms, so that the person’s date of claim becomes the date that the Centre is first contacted.

For further information please email info@carerssupport.org

Training for carers

Carers Direct runs online self-study learning programmes to help carers in their caring role.

The programmes help carers to:
Understand how the care system works

Understand how caring affects their life and enable them to balance their commitments and manage their time and finances more effectively

Communicate more effectively with the person that they care for as well as health and social care professionals

Understand the emotions that they may experience in caring and find practical ways to deal with these emotions.

For further information please click here

Click here to return to The Good Practice diagram
Good Practice Exemplars: carer support services
Caring at end of life

To learn more about programmes set up to support carers of those at the end of life please click here and here.

Moving forward
For more information on the Suffolk family Carers project, which supports young carers who are moving on into education and work; and transitioning from child to adult services: click here.

To learn more about work in North Wales that helps older carers find the best solution when they are no longer able to care for a child with learning disabilities please click here.
References


5. West Byfleet (1998), Pilot Study in West Byfleet, Surrey: Developing a whole system approach to the analysis and improvement of health and social care for older people

Market development is a key commissioning task. Maintaining a dialogue and understanding in depth the business model of both current and qualified providers is a prerequisite for great commissioning.

Market development initiatives include:

- Running provider dialogue events (virtual or face to face) on a regular basis to keep providers up to speed with commissioners’ thinking and likely changes in service specification
- Involving providers in commissioning work so that their ideas and insights inform strategy development
- Funding ‘umbrella’ organisations that support existing and new voluntary sector providers and social enterprises to get started, share economies of scale e.g. by offering centralised business support services - and develop sustainable businesses. These umbrella organisations are also a great source of insight about the business challenges third sector providers face
- Seeding innovation through small grants; providing innovation management support to get innovative ideas off the ground
- Supporting providers to adopt coproduction principles. Coproduction is about those who use services delivering them in other words, it is about carers helping each other to stay resilient and healthy. The People Powered Health programme funded by NESTA has produced a directory of good practice examples of coproduced service, click here for more details on this directory.

Click on the tabs below for more information:

- Workforce and provider development
- Social value
- Specific funding allocations
- Contracting
Commissioners need to think about investing in provider and workforce development.

Making services more responsive to carers often requires only small tweaks in service design. However, it does require big changes in front line teams’ attitudes and behaviour towards carers - and recognition that carers are resourceful experts and knowledgeable partners who play a major role in co-ordinating and quality assuring the clinical care of their loved one.

A big part of carers’ interaction with the NHS is with primary care. GP practice teams need to be a focus for commissioners. Pharmacies, community care and the acute sector providers also need to be developed. Most of the change does not require new work. It just requires work to be done differently.

Changing workforce culture is also key. Setting out with the intention of driving significant change in attitudes, behaviour and professional practice through commissioning requires investment in change management.

Explore with your providers - as part of market and provider development - the barriers and opportunities around workforce development; and what needs to happen to change culture and professional practice.
7. Procurement and contracting

Social value

The Public Services (Social Value) Act² came into effect in 2012. It seeks to rebalance the public services market in favour of smaller, community-based social enterprises and charities and requires local authorities and the NHS to value providers’ local knowledge, expertise and connections within procurement processes. It is hoped that this will help charities and small businesses win a greater share of the public services budget.

Social value requires commissioners to adopt a more sophisticated procurement approach - both in terms of how they determine value - and how they measure outcomes. Social value considers the wider social and environmental impact when short listing suppliers and asks:

“If we spend £1 on public services, how can that £1 add value and produce a wider benefit to the community?”

Understanding providers’ social value proposition is going to become an increasingly important part of procurement in health and social care. Commissioners need to get to grips with the concept. Click here for a useful guide to the legislation.

All procurement work undertaken for support services for carers should recognise and reward social value.

Click on the tabs below for more information:

- Market development
- Workforce and provider development
- Specific funding allocations
- Contracting
Specific funding allocations

Between 2011 and 2015 and as part of the Government’s Carers’ Strategy, an additional £400 million has been provided in allocations to Primary Care Trusts in England (and CCGs subsequently) to improve support for carers of all ages. Councils receive a Carers’ Grant within their General Local Government Allowance Grant, rising in line with inflation from 2011-15. Added together, this is a significant amount of money that could make a real difference to the lives of carers.

As well as this allocated funding for carer support, commissioners can choose to invest more in supporting carers if they feel it is a priority.

Personal budgets

Government policy is moving towards giving carers autonomy and choice about the services they want to commission in the form of a personal budget. However, giving carers personal budgets does not mean commissioners abdicate responsibility. Personal budgets are still in their infancy. People need a lot of support so that they can become effective ‘personal budget commissioners’. Where personal budgets are available, commissioners need to see their introduction as a major change and invest in supporting carers to develop their capability and skills so that they are able to commission effectively for themselves.

Commissioners also need to ensure carers have really good information about the services available locally so that they know what their options are and can put together the right mix of services.

Carers play a vital role in our system and must receive help and support from local organisations. Following a joint assessment of local needs, health commissioners need to agree policies, plans and budgets with local authorities and voluntary groups to support carers and where possible using direct payments or personal budgets.

Click on the tabs below for more information:

- Market development
- Workforce and provider development
- Social value
- Contracting
7. Procurement and contracting

Contracting

Commissioners are recognising that contract design can have a big impact on how providers respond. There is currently a move towards more collaborative approaches that encourage providers to work together and integrate care. A number of case studies are available at the Right Care website. Examples include: the prime contractor model, the COBIC approach and alliance contracting. These models may work especially well to support contracting for carer services and social value as they enable a range of providers to work together to deliver shared outcomes and improvement for carers.

Outcomes, monitoring and evaluation

Indicator 2.4 of the NHS Outcomes Framework 2013/14 within the domain ‘Enhancing Quality of Life for Long term Condition’ focuses CCGs on improving health related quality of life for carers as measured by the average health status score for individuals reporting that they are carers, derived from responses to the EQ-5D survey instrument. This means that clinical commissioners will be held to account for improving quality of life for carers within their communities by the NHS Commissioning Board.

As well as national measures like this one, commissioners can define local outcomes that reflect local areas for quality improvement and set their expectations for how providers will add social value and deliver services that address what matters to people and families.

There’s the question of proving social value: how does that intangible sense of “doing good” show up on the spreadsheet?
References

2http://www.legislation.gov.uk/ukpga/2012/3/contents/enacted
3http://www.rightcare.nhs.uk/casebooks
5http://www.lhalliances.org.uk/
Once we have analysed data and planned our commissioning approach, worked with carers to understand how best to engage them in commissioning, explored what matters to them, worked with carers to specify and co-design services that build on what works, procured those services and put in place ways of tracking progress, the final piece of the commissioning jigsaw is to lead and oversee progress towards service improvement.

Delivering improvement is a change management challenge. Whilst managing change can seem daunting, there is a lot of evidence to help commissioners understand how to manage change effectively. This has been summarised as The NHS Change Model and provides a helpful way of thinking about making change happen.

Click here to find out more about The NHS Change Model.

The NHS Change Model is designed to help both commissioners and providers improve how they manage delivery of NHS goals for quality and value. It creates a common language for change. There are eight components in the NHS Change Model based on evidence about what works and NHS managers’ experience of the critical success factors in NHS improvement work. The model was created by bringing together experts in the field with those who have succeeded in making change happen at the frontline.
The three-level commissioning model

**CARER CHAMPIONS**

RCGP has developed a network of GPs as ‘Carer Champions’ who can support improvement work and commissioning. Click here to find out who your local champion is.

**Level 1: Primary care**
- Increased identification and signposting of carers

**Level 2: Carers organisation**
- Carer support, advice and advocacy

**Level 3: Health services support**
- e.g. Community rehabilitation team, district nurse support

**Level 3: Social services support**
- e.g. Emergency plan, respite

**Level 3: Third sector support**
- e.g. Carer support groups, day centres

**CARER AMBASSADORS**

RCGP has developed a network of carers trained as ‘Carer Ambassadors’ who can support improvement work and commissioning. Click here to find out who your local ambassador is.

---

**The RCGP three level model for improvement**

Improving support services for both adult and young carers is a complex change process because services need to reflect the diverse needs of carers of all ages, ethnic and social backgrounds. Successful improvement also requires co-operation across health, social care and the voluntary or third sector.

To simplify how we think about this complex change, the RCGP has devised a three-level change model.

Commissioners who want to drive improvement in carer support services need to work with providers at all three levels to embed improvement and change, applying the principles of good practice in change management, summarised in the NHS Change Model.
The three-level commissioning model

Level 1: Primary care

All primary care providers and schools should:

1. Identify a carers’ champion

2. Build and maintain a carer register

3. Input into and engage with work led by the CCG to co-ordinate support activities for carers

4. Seek and find carers, including young carers, those from ethnic minorities and the lesbian, gay, bisexual and transgender communities

5. Involve carers by asking for permission to share confidential information with carers and involving carers as part of care planning

6. Improve service access e.g. by providing appointments and ‘flu vaccinations at convenient times for carers and proactively screening for depression

7. Be able to signpost carers to useful information and support

8. Offer specific support to young carers including assessment of whether the young person is taking on an inappropriate level of care, and

9. Audit to measure improvements in carer support
The three-level commissioning model
Level 2: Carer organisations

Carers organisations provide:

1. Emotional support for carers through carers support workers, carers groups or peer networks
2. Financial and benefits advice
3. Advocacy
4. Information about issues that matter to carers
5. A hub to signpost carers to other services

All improvement work should build on the work of Carer Centres and other services provided by National and local carers' charities and condition-specific organisations - such as The Stroke Association, Parkinson's UK, The Alzheimer's Society and Mind.

The key National contacts are:

- **Carers Direct Helpline: 0808 802 0202**
  - Visit [www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx](http://www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx)
- **Carers Trust**
  - Visit [www.carers.org](http://www.carers.org)
- **Carers UK**
  - Visit [www.carersuk.org](http://www.carersuk.org)
- **Citizens Advice Bureau**
  - Visit [www.adviceguide.org.uk](http://www.adviceguide.org.uk)

For a full list of local Young Carer Services click here.
The three-level commissioning model

Level 3:

Statutory or third sector providers may also drive improvement through services commissioned specifically to meet the needs of carers, including:

1. Health care organisations e.g. district nursing services, intermediate care, specialised GP services

2. Social care organisations e.g. emergency plans, carer assessments, professional home carers, respite care

3. Third or voluntary sector organisations e.g. day centres, sitting services

Health services support

Actions include:

- District nurses teaching carers how to undertake specific nursing tasks e.g. lifting and handling, administration of medicines
- Community matrons and district nurses providing carers with nursing support to manage complex medical problems at home
- Intermediate care services that support community based rehabilitation and proactive care management to prevent crisis and hospital or residential care admission
- Rapid access to psychological therapy services for carers living with high levels of distress or who are depressed or anxious
- Annual health checks for carers.

Social services support

The key action for social care is to undertake carer needs assessment and oversee implementation of a care plan for adult carers providing “regular and substantial” care that covers:
- Provision of respite care
- Help with housework and domestic tasks
- Equipment or adaptations to the home
- Emotional support
- Emergency planning support so carers have peace of mind knowing there is plan to provide emergency substitute support, should they need to leave in an emergency.

Third sector

Third sector organisations often provide the support services identified in care plans in response to needs assessment. Some will be funded by commissioners; others may be supported through donations. Services may include:
- Sitting services and day centres to give carers a break
- Services and activities to support young carers
- Carers clinics that provide advice and maybe run from GP surgeries.
References

1http://www.changemodel.nhs.uk
As the Caring Journey illustrates, for many carers, primary care is a first port of call and an important source of support.

Reviewing and commissioning primary care based support and health services for carers is an essential part of a robust carer commissioning strategy.

NHS England and its Area Teams will be mainly responsible for commissioning primary care services; clinical commissioning groups (CCGs) will play an important role in supporting member practices to improve care for carers.

The RCGP has already done extensive work, providing good practice guidance and a framework for primary care service development. To find out more about this please click here.

Primary care and CCG commissioners can apply this service framework to the development of support for carers in general practice - and more widely with community pharmacists, dentists, opticians and other primary and community based care providers.
9. Primary care commissioning for carers

Because carers may not identify themselves and therefore may be ‘invisible’ to health and social care services, commissioners wanting to support carers need to consider investing in initiatives that identify carers. Once carers are known to the system, they can be signposted to existing support services and supported to keep well and sustain their caring role. Because carers have frequent contact with the primary healthcare team either through the person they care for or for their own healthcare needs, primary care is a good place to do this. Successful initiatives apply a range of approaches, including:

- Questionnaires at registration
- Notices asking carers to self-identify
- Engaging secondary care providers by including a box on discharge summaries that identifies the name of a carer
- Notes on annual ‘flu reminders for patients that their carers may contact the practice for ‘flu vaccination
- Opportunistic inquiry during consultations for other health issues
- List searches for spouses or parents of people with diagnoses likely to necessitate caring e.g. stroke, dementia, learning disabilities
- Discussions at diagnosis or after hospital discharge
- List searches for children who live with an adult or sibling with a long-term condition that affects their ability to care for themselves
- Maintaining a carer register.

Commissioners can support providers to undertake this work internally - or can fund dedicated carer support workers through carer support organisations.

**WARNING!** Carers may not respond to the label ‘carer’ - so you need to work hard to develop an effective identification campaign. Involve carers in campaign design. They can help you get it right first time.
Key investments in primary care are:

Supporting providers to establish carer leads and undertake audit
Carer leads co-ordinate the primary care team’s work to support carers. They champion their cause within GP practices and with other providers and can lead audit work to identify how primary care support for carers can be improved and made more carer-friendly.

Involving carers in the care of their loved one
One of the greatest frustrations mentioned by carers is not being recognised and involved in discussions about their loved one’s care. This may be linked to issues surrounding patient confidentiality and also lack of recognition of carers. But the insight and understanding of carers is a valuable asset that can help improve treatment and outcomes. Training for both professionals and carers themselves, and obtaining signed consent from patients to share medical information with carers, can support greater carer involvement in decisions about care.

Providing information and support for carers
Carers tell us that they do not know where to get information about available support. All primary care providers can play a valuable role in addressing this problem by signposting carers to sources of reliable information, making it easy for them to find the services they need to support them. The community pharmacy contractual framework includes signposting.

Support for young carers
Primary care providers can play a key role in a whole family approach to supporting young carers. Successful support programmes are likely to involve many community partners, including schools, and to focus on supporting young people who are carers to thrive and reach their full potential.

Improving carers’ health
Carers are a high risk group with raised all-cause mortality; they are particularly at risk of depression. Commissioners may consider investing in targeted carer health checks that ensure that carers health needs are assessed proactively.