



*Herts Valleys
Clinical Commissioning Group*

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COMMITMENT TO CARERS Carers' Strategy 2015-2018



INTRODUCTION

I am delighted to be able to introduce our new Carers Strategy for the CCG which will run from 2015-18.

Carers are part of the fabric of our society. One in three of us will take on a caring role at some point in our lives. In one sense it is a very normal part of life.

But it is not something, usually, that you choose. Your parent suddenly has an accident or a stroke, or imperceptibly develops dementia. Your partner has a breakdown or is diagnosed with MS. Your child is born with a disability.

So, totally unexpectedly, along with the complexity of navigating the world of health and social care, of equipment and adaptations and assessments and medication and benefits, there is all the emotional impact of now being 'a carer'. It may be very hard to stay in work. Friends may drop away. Your own health may start to suffer.

Working in a busy general practice, I know that there are occasions where we are unable to spend as much time with carers as we would like. That is why I am so committed to making sure that GPs and our practice teams know how to signpost carers to the people out there who can help. Through groups like *Carers in Hertfordshire* and signposting organisations like *HertsHelp* and now our new community navigator service, we hope to make recognition of carers easier for us and more useful to them - helping them start the journey sooner to find the information and support they need and deserve.

Carer champions in each of our practices in west Hertfordshire have been a critical tool in doubling referrals to *Carers in Hertfordshire* and helping practices become more 'carer-friendly'. The role of the carer champion includes keeping a database of carers registered at the practice and searching for opportunities to develop and improve support that the practice can provide for them. So for example some practices offer flexible appointments to carers while others offer support sessions where carers meet, share experiences and learn more about wider support available to them. Signposting to the range of services available to carers is a key part of the role of the practice carer champion.

We know we still have a long way to go though.

Similarly we need to know that hospital care, community nursing and other services we purchase for the population are helping carers to see that they are doing something out of the ordinary and there is, and should be, support for them. Which is why we are making it a requirement for the need for carers to be identified and helped to be reflected in all our contracts with providers.

How often is it that a five minute conversation can make a huge change to someone's life? We hope that this strategy will make many more of those conversations happen.

If you are a carer we hope that this strategy will help you to be heard and supported. If you would like to discuss how you can be involved in the next steps, please do not hesitate to contact Tim Anfilogoff at tim.anfilogoff@hertsvalleysccg.nhs.uk for details.

Dr Nicolas Small, GP, Chair of Herts Valleys CCG

Brief Summary

This strategy sets out HVCCG's Commitment to Carers.

What this means is that we are working hard to acknowledge the importance of carers in everything we do. The CCG accordingly has committed itself to:

- Treating carers as a 10th Equality and Quality Inclusion Protected Category – so that any discussions of major changes of policy or service must consider the impact on carers
- Negotiating a 'carers' policy' with all providers we commission services from setting out what carers should expect from the service
- Showing how our leadership role in primary care can be used to improve support to carers
- Being a flexible carer-friendly employer and encouraging providers to as well
- Being an active partner in Hertfordshire's multi-agency carers' strategy (since we know that carers suffer when services do not work together effectively)

1. Who are Family Carers?

By **carers** we mean 'family carers' or 'unpaid carers'.

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 [age-]-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 (RCGP)¹.

At the time of the 2011 Census, there were 55,000 people in Herts Valleys looking after friends or family members (who would not be able to cope without such help). Research indicates that about 50 new people become carers **each day** in West Hertfordshire. Currently we know that many care for years before they understand that there may be support for them.

2. Why Support Family Carers?

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 (RCGP).²

2.1 The National Picture

The first National Carers Strategy, published in 1999, encouraged primary care to offer family carers annual health-checks. Since then there has been an increasing focus on promoting the health and wellbeing of carers – either through the duties of the local authority with social services responsibilities (new duties come into force on 1 April 2015 in the Care Act) or through primary care. Here the Royal College of General Practitioners is taking a very active lead. In May 2014 NHS England also published its own 'Commitment to Carers'³.

Some of the health impacts of caring are listed in Appendix 1.

Of particular relevance to this strategy is the fact that 66% of carers feel that healthcare staff don't help to signpost them to relevant information or support, and when information is given, it comes from charities and support groups⁴. Addressing the current patchiness of health services in signposting carers to available support is an obvious way to release additional value from work already funded in the voluntary sector and social care while reducing demand on the NHS.

¹ <http://www.rcgp.org.uk/clinical-and-research/clinical-resources/~media/Files/CIRC/Carers/RCGP-Commissioning-for-Carers-2013.ashx>

² As above

³ <http://www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf>

⁴ NHS England & NHS Improving Quality. (2014) *Commitment for Carers: Report of the findings and outcomes*.

This strategy is based on the assumption that a key intervention for a range of professionals is to help carers identify themselves – it will then often be charities and support groups and social care that then provide the detailed advice and support.

2.2 The West Hertfordshire Picture

The value of the ‘work’ the 55,000 family carers in West Hertfordshire do is about £1bn (more than the CCG’s budget). With our ageing demography and the very real financial challenges that the public sector in Hertfordshire faces it is critical that we focus on giving carers more recognition and support not less: carers are generally desperate to carry on caring for their loved one but frequently describe their ‘invisibility’ or the need to ‘fight’ to get what they need to look after the person they are caring for.

In Hertfordshire, we have shown through a range of initiatives how much value there is identifying carers and supporting the flexibly (for example, Carer Friendly Hospital (Lister Hospital), Make a Difference for Carers (*Cares in Hertfordshire*), Crossroads Social Return on Investment study (2014), Baker Tilly’s Social Return study on Carers’ Centres (2011)).

Carers Champions in primary care have contributed to a doubling of referrals to *Carers in Hertfordshire* from primary care.

But there is much still to be done to link up health, social care and the voluntary sector into a joined up vision of how to support carers better. As we move to more patient-centred care nearer to home it is crucial that a fully integrated approach to supporting carers is developed and implemented. Otherwise, apart from the distress to patient and carer, the NHS will continue to pay the costs of crises involving **two** people’s poor health, including sometimes **two** acute admissions, when a more proactive and supportive approach, valuing the role of the carer, could have delayed or prevented one or both.

For young carers, not only is it important that we have a whole system approach to identification, where their role is identified, and action taken to mitigate age-inappropriate caring roles are sensitively considered, but also those providing services to the cared for person (whether adults or siblings) factor this into the support provided.

3. Roles of the CCG

This strategy is structured around the following key roles of the CCG:

- Commissioner
- Leader in primary care
- Employer
- Partner in the Multi-Agency Carers Strategy and in Integration Work

This is not a standalone strategy. Its principles are shared with ENHCCG and it is fully integrated with the Hertfordshire Commitment to Carers, the Health and Wellbeing Board’s Strategic Priority on Carers, The NHS England Commitment to Carers, preparations for the Care Act and other national policy and legislative drivers.

4. Carer Engagement

The thrust of this strategy is based on national and local research into the needs of carers. This includes the active engagement of local carers either directly at events or through the Carers Reference Group or key partners like *Carers in Hertfordshire*, *Crossroads* and other charities which work with carers. This needs to continue and develop both in the CCG and among providers and partners.

A consultation paper on this strategy document was sent out in draft to carers from the Multi-Agency Carers Strategy Reference Group (about 45 of whom live in Herts Valleys) and to our patient and public involvement networks during October. Tim Anfilogoff met with carers on 5 November and presented the strategy to Patient and Public Involvement Committee on 22 October. There has been a warm welcome for the strategy.

Carers also took part in a very successful event on 12 November (Carers Champions and Community Navigators' event) and carers will be part of the launch of the strategy on 28 November.

Perhaps more importantly, carers will be engaged in the writing of provider policies and in monitoring the strategy's action plan over the three years from 2015 to 2018. An engagement form for those carers wishing to be involved is attached at Appendix 5.

5. The Strategy

5.1 CCG as Commissioner – (Carer-proofing Commissioning)

5.1.1 Equality Impact Assessment

There are two significant reasons for adding 'carers' to the list of protected groups whenever an Equality Impact Assessment is carried out:

- The sorts of health and economic inequalities faced by carers listed at Appendix 1
- The ruling in the European Court (Coleman v Law 2008) shows that carers can be discriminated against by association with disability, thus indirectly making them a protected group⁵

While we wish to support all carers, we recognise that they can have very specific needs. This means we, and partner agencies, have to be able to understand the implications of their different situations to provide them with the right support.

In particular to deliver best practice in supporting carers (and therefore the patients they care for) this strategy is generic in its scope but acknowledges:

- Quality support will always reflect the specific impact of different conditions: there are particular stresses caring for someone with dementia who turns night into day, or an autistic child who is very physically active or a person with an invisible condition. Good support will include professionals being aware of these specific impacts
- Young carers should always be helped to access the support that prevents them taking on, or continuing to struggle unaided with, age inappropriate caring responsibilities. The Office for National Statistics reports that there is growing evidence pointing to the adverse impact on

⁵ Carers and their Rights, Professor Luke Clements – and see Appendix 2 EQIA

the health, future employment opportunities and social and leisure activities of those providing unpaid care, **particularly in young carers**⁶.

- The legislation around parent carers of disabled children is different from those caring for adults over 18. This places a duty on all agencies to work together to ensure good communication and smooth transitions between services rather than expecting carers to do all the work of co-ordination
- Older carers in their later years who have had a life-long responsibility for offspring with learning disabilities will need support to plan appropriately for care after their own death – and their caring roles may be particularly vulnerable
- Carers with specific linguistic or cultural needs may need specific support
- The need to continue to identify which particular groups of carers may find it hardest to get the support they need

5.1.2 Carers’ Policies in Provider Contracts

The CCG is committed to ensuring that all services it commissions are signed up to the key elements of this strategy. This requires the CCG to negotiate the inclusion of **‘Carers’ Policies’** in all contracts. While there will be varying levels of amount and type of contact with carers, depending on provider, all services need to ensure that no carer goes unidentified through lack of awareness on the part of its staff. This is critical both to improving outcomes for patients and carers, but also to reducing crisis and saving money in the system. We know many carers report they care for years before anyone notices them enough to tell them about the practical and emotional help that may be available to them.

We will therefore negotiate **Carers’ Policies** with each provider, including Primary Care (as appropriate in discussion with NHS England using the CCG’s leadership role if not its commissioning role). We will seek to broaden and deepen providers’ commitments over an appropriate timeframe during the three years of this strategy, to increase the awareness of their staff and their ‘offer’ to carers once identified. The following table sets out the **mandatory** themes that will need to be included, some of the **key tasks** that will be needed to deliver them, and some of the implications for the CCG:

Theme	Key Tasks	Implications for CCG
1. The provider’s duties around identification of carers	<ul style="list-style-type: none"> ○ Creating a carer-friendly environment: displaying leaflets and posters, providing places and opportunities for carers to talk, signposting to carers’ organisations to help carers self-identify ○ Ensuring all staff are expected and proportionately trained to be carer-aware ○ Recording numbers of carers identified per year ○ Measuring outcomes for carers identified (access to other services, satisfaction of carer etc) ○ Having a senior level carers’ champion to ensure young carers are identified and supported appropriately 	<ul style="list-style-type: none"> ○ A pragmatic negotiation with providers around: <ul style="list-style-type: none"> ○ Workforce Development ○ Training packages already commissioned/available through <i>Carers in Herts</i> and others ○ Changes to systems to ensure partners (primary care, community nursing, social care, <i>Carers in Herts</i> etc) are notified of carer identification ○ Evidence of improved outcomes for carers is collected

⁶ <http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/provision-of-unpaid-care-in-england-and-wales--2011/sty-unpaid-care.html>

Theme	Likely elements	Implications for CCG
2. The provider's duties in providing a quality service	<ul style="list-style-type: none"> • Ensuring carers' views about care are sought where the patient is not opposed to this • Ensuring carers' own health is not being put at risk through any intervention or lack of intervention • Ensuring carers' knowledge and expertise is fully respected and used in providing the most appropriate interventions for patients and their families/carers • A clear agreement with identified carers as to what they can expect, how professional input will work with the care they give themselves, and what support and advice they can have about their caring role • A commitment to integrating support with other relevant agencies (social care, voluntary sector, other health providers) • Ensuring carers can access key signposting information so they can get independent advice and support • Systematic recording and sharing of information which the patient and carer consent to being shared between providers to help the carer to care 	<ul style="list-style-type: none"> • As above. It will be critical in terms of resourcing to offset small additional burden in terms of time with carers with evidence of reduction in crisis (as evidenced by the Carer Friendly Hospital project, Make a Difference for Carers etc)
3. The provider's duties as an employer	<ul style="list-style-type: none"> • Ensuring that carers who work for the provider know their minimum statutory rights to emergency leave and to request flexible working • Ensuring that carers have access to independent information and advice if they are struggling to balance work and care 	<ul style="list-style-type: none"> • CCG's membership of <i>Employers for Carers</i> gives it access to best practice and business cases around retaining staff with skills who are carers and supports its leadership role in the NHS
4. The provider's duties to demonstrate outcomes for carers	<ul style="list-style-type: none"> • Providers will work with the CCG and Public Health on developing an outcomes model which supports the system as whole to support carers and demonstrate the benefits to carers and to the system of doing so • Key outcomes will be: <ul style="list-style-type: none"> ○ Carers identified ○ Carers support needs assessed ○ Carers signposted ○ Carer self-reported outcomes – more able to cope, reduced stress etc ○ Carers outcomes as measured by survey (including tools like Quality Metric SF12) 	<ul style="list-style-type: none"> • An initial literature search by a PH registrar of evidence of cost effective outcomes to support carers has shown the evidence base is not well developed – local evidence (eg Carer Friendly hospital, Crossroads SROI is in fact stronger) • Future investment decisions should be based on evidence of what carers value with rigorous monitoring and evaluation to build the evidence base going forward

Theme	Likely elements	Implications for CCG
5. The provider's duties to engage carers	<ul style="list-style-type: none"> Providers will have an open offer to carers to feedback on their experience of the service as individual carers Providers ensure carers are able to engage routinely in the development and improvement of services 	<ul style="list-style-type: none"> To ensure that this is monitored and learning informs service development and commissioning The need to join up engagement processes so carers are not over-consulted/confused

5.2 CCG as Leader in Primary Care

To date the CCG has provided encouragement, supported by resource, to practices to improve the offer to carers, particularly around identification and sign-posting. There is more that can be done in terms of promoting best practice in particular around:

- Explicit Guidance on a format for Health-checks for Carers (including young carers)
- Adoption of RCGP Commissioning for Carers⁷ and the RCGP⁸ Carers Charter and monitoring their impact
- Promoting strategic approaches to improve the health of carers (in partnership with Public Health) including: signposting to peer support and self-management, identifying carer groups most at risk of ill health and best possible interventions, provision of flu jabs to carers
- Developing a better understanding of the risk of patients of being admitted to hospital because of a preventable crisis – this process is sometimes called ‘risk stratification’ - to include the fact that the patient is or has a carer and other ‘social’ (not solely clinical) factors such as fuel poverty, poor housing, social isolation. We think our new Community Navigators will be a significant development in this area
- Developing a new commissioning approach from April 2015 to the Carers Champions role will be established to give predictability around funding, rewarding activity that makes a difference to carers and allowing the CCG to improve its evidence base.
- Exploring the possibility of a ‘breaks prescription’ service to help make sure carers can get to appointments so they can look after their own health

5.3 CCG as Employer

It is in the interest of the CCG and all its providers, that any carer employed by them is not put in the invidious position of having to choose between working and caring, or, through struggling to juggle their various commitments, becoming stressed or ill.

The CCG has therefore joined *Employers for Carers* (EFC) a forum set up by Carers UK and major businesses supporting employers to retain employees who are caring for a family member.

In the short term, the CCG will use EFC to help clarify its offer to carer employees, particularly by improving the availability of flexible working (subject to individual business case).

⁷ <http://www.rcgp.org.uk/~media/Files/CIRC/Carers/RCGP-Commissioning-for-Carers-2013.ashx>

⁸ At Appendix 4

The intention is that at some point in the future all NHS Employers in Hertfordshire will create an umbrella membership of EFC (as in some other parts of the country) or create a similar joint commitment to the agenda which carers can take advantage of.

5.4 CCG as Partner in Multi-Agency Carers Strategy and in Integration Work

All aspects of all services may have an impact on the ability of carers to carry on caring.

The CCG will therefore work in a fully collaborative way in developing the carers' strategy, in particular:

- Being an active member of all multi-agency carers' groupings (with providers, commissioners and voluntary sector partners etc)
- In partnership with District and Borough Councillors and Public Health working to ensure that the health of carers is supported across West Hertfordshire
- Engaging with ENHCCG wherever appropriate to ensure effective pan-Hertfordshire strategic approaches to supporting carers (eg joint commissioning of countywide voluntary sector activities)
- Ensuring true integration in all new developments for carers (and that all integration developments have positive impacts for carers) for example:
 - Integrated carer support planning developments
 - Linking carers' policies between providers to ensure effective referrals and information sharing
 - Prevention of admission strategies and risk stratification methodologies factor in the crucial role of carers
 - Analysing the interaction of social and health care (and voluntary sector) interventions on carers to ensure there are no inappropriate pressures in the system through another part of the system failing
 - Supporting simple sign-posting strategies, critically ensuring *HertsHelp, Carers in Hertfordshire, 111* and other key contact points for carers are linked together making it as simple as possible for carers to get to the help they need.

About This Document:

Author: Tim Anfilogoff, Integration Lead

Draft: 5

Date signed off by Board: 6 November 2014

Life of Strategy April 2015 – March 2018

Scope:

This strategy relates to all family carers, that is:

- Adult carers of adults with disabilities and/or illness
- Adult carers of children with disabilities and/or illness (that is, parent carers but NOT parents of non-disabled children)
- Children and young people who have caring responsibilities for family members (young carers)

Legislation/Policy:

Compassion in Practice (2012), Francis Report (2013) and the NHS Outcomes Framework (2012-15) all emphasise the importance of engaging family carers to ensure services are safe and of high quality.

This strategy is also influenced by the NHSE Commitment to Carers and the implementation of the Care Act and the Children and Families Act. In particular, it should be noted that while the carers' movement is a generic one (ie Carers in Herts and Crossroads will support all types of carers) there are different legislative frameworks around carers of children and children who are carers.

Equalities Implications:

Board has decided that one key element of delivering the strategy is the addition of carers as a 10th protected group within the CCG Equalities and Quality Inclusion Analysis process (see Appendix 2).

Financial Implications:

Further modelling needs to be done, but there is evidence from the Carer Friendly Hospital model, as operated at Lister Hospital, and a range of other interventions, that supporting carers better can save money. Many interventions required by carers' policies in contracts will already be good practice as encouraged by the Royal College of General Practitioners (RCGP), National Carers Strategy, Better Care Fund guidance etc.

The CCG will negotiate with providers as to how best to deliver improvements for carers within existing budgets where possible but will also be keen to explore commissioning interventions which can demonstrate improvements for carers *and* savings for the system.

Negotiations with providers for year one will take place between now and the end of February 2015.

Discussed so far with: Commissioning Executive, 11 September, Nicolas Small, David Evans,

Integration Team, Carers Strategy Task and Finish Group (including Zunia Hurst and Kirsty Moore, RCGP carer leads, Carers in Hertfordshire, ENCCG, HCC, HCT, HPFT etc), Shirley Regan, Childrens Services (HCC), Carers Strategic Commissioning Group, Carers Reference Group and Dacorum Carers' Hub, Individual providers, Stroke Leadership Group etc