

Evaluation Framework

This section sets out

- The key outcomes for carers and carers’ support in Barking and Dagenham
- Recommendations for new and modified services that will help to meet these outcomes in the future
- Summaries of key evidence from this project so far that relates to the desired outcomes, including evidence of any disproportionate impacts on key groups of carers
- Existing national and local outcomes and improvement indicators to monitor progress against
- How mainstreaming carers aligns with Better Care Fund plans
- Why investing in carers’ support can lead to savings elsewhere

Summary of key outcomes

1	Carers are identified at the earliest opportunity and offered support to prevent, reduce or delay their needs and the needs of their cared for
2	Carers are provided with personalised, integrated support that is tailored to their assessed needs and aspirations, gives them choice and control and allows them to take a break
3	Carers are involved and consulted in the care and support provided to their loved ones, treated with respect and dignity and have their skills and knowledge recognised
4	Carers are supported to improve and maintain good physical and mental health and wellbeing
5	Carers are supported to improve their individual social and economic wellbeing, reduce isolation and fulfil their potential in life
6	Carers are supported to cope with changes and emergencies and to plan for the future
7	Carers are supported when their caring role is coming to an end and to have a life after caring

Outcome 1: Carers are identified at the earliest opportunity and offered support to prevent, reduce or delay their needs and the needs of their cared for

Outcome measures	Existing outcome sources
<ul style="list-style-type: none"> • Carer identification is embedded across all health, social care and statutory services • Carers are identified at the earliest opportunity regardless of their own level of awareness • Carers are able to access information, advice and services to prevent, delay or reduce their needs for support and the needs of their cared for 	<ul style="list-style-type: none"> • National Carers' Strategy (2010) • Adult Social Care Outcomes Framework • Care Act (2014) • Caring for Carers in Barking and Dagenham (2011-15) • Joint Health and Wellbeing Strategy • Social Care Commissioning Plan • Integrated Care in Barking and Dagenham, Havering and Redbridge: The Case for Change • Better Care Fund Scheme 2: Improved hospital discharge • Better Care Fund Scheme 5: Integrated commissioning • Better Care Fund Scheme 6: Support for family carers • Better Care Fund Scheme 8: Prevention • Better Care Fund Scheme 10: Equipment and adaptations • Better Care Fund Scheme 11: Dementia Support

Improvement indicators

- The proportion of carers who find it easy to find information about support (ASCOF 3D Part 2)

Carers most at risk

Male carers More than 4 in 10 carers in Barking and Dagenham are male, yet men are underrepresented in service provision and so are more likely to be caring without support. The largest male carer populations are in Abbey, Gascoigne and River.

BME carers A third of carers in Barking and Dagenham are from a BME background; however, some ethnic groups such as Indian and Other White are underrepresented in service provision. The largest BME carer populations are in Abbey, Gascoigne and Longbridge.

LGBT carers National evidence suggests that LGBT people are less likely to be visible to services; there is no specific social care support offered or engagement with the local LGBT community so they are likely to be a hidden group in Barking and Dagenham.

Carers of people with dementia Identifying people with dementia and their carers early is a key priority of *Better Care Fund Scheme 11: Dementia Support*; early diagnosis helps to find the right treatments and best sources of support.

Carers with learning disabilities Nationally, carers with learning disabilities remain a largely hidden group, with very little data available to measure the level of mutual caring. Lack of awareness and understanding amongst staff is a key issue. As family carers start needing more support themselves, families develop routines and ways of coping that mean that both the older person and the person with learning disabilities are looking after each other. A growing number of people with learning disabilities are providing regular and substantial care for their ageing relatives.

Carers within primary and secondary care Carers indicated that in primary care, carer identification needs improvement, and there is a need for consistency across all GP practices to support carers at risk and refer them to appropriate support. Evidence indicated that the secondary care acute trust is not at present able to identify carers on wards at an early stage; there is a pilot discharge project that supports carers through the hospital discharge procedure and into reablement but this has limited resources.

Recommendations

Mainstreaming of carer identification

The Council and CCG work together to ensure carer identification is mainstreamed across health and social care, including mental health and substance misuse and other statutory services that have regular contact with people and families, such as housing and cultural services. Carer identification and support should be a key part of all Better Care Fund schemes (see *Appendix 1: Better Care Fund – Mainstreaming Carers*). Carer identification shouldn't be reliant on people having the recognition that they are caring. This may mean a significant shift in working cultures, but will ensure carers of all ages are more likely to be identified and the needs of carers and opportunities to identify, engage, partner with and support them are built into all statutory activity and become everyone's responsibility. This is particularly important with the potential for increased identification of carers as a knock-on effect of an increase in self-funders coming forward for assessment due to the Care Act.

Appointing carers' leads

It may be beneficial to appoint carers' lead roles within services, or jointly across services, to commission support for carers, champion the mainstreaming of carer identification and support and offer advice and support to colleagues. This needs careful consideration as carers' leads can sometimes assume or be given total responsibility for carers, when mainstreaming carers should be intrinsic to all services and everyone's responsibility. A commitment to mainstreaming carers needs to be led from the most senior level of the organisations involved and cannot be solely a commissioning or operational responsibility.

Implementing a carers' referral protocol

A carers' referral protocol to be implemented, to support mainstreaming and wider access to carers' support outside of that which the

particular service can offer itself; for example, a GP could support a carer with their health needs, but may need to refer them to social care for an assessment or to the local carers' service for information about peer support groups. This protocol should include clear referral pathways or, at the very least, signposting so that services can easily divert carers to relevant community support, and carers and services understand the specific types of support available including preventative information, advice and training; this could be complemented by a wide roll out of face-to-face and/or online carers' awareness training for professionals, and an online guide for carers to support them to, for example, navigate health and social care services. Navigation sessions could also be held for staff in social care and health, as part of their learning time, to increase their understanding of carers' support available locally; these could be coordinated by the commissioned carers' service but would need to cover the breadth of support available in the area.

Carer identification and support at GP practices

Carer identification, signposting and support to be offered at all GP practices as they are often the 'first point of contact' for carers; consider a targeted programme that may require the investment of dedicated resources, such as a clinical carers' lead at the CCG and/or the recruitment and use of volunteers. Identify GP champions at each practice and/or within cluster teams; ensure all new patients and all health screening asks for details about any caring responsibilities; make full use of the GP Carer Register; encourage practices to adopt a carers' charter; and encourage use of flexible/extended appointments for carers. This can also support the aims of *Better Care Fund Scheme 11: Dementia support* to signpost service users and carers to support at point of diagnosis. Use GP teaching forums to put across the clinical benefits of supporting carers including early identification of carers' own health problems through activities such as regular health checks and depression screening, and a carer's role in helping to meet a patient's needs. Make use of existing resources, such as the RCGP's Caring for Carers Hub¹ when it is available, aimed at helping primary care staff to focus on the health and wellbeing needs of carers; the RCGP's commissioning guide for CCGs on the importance of identifying and supporting carers; and the GP Champions programme which offers knowledge and expertise, GP to GP, on the business benefits of identifying and supporting carers.

Identifying carers in hospital

Continue and improve identification and support of carers in hospital through the Joint Assessment and Discharge Service and in conjunction with the carers' hospital discharge project (if still running) to improve hospital discharge arrangements and prevent readmissions. This supports the aims of *Better Care Fund Scheme 2: Improved hospital discharge*. This could include understanding the information and learning needs of carers, such as moving and handling, use of equipment and the objectives of reablement. For those carers who do not live with their cared for, the service can work around the needs of the carer including arranging for a weekend discharge.

Accessible communications for underrepresented groups

Reconsider all communications and promotional activity around being a carer and support for carers to ensure that it is accessible to

¹ <http://www.rcgp.org.uk/clinical-and-research/clinical-resources/carers-support.aspx>

people who do not identify with the term 'carer' or have not yet labelled themselves as such; target communications and specific services at underrepresented groups and communities including men, BME groups, LGBT people, and adults with learning disability who may be caring for ageing frail parents (known as 'mutual caring'). Target low level information and advice, such as leaflets and posters, at locations that carers regularly visit such as supermarkets, pharmacies and libraries. Develop joined up working practices between learning disability and older people's teams to share information and support that addresses the interdependent needs of mutual caring roles. Use existing resources to improve processes, such as the Foundation For People With Learning Disabilities Mutual Care Project², which champions innovation and good practice for this discrete caring group.

Preventative approaches

Consider as part of mainstream preventative approaches, including *Better Care Fund Scheme 8: Prevention*, focussed preventative offers to carers that seek to delay their own needs both as a carer and as a service user. This would focus on key aspects that support the carers' own health and wellbeing and ability to cope with caring, and seek to promote the independence of the 'cared for' and thus reduce reliance upon the carer. Support could include financial and benefits checks; screening for physical and mental health conditions; access to peer support networks; access to therapies and relaxation days; and emergency/contingency planning. A simple OT assessment for low level equipment, telecare and telehealth could support both carer and cared for; such as grab rails, raised toilet seats, key safe, community care alarm and mobility aids. This would support the aims of *Better Care Fund Scheme 10: Equipment and adaptations*. A preventative approach could also include a carers' skills audit, to identify training and learning needs such as moving and handling.

Summary of key evidence related to this outcome

Identifying carers in the population

There is a large hidden carer population in Barking and Dagenham. Of the 16,000 carers identified by the Census, an estimated 1,000 (6%) were actively supported by the Council and/or Carers of Barking and Dagenham in 2013/14. Almost half of the carers provide 20 or more hours of unpaid care a week and are likely to have higher support needs.

More than 4 in 10 carers are men but male carers are significantly underrepresented in service provision. Working age carers are underrepresented by statutory services and working carers are likely to be underrepresented in service provision. Half of the carers in Barking and Dagenham are in full-time or part-time work; the highest proportions of working age carers are in Abbey, Becontree and Gascoigne.

Some carers spoke of outreach activities such as Carers Week events and stalls in libraries as a successful way in which they were identified, and the immense relief they felt after this; however, this was often years into their caring role and despite having been in

² <http://www.learningdisabilities.org.uk/our-work/family-friends-community/mutual-caring/>

contact with numerous professionals before this point.

Challenges with identifying carers

Stakeholders and carers alike in Barking and Dagenham spoke of difficulties with carer identification due to the time it takes for people to recognise that the relationship with their loved one has changed and that they are providing them with more support on a regular basis.

For many, the term 'carer' did not resonate. Some feared the formality of making themselves known to statutory services and the perceived responsibilities that may come with that. There was also a general feeling that people in the local community are reluctant to ask for help and just 'manage'.

Some challenges were raised in terms of identifying certain communities and groups of carers:

- Eastern European carers do not come forward for support
- Some Asian communities do not understand the term 'carer' and are fearful of engaging with statutory services
- Information on LGBT carers and service users is not routinely monitored and there is no specific support available for these groups alongside mainstream services
- Working carers are more difficult to identify as they are often not able to attend activities or promotional events
- Young carers worry about what their friends may think or what will happen to their families if they ask for help

Specific challenges that affect carer identification from a health service perspective were mentioned including:

- A lack of knowledge amongst GPs about effective social interventions for carers and their clinical benefits; and what is available locally in terms of support for carers
- Difficulties due to time and resources in identifying all carers in hospital at the earliest stage and providing them with support leading up to discharge; also the potential negative ramifications on this if the carers' hospital discharge pilot is discontinued
- Identifying carers of people with mental health problems who do not come forward as they worry about what the expectations may be on them when they are identified

Carers talked about a lack of understanding of the local services available to support them and how to access and navigate statutory support. Some professionals said similarly that identifying carers was a challenge as it was not clear what they could offer them in terms of support afterwards. Issues with record keeping and data sharing mean that information on carers and their needs is not easily monitored or shared between services, including the council, health and their commissioned services.

Early intervention and prevention

Some frontline professionals said that carers often only come into contact with them at the point of crisis – either when the carer is too ill to continue providing care, or the needs of the person they are looking after have escalated to the point that they can no longer cope.

Some carers had their own physical and mental health needs that they were neglecting and had not sought medical treatment for.

Preventative information, advice and support is available from Carers of Barking and Dagenham including a comprehensive training programme that covers dementia care, mental health awareness and lifting and handling. However, professionals – including those on the frontline – were not all aware of this offer and in general were not aware of the specific services that are available to support carers.

Some carers were grateful to receive a newsletter from Carers of Barking and Dagenham regularly, but felt they needed something more.

Many carers were unclear what their support needs were or what they could reasonably ask for; a number of them had health and wellbeing needs that were not being addressed such as physical health problems, insomnia and isolation. Some carers in the learning disabilities group felt that support for long-term family carers was lacking from Carers of Barking and Dagenham, and that it dealt mainly with dementia. However, one carer in the learning disabilities group said they found Carers of Barking and Dagenham to be very helpful and supportive when they needed them.

Outcome 2: Carers are provided with personalised, integrated support that is tailored to their assessed needs and aspirations, gives them choice and control and allows them to take a break

Outcome measures	Existing outcome sources
<ul style="list-style-type: none"> • Carers have access to integrated and personalised services to support them in their caring role and which offer choice and control • Support for carers is tailored to their individually assessed needs and aspirations • Services are accessible to all and consider the specific needs of different communities and groups of carers • Carers are able to access support that allows them to take a break when they need to 	<ul style="list-style-type: none"> • National Carers' Strategy (2008) • National Carers' Strategy (2010) • Adult Social Care Outcomes Framework • Care Act (2014) • Caring for Carers in Barking and Dagenham (2011-15) • Joint Health and Wellbeing Strategy • Social Care Commissioning Plan • The Business of Care in Barking and Dagenham • Integrated Care in Barking and Dagenham, Havering and Redbridge: The Case for Change • Better Care Fund Scheme 5: Integrated commissioning • Better Care Fund Scheme 6: Support for family carers • Better Care Fund Scheme 7: Care Act implementation
Improvement indicators	
<ul style="list-style-type: none"> • Carers receiving self-directed support (ASCOF 1C Part 1b) • Carers receiving direct payments for support direct to carer (ASCOF 1C Part 2b) • Overall satisfaction of carers with social services (ASCOF 3B) 	
Carers most at risk	
<p><i>High intensity carers</i> Carers in a high intensity caring role (20 or more hours a week) are more likely to suffer the negative impacts of caring and have the greatest need for support. Almost half of the carers in Barking and Dagenham fall into this category; Parsloes, Goresbrook and Heath have the highest proportion.</p>	

Carers at breaking point Inadequate support including access to care services, breaks and medical treatment are identified causes of crisis and along with other stresses and pressures including exhaustion and physical strain, can come together to push carers over the edge.³

Recommendations

Self-directed support offer

Consider a range of methods for implementing a separate self-directed support offer for carers following carer's assessment, which is not reliant on the cared for having their own personal budget, and which supports the carer to continue to fulfil their caring role and considers their health and wellbeing needs and desire to take a break. Access to a range of universal 'free' services and opportunities to take a break from caring, including those already offered by Carers of Barking and Dagenham such as training and activities, could form part of a self-directed offer so that carers could choose themselves from a range of 'paid' and unpaid support to meet their needs.

Direct payments

A self-directed offer for carers could include access to a separate payment, direct to carers, and based on eligibility; however, this payment must not be towards the costs of services that are provided to the service user e.g. replacement care. The process for accessing personal budgets and direct payments for carers should be clear and form part of a 'pathway' and/or online guide that both professionals and carers can follow.

Preventative payments

Barking and Dagenham could also consider the use of preventative payments for carers who do not meet eligibility criteria for a direct payment. These could be administered by a third party such as Carers of Barking and Dagenham, for those carers who may not be caring for a person with critical or substantial needs, but may, for example, struggle to afford a one off item, such as a washing machine, driving lessons or something else which could significantly improve the experience of caring, or a carer's individual wellbeing.

FLEXIBLE BREAKS SCHEME

A FLEXIBLE BREAKS SCHEME COULD SUPPORT CARERS TO TAKE BREAKS FROM THEIR CARING ROLES AND TO PROMOTE HEALTH AND WELLBEING, INCORPORATING ALREADY EXISTING SERVICES E.G. DAY TRIPS AND ACTIVITIES. THIS SCHEME COULD BE SUPPORTED BY GP ENDORSEMENT AND SPECIFICALLY TARGET CARERS WHOSE HEALTH AND WELLBEING IS AT RISK AND/OR WHOSE CARING ROLE IS AT RISK OF BREAKDOWN; CARER BREAKDOWN CAN LEAD TO COSTLY INTERVENTIONS FOR THE HEALTH AND SOCIAL CARE SYSTEM INCLUDING HOSPITAL AND RESIDENTIAL CARE ADMISSIONS (SEE ALSO *APPENDIX 2: BUILDING THE 'INVEST TO SAVE' ARGUMENT*).

³ Carers at breaking point (Carers UK, 2014)

ACCESSIBLE SUPPORT

Ensure support is accessible to all carers in the community, in particular groups that are underrepresented in service provision e.g. male carers, BME carers and LGBT carers. Services should be ready to consider any specific needs or concerns these groups may have, which could be understood through engagement with individuals or relevant local/national organisations..

Stimulating the market

Improve choice and control for carers through stimulation of the market in services to support them, particularly within the voluntary sector, where condition-specific or equality-specific organisations could provide insight to new, innovative models of support for carers, or partner with other organisations to do so. This could help improve the diversity of services on offer to carers, to better reflect the makeup of the population. Encourage other public, private and voluntary sector services to be more accessible to carers. These services could be accessed via a personal budget and/or as part of a universal offer for carers.

Summary of key evidence related to this outcome

Self-directed support

Compared to other local authorities in its comparator group offering self-directed support for carers, Barking and Dagenham performs well below average. It does not have a separate personal budget or direct payment scheme for carers; however, carers can access respite and replacement care through the service user's budget. The Adult Social Care Market Position Statement cites 'more options for carers to have a break from their caring role and to purchase respite with a personal budget' as a commissioning priority. The opportunity to invest in carers support using the Better Care Fund also cites the importance of carers' breaks.

There was confusion from some professionals and carers about how the personal budget process works now. Social workers raised that they used to be able to offer carers a personal budget in their own right and that this was very popular and gave them something tangible and valuable to offer following a carer's assessment; they couldn't understand why this had changed.

Some carers said that they could see the benefits of a personal budget so that they could find support that was tailored to their own requirements. It was noted that there was a lack of specific support or understanding of the needs of some cultural and faith communities, and LGBT people.

Integration and partnerships

Integration of health and social care support for carers is limited in comparison to support for service users. Some of the financial and commissioning commitment is there – as is the commitment to a joint carers' strategy – but integrated services need development and that commitment at the strategic end should translate to delivery, for example in hospitals and GP practices. Carers are not currently a strong feature in the integrated care teams or cluster teams. Carers of Barking and Dagenham spoke of good relationships and integration with GPs, but other professionals (including one GP) and many carers felt that there was a lot of work to be done in terms of

involvement, recognition and support for carers at GP practices.

There was little evidence of partnerships with or within the voluntary sector to support carers – for example, between Carers of Barking and Dagenham and condition-specific, or equality-specific, charities. Although a few professionals spoke of strong working relationships in the voluntary sector – and clear signposting between agencies to avoid duplication – some thought there is room for more partnership working and additional organisations working in health, social care and welfare. There is limited choice for carers as Carers of Barking and Dagenham is the sole provider of carer-specific services, and carer-friendly and carer-ready universal services are not well developed.

Carers' assessments

Some frontline professionals felt that the separation of a service user's and carer's assessment means that social work assessments are only focussed on carers' needs with regards to the care of their loved one, and their individual needs are disregarded and redirected to Carers of Barking and Dagenham for a separate assessment. However, some social workers saw themselves as an advocate for the service user, and felt that a separate, external carer's assessment was more beneficial for carer and cared for. It seemed difficult to strike the right balance between the two, but all agreed that carers needed an holistic assessment that considered their own needs and aspirations as well as those needs related directly to their caring role.

Social workers said that they leave a carer's self-assessment form with a carer when they do a service user assessment; however, some social workers were unclear as to whether they should fill this in with the carer or if it's acceptable to leave them to do it themselves. They said there is no formal referral process to Carers of Barking and Dagenham, and no easy way of knowing what support the carer ultimately receives and the outcomes of this. One social worker asked 'what can you offer a carer following a carer's assessment?' and this view was echoed by others.

Outcome 3: Carers are involved and consulted in the care and support provided to their loved ones, treated with respect and dignity and have their skills and knowledge recognised

Outcome measures	Existing outcome sources
<ul style="list-style-type: none"> • Carers are respected as expert care partners throughout the care process and treated with respect and dignity • Carers are actively and positively involved and consulted in the care and support provided to their loved ones • Carers are involved in the planning and design of local services 	<ul style="list-style-type: none"> • National Carers' Strategy (2008) • National Carers' Strategy (2010) • Adult Social Care Outcomes Framework • Care Act (2014) • Caring for Carers in Barking and Dagenham (2011-15) • Social Care Commissioning Plan • Integrated Care in Barking and Dagenham, Havering and Redbridge: The Case for Change • Better Care Fund Scheme 1: Community Health and Social Care Teams • Better Care Fund Scheme 2: Improved hospital discharge • Better Care Fund Scheme 3: New model of intermediate care • Better Care Fund Scheme 4: Mental health support outside hospital • Better Care Fund Scheme 6: Support for family carers • Better Care Fund Scheme 9: End of life care • Better Care Fund Scheme 11: Dementia support
Improvement indicators	
<ul style="list-style-type: none"> • The proportion of carers who report that they have been included or consulted in discussions about the person they care for (ASCOF 3C) 	
Carers most at risk	
<p><u>Carers of people with mental health problems</u> Within mental health services, barriers including confidentiality have prevented carers from being fully involved and consulted in the care and support provided to their loved ones.</p>	
<p><u>Carers of people who are in hospital</u> There is a lack of support for carers throughout the hospital journey, and a risk that support provided to carers whose loved ones are being discharged will suffer if the carers' hospital discharge project loses its external funding.</p>	

Recommendations

Ensuring carers are involved in their cared for's assessment

Ensure carers are always involved in community care assessments if they are providing care to meet someone's needs, so that their perspective and experience supports a better understanding; this may involve more than one carer if they are not caring alone. Always offer service users and carers the opportunity to have a joint or a separate assessment. Carers' assessments should cover in detail carers' ability and desire to continue providing care. Recording and monitoring processes need to be tightened to capture all carers' assessments, and training rolled out to support this if necessary.

Ensuring carers are involved and supported to provide care at home

To support *Better Care Fund Scheme 1: Community Health and Social Care Teams* and *Better Care Fund Scheme 3: New model of intermediate care*, and to help prevent hospital admissions, carers should be fully involved and supported as an equal partner in the work of the integrated care teams and as part of the Community Treatment Team and Intensive Rehabilitation Service. This aligns with work to improve support to end-of-life carers (see *Outcome 7*) and dementia carers who are able to care for their loved ones at home.

Supporting carers of people with mental health conditions

Improve carers' experiences in acute and non-acute mental health services by rolling out the Triangle of Care⁴ approach throughout the North East London NHS Foundation Trust with an aim to have true collaboration between mental health professionals, service users and carers. This could be a substantial culture shift, and will require a programme of work and training to implement, but has wide ranging benefits for all involved. Thought should also be given to clear policy and practice protocols around confidentiality and sharing of information, to ensure that confidentiality is never an unnecessary barrier for carers. This supports the aims of *Better Care Fund Scheme 4: Mental health support outside hospital*.

Involving carers during the hospital journey

In line with improving identification and support of carers in hospital through the Joint Assessment and Discharge Service – and supporting the aims of *Better Care Fund Scheme 2: Improved hospital discharge* – develop mechanisms to identify, recognise and support carers throughout the hospital journey and ensure their involvement and inclusion in discharge planning to prevent further admissions. This is an ambitious piece of work requiring the full support of the acute trust and recognition of the potential cost, clinical, social and organisational benefits of such an approach. This has the potential to be a low cost activity as a key success measure is the ability of staff to maintain and sustain a change in behaviour; for example, in how carers are greeted and approached by staff, included in assessment and care planning conversations, and assumptions not being made about their ability and willingness to provide care after discharge. This recommendation would lend itself well to a small scale pilot project in one discrete area of acute care in order to analyse

⁴ The Triangle of Care: Carers Included, A Guide to Best Practice in Mental Health Care in England (Carers Trust, 2013)

the cost benefit of the approach; elderly care, for example.

Carers as part of a wider workforce

Consider implementing a training and learning programme for carers that considers their needs as part of a wider workforce; for example, moving and handling, health and safety, safeguarding. Learn from the successes of the training courses delivered by Carers of Barking & Dagenham and look to mainstream these into wider commissioning programmes of work. For example, building carers into any re-ablement contracts, such that they are aware of the principles and objectives of re-ablement and their learning needs are identified. Try to shift the view of carers as a 'resource' and more towards 'co-worker' and 'colleague'; people with skill and knowledge to share that can contribute towards service user outcomes.

Involve carers in service design

Work in partnership with carers, alongside service users, to improve services. This should be standard across all health, mental health, social care and other statutory services to ensure carers' voices are heard across the whole system and carers are able to influence decisions about services that affect them and the people they care for.

Summary of key evidence related to this outcome

Carers being involved and consulted

6 in 10 (58.7%) carers report that they have been included or consulted in discussions about the person they care for, which is below England and London average and low against comparator councils.⁵

More than three quarters (78.5%) of carers' assessments are carried out separately to the service user; however, feedback from frontline professionals indicated that many more joint assessments do take place and these are not necessarily recorded in a way that can be picked up by current monitoring processes e.g. free text fields are used.

Health professionals said that GPs do not always involve carers in care planning and that carers could be more involved in Integrated Care Team meetings. Dementia carers spoke of GPs not giving them the information they needed to care effectively, causing uncertainty and confusion. A number of carers said GPs had never broached the subject of them being a carer.

Involving carers in patient care at hospital was said to be difficult when there are so many competing priorities, and if this does happen it's usually at the point of discharge. The externally-funded carers' hospital discharge pilot run by Carers of Barking and Dagenham had helped more than 75 carers through the discharge process and beyond, with excellent outcomes recorded for carer and cared for.

⁵ National Carers' Survey 2012/13 – results should be viewed with some caution due to a low response rate

Involving carers when carrying out mental health assessments was said to be more difficult due to confidentiality issues. Also, carers generally don't feed into mental health service design and delivery.

Overwhelmingly carers reported that to 'get it right' for them, professionals just had to 'get it right' for the person they are looking after; the health and wellbeing of their loved one is paramount and if they feel satisfied and confident with their care, it improves their own quality of life. One example of this was a mother of a man with mental health issues, who felt he had been suffering due to a change in supported accommodation provider, which had meant an increase in the burden of her caring role.

Carers talked of having to carry out tasks that they didn't feel confident with, such as moving and handling, because their cared for had said it was not a problem for them and the carer had not been consulted about it.

Treatment by professionals

Carers, particularly those in the learning disabilities group, said that building positive relationships with social workers was important to them and made them feel more valued. They found it frustrating to liaise with different workers, and have to continually explain their circumstances. The annual review process was cited as an example of this. Carers also said they had to chase review meetings. Documents received following assessment were said to often be an inaccurate reflection of what had been said, and the carers would have to correct this.

One carer of an adult child with learning disabilities said that carers are tired of going between hospitals and GPs and no one taking notice of their concerns. Another carer said that professionals get one view when they talk to his daughter alone and a fuller picture when they speak to her in his presence, as she will tell them "what they want to hear".

One carer spoke highly of the support she had received from physiotherapy and social workers, including feeling valued and that her views were listened to. Staff at Heathlands Day Centre were highly praised for their dedication, communication with carers and for keeping loved ones safe and happy.

Consultations with carers

Consultations with carers to understand what they think and feel have included the National Carers' Survey in 2012/13 and a follow up to improve the response rate in 2013/14. The next national survey is due to be run in 2014/15. The GP Patient Survey collects the views of patients, including some who are carers. Healthwatch Barking and Dagenham are also running a consultation with over 200 carers about their experiences and involvement in safeguarding processes; the findings of this survey will be followed up by the Safeguarding Adults Team.

Outcome 4: Carers are supported to improve and maintain good physical and mental health and wellbeing

Outcome measures	Existing outcome sources
<ul style="list-style-type: none"> • Opportunities to improve and maintain carers' physical and mental health are embedded across health, social care and statutory services • Opportunities to promote carers' good physical and mental health are embedded into the wider range of local services they come in to contact with • Carers are provided with all the information and support they need to stay healthy and well and make positive lifestyle choices • Carers are supported to ensure their caring role is not putting them at risk and they have all the information they need to care safely 	<ul style="list-style-type: none"> • National Carers' Strategy (2010) • Adult Social Care Outcomes Framework • Public Health Outcomes Framework • Joint Health and Wellbeing strategy • Care Act (2014) • Caring for Carers in Barking and Dagenham (2011-15) • Better Care Fund Scheme 1: Community Health and Social Care Teams • Better Care Fund Scheme 5: Integrated commissioning • Better Care Fund Scheme 6: Support for family carers • Better Care Fund Scheme 7: Care Act implementation • Better Care Fund Scheme 8: Prevention
Improvement indicators	
<ul style="list-style-type: none"> • Health-related quality of life for carers (NHSOF 2.4) 	
Carers most at risk	
<p><u>Carers with poor health outcomes</u> Carers in Chadwell Heath, Eastbury and Valence have the worst self-reported health outcomes in the borough.</p>	
<p><u>Older carers</u> Carers aged 65 and over are more likely to be high-intensity carers and are more likely to be in poor health. River, Parsloes and Goresbrook have the highest proportion of older carers who provide 20 or more hours of unpaid care a week. Chadwell Heath, Mayesbrook and Parsloes have the highest number of older carers whose health is 'not good'. Caring in poor health is considered a critical risk factor to the sustainability of a caring role.</p>	
<p><u>High intensity carers</u> Carers in a high intensity caring role are more likely to suffer the negative impacts of caring on their physical and mental health. Almost half of the carers in Barking and Dagenham provide 20 or more hours of unpaid care a week; Parsloes, Goresbrook and Heath have the highest proportion. Heath, Parsloes and River have the highest proportion of carers providing 50 or</p>	

more hours a week.

Recommendations

Support for carers at GP practices

Ensure support for carers is embedded and championed as part of a targeted programme to encourage GP practices to adopt a positive commitment to carer identification and support. This could be led by a clinical carers' lead at the CCG. As well as, and as part of, ensuring carers are looking after their own health needs, carers could have special access to interventions and schemes such as exercise on referral and books on prescription. Carers could also be offered flu jabs in accordance with NHS guidance. It may be worth considering a social prescribing model for carers (and all patients) who report low mood and depressive symptoms, instead of traditional drug therapy models, which has been evidenced in one CCG locality in the East of England to contribute towards cost savings in SSRI prescription budgets.

Preventative health programmes

Ensure carers are considered as an integral part of *Better Care Fund Scheme 8: Prevention*, aimed at improving health broadly, as a cost-effective way of using existing programmes of work in a carer friendly way. In line with poor health outcomes in the area, and the negative health inequalities experienced by carers, a 'carers' health drive' could target carers for preventative public health programmes including smoking cessation, healthy eating and obesity, physical activity, and alcohol misuse. Healthy eating and keeping fit and healthy could be a part of the ongoing training programme for carers. Carers could be offered access to flu jabs, as a preventative measure. Discounted, or free, access for carers to local leisure facilities could also be negotiated.

Providing carers with preventative advice and support in the community

Negotiate formal and/or informal partnerships with local health venues such as pharmacies to embed carer identification, information and support into places that carers regularly visit. Preventative health checks and flu jabs for carers could be offered by community pharmacies to take some of the pressure off primary care; as a pilot this could take place in areas with the worst self-reported health outcomes for carers e.g. Chadwell Heath, Eastbury and Valence. This could be another project that would benefit from the use of volunteers, who could help to meet and greet carers, and support staff teams in collecting information and answering general questions. Older carers and carers that provide 20 or more hours of care a week could also be targeted, as they are shown to have the poorest health outcomes. At the same time, carers could be targeted for other preventative activities as outlined above and/or referred to formal support.

EMOTIONAL SUPPORT FOR CARERS

EMOTIONAL SUPPORT COMES IN ALL SHAPES AND SIZES – ONE SIZE DOES NOT FIT ALL. SUPPORT GROUPS ARE NOT FOR EVERYBODY AND MORE COULD BE DONE TO PROVIDE A WEB OF EMOTIONAL SUPPORT THAT WOULD SUIT A WIDER GROUP OF CARERS. TRAINED VOLUNTEERS INCLUDING EX-CARERS COULD BE USED TO EXPAND ON THE TELEPHONE SUPPORT OFFERED BY CARERS AND BARKING AND DAGENHAM AND PROVIDE A

'LISTENING EAR' SERVICE FOR CARERS, WHICH WOULD GIVE THEM SOMEONE TO TALK TO WHEN THEY NEED SOME EXTRA SUPPORT TO COPE. AN ONLINE MENTORING SERVICE, SUCH AS CARERS TOGETHER, COULD ALSO BE CONSIDERED.⁶ PROVIDING CARERS WITH ACCESS TO SPECIALIST COUNSELLING AND THERAPIES, THROUGH IAPT OR THE VOLUNTARY SECTOR, COULD HELP THOSE WITH MORE COMPLEX EMOTIONAL SUPPORT NEEDS. 'MEN'S SHEDS' IS ONE EXAMPLE OF GROUP SUPPORT FOR MALE CARERS THAT BRINGS PEOPLE TOGETHER AROUND A SHARED INTEREST AND ACTIVITY, SUCH AS GARDENING, AS WELL AS THE EXPERIENCE OF CARING. EMOTIONAL SUPPORT DOES NOT ALWAYS HAVE TO BE FACILITATED BY A 'PROFESSIONAL' IN A COUNCIL FUNDED BUILDING.

Safeguarding training

Once the findings of the Healthwatch research into carers and safeguarding are published, some consideration could be given to a training course for carers around safeguarding including understanding the safeguarding process, what to do in situations where carers are at risk of harm, and how to prevent carers causing inadvertent and unintentional harm to the person they care for. A part of this course could also be a skills audit to identify their training and learning needs in relation to their caring role.

Summary of key evidence related to this outcome

Health outcomes and inequalities

The Health and Wellbeing Strategy 2012-15 recognises that the residents of Barking and Dagenham are not as healthy as they should be and that compared to other parts of the country, they don't live as long and many die early from cancer or heart disease. Prevention is a key theme and identifies five priorities:

- To support more people to successfully quit smoking
- To get more people participating in the recommended levels of physical activity for health
- To raise awareness of the need to adhere to the recommended guidelines for sensible drinking
- To support more people to achieve and maintain a healthy weight
- To raise awareness of the early signs and symptoms of disease

Barking and Dagenham's Better Care Fund Plan Scheme 8: Prevention is also aimed at improving physical and mental health in the population, with a focus on:

- Improving premature mortality
- Tackling obesity and increasing physical activity
- Improving community safety
- Improving mental health
- Reducing injuries and accidents

⁶ <http://timebank.org.uk/carers-together>

National research demonstrates the health inequalities between carers and non-carers, with carers facing negative impacts on their physical and mental health as a result of their caring role. Research shows that this is no different in Barking and Dagenham, with poorer health outcomes for carers that get worse as their caring role intensifies. People providing 20 or more hours of unpaid care a week have poorer self-reported health outcomes than non-carers at all ages apart from the oldest old. Census results show that carers are caring for longer – with almost half of the carers in Barking and Dagenham providing 20 or more hours of unpaid care a week – which makes this an even more serious concern.

More than 5,000 carers in Barking and Dagenham (including more than 1,500 aged 65 and over) declare their health to be ‘not good’. This includes more than 1,400 carers (almost 500 aged 65 and over) who declare their health to be ‘bad or very bad’; with the poorest self-reported health outcomes for carers in Chadwell Heath.

61% of carers in Barking and Dagenham reported a long-standing health condition against 46% of non-carers; this rises to 73% of carers providing 50 or more hours. Carers are more likely to suffer from high blood pressure, arthritis and long-term joint problems. They are also more likely to suffer from pain/discomfort and anxiety/depression, which are dimensions of poor health-related quality of life.

GP support for carers’ health

Carers said that there should be more support at GP practices as they are their “first point of contact”. It was said that there is a lack of information for carers at GP practices e.g. leaflets or posters. Some talked about feeling let down by their GPs, who had never recognised their caring role even though they often attended appointments with their loved ones. One carer said she doesn’t have the time to organise her own GP appointments, despite suffering from severe insomnia; however, she often organises and attends appointments for the people she cares for. One carer who uses mental health services felt strongly that those services had a responsibility to help him to understand the impact caring may be having on his mental health condition.

Professionals, including one GP, said that GPs cannot always see the clinical benefits of supporting carers and referring them on for assessments. One professional felt there was a need to support carers to access mainstream services to improve their health rather than relying on costly bespoke services and initiatives. One health professional felt that adding things into GP contracts was not the right way and that contractual levers could be difficult; “it’s better to talk to deliverers”.

Dementia carers spoke of “keeping themselves well” to cope with the physical and mental pressures of their caring role. One carer said she had a different doctor to her husband and rarely had time to make an appointment and “list” her problems. One learning disability carer spoke of cancelling appointments including operations because they could not get respite.

An evaluation of the Department of Health's Demonstrator Sites programme⁷ hypothesised the potential significant cost savings of undertaking health and wellbeing checks on carers and identifying undiagnosed conditions. The study showed that health checks frequently led to diagnosis of previously unknown conditions and referred many carers for earlier, and less costly, medical intervention, which ultimately supported them to care for longer.

Carers and safeguarding

Barking and Dagenham's Safeguarding Adults process recognises carers as a group that is potentially 'at risk' of harm or abuse. They may be subject to harm themselves, or may need information, advice and support to prevent them causing inadvertent harm to others. A large scale survey of carers around safeguarding issues is being carried out by Healthwatch.

⁷ Evaluation of the National Carers' Strategy Demonstrator Sites Programme (University of Leeds, 2011)

Outcome 5: Carers are supported to improve their individual social and economic wellbeing, reduce isolation and fulfil their potential in life

Outcome measures	Existing outcome sources
<ul style="list-style-type: none"> • Opportunities to improve carer’s individual social and economic wellbeing are embedded across health, social care and statutory services they come in contact with • Carers are able to have their own life alongside their caring role and avoid becoming socially isolated • Carers are able to access support to enable them to fulfil their educational and employment potential • Carers in employment are able to access the information, advice and support they need to understand their rights and sustain themselves in their caring role • Carers are supported to maximise their income and access information and advice related to their financial situation 	<ul style="list-style-type: none"> • National Carers’ Strategy (2010) • Adult Social Care Outcomes Framework • Public Health Outcomes Frame work • Care Act (2014) • Caring for Carers in Barking and Dagenham (2011-15) • Better Care Fund Scheme 5: Integrated Commissioning • Better Care Fund Scheme 6: Support for family carers • Better Care Fund Scheme 7: Care Act implementation • Better Care Fund Scheme 8: Prevention
Improvement indicators	
<ul style="list-style-type: none"> • Carers can balance their caring roles and maintain their desired quality of life (ASCOF 1D) • Proportion of people who use services and their carers, who reported that they had as much social contact as they would like (ASCOF 1I) 	
Carers most at risk	
<p><u>Working and working age carers</u> 8 in 10 carers in Barking and Dagenham are of working age but working age carers are underrepresented in social care data. Almost half of the borough’s carers are in employment. The highest proportions of working age carers are in Abbey, Becontree and Gascoigne.</p> <p><u>Carers in wards with high income deprivation</u> Carers face serious and lasting financial consequences due to the costs of caring. There is some correlation between higher proportions of carers in the population and higher levels of income deprivation in parts of Chadwell Heath, Parsloes and River.</p> <p><u>Socially isolated carers</u> National evidence and local engagement suggests certain BME groups (including Pakistani and Bangladeshi) and young carers are more likely to be socially isolated.</p>	

Recommendations

CARERS' ASSESSMENTS

ENSURE CARERS' ASSESSMENTS SUPPORT AND PROMOTE CARERS TO HAVE A LIFE OF THEIR OWN OUTSIDE OF CARING, ACCESS TO EDUCATION AND TRAINING, AND TO BE ABLE TO SEEK WORK; AND ENSURE PROFESSIONALS ARE FULLY AWARE OF THE SERVICES AVAILABLE TO SUPPORT CARERS IN THIS REGARD AND REFERRAL PATHWAYS ARE IN PLACE. THIS SUPPORTS THE AIMS OF *BETTER CARE FUND SCHEME 7: CARE ACT IMPLEMENTATION* AND THE RELEVANT DUTIES IN THE CARE ACT THAT PUT SUPPORT FOR CARERS ON A PAR WITH SERVICE USERS.

REFERRAL TO WORK AND TRAINING OPPORTUNITIES

CARE CITY WILL PROVIDE A RANGE OF BACK TO WORK AND TRAINING OPPORTUNITIES FOR CARERS WHO ARE LOOKING TO UTILISE THEIR SKILLS TO FORGE A CAREER IN THE LOCAL SOCIAL CARE FIELD. THE PARTNERSHIP IS BETWEEN NELFT, LBD AND OTHER PARTNERS AND IS SET TO BE LAUNCHED IN THE NEXT FEW YEARS. ONCE IN PLACE, CARERS COULD BE REFERRED TO THIS SERVICE. CURRENTLY, DABD OFFERS A RANGE OF TRAINING WHICH CARERS COULD BE REFERRED INTO, INCLUDING BASIC SKILLS AND EMPLOYMENT SUPPORT.

CARERS' EMPLOYMENT CHAMPIONS

CARERS' CHAMPIONS IN JOBCENTRE PLUS AND LOCAL JOB SHOPS COULD PROVIDE SPECIALISED SUPPORT FOR CARERS SEEKING EMPLOYMENT AND RETURN TO WORK ACTIVITIES. THIS SUPPORT WOULD BE PARTICULARLY IMPORTANT FOR CARERS WISHING TO RETURN TO WORK AFTER LONG PERIODS OF CARING.

SUPPORT FOR CARERS IN EMPLOYMENT

A PROGRAMME OF WORK TO SUPPORT CARERS IN EMPLOYMENT, THROUGH LOCAL BUSINESSES AND CHAMBER OF COMMERCE MEMBERS, COULD SEE BENEFITS FOR EMPLOYERS AND CARERS, AS WELL AS THE LOCAL ECONOMY. THIS IS AN OPPORTUNITY TO DEVELOP CARER FRIENDLY POLICIES AND PRACTICE AND IDENTIFY AND ENGAGE WITH CARERS IN THE WORKPLACE, WHICH WOULD INCREASE RETENTION OF SKILLED WORKERS WHO MAY OTHERWISE GIVE UP WORK TO CARE. EMPLOYERS FOR CARERS⁸ OFFERS PRACTICAL ADVICE AND SUPPORT FOR EMPLOYERS SEEKING TO PROMOTE BETTER SUPPORT FOR CARERS IN THEIR WORKFORCE.

PEER SUPPORT

ENSURE ALL CARERS' SUPPORT GROUPS ARE PROACTIVELY FACILITATED, SO THAT CARERS ARE ENCOURAGED TO BE INDEPENDENT AND ANY CONCERNS THAT CARERS RAISE ARE ACTIONED. NEW MEMBERS SHOULD BE REGULARLY SOUGHT, AND LONG-TERM DEPENDENCY DISCOURAGED. GROUPS COULD INCLUDE AN ELEMENT OF TEACHING CARERS NEW SKILLS E.G. RELAXATION TECHNIQUES, CV WRITING, FINANCIAL ADVICE, AS WELL AS PROVIDING EMOTIONAL SUPPORT. PEER SUPPORT NETWORKS COULD BE DEVELOPED THROUGH THE AGE, CONDITION AND EQUALITY SPECIFIC VOLUNTARY SECTOR AND LINKED INTO OTHER INITIATIVES IN THE BOROUGH THAT SEEK TO MINIMISE

⁸ <http://www.employersforcarers.org/>

ISOLATION AND LONELINESS. IN THE LONG RUN, GROUPS MAY BENEFIT FROM ENCOURAGEMENT AND SUPPORT TO BECOME SELF-SUFFICIENT, WHICH WILL INCREASE THEIR RESILIENCE.

TARGETED FINANCIAL SUPPORT

CARERS IN WARDS WITH THE HIGHEST LEVELS OF DEPRIVATION COULD BE TARGETED FOR BENEFIT CHECKS AND INCOME MAXIMISATION E.G. CHADWELL HEATH, HEATH AND THAMES.

Summary of key evidence related to this outcome

Carers' quality of life

The National Carers' Survey asked carers to rate whether their needs were met under six quality of life domains: occupation, control, personal care, safety, social participation, and encouragement and support. They were then given a score based on their answers. Overall, Barking and Dagenham scored 7.6, which is below the England (8.1) and London (7.7) average. The highest score nationally was 9.8.

Carers and employment

A third of carers aged 16 and over in Barking and Dagenham (33%) are in full-time employment, compared to 39% of non-carers. Carers are more likely than non-carers to be in part-time employment. Carers' ability to work is reduced by the intensity of their caring role, with 6 in 10 people who care for 1 to 19 hours a week in some type of work, compared to 3 in 10 people who provide care for 50 or more hours a week. Over 750 people are in full-time employment and providing care for 50 or more hours a week. They are likely to be a group with high support needs.

The opportunities for carers to reskill or return to the job market while they are caring or when their caring role ends are not clearly defined. When launched, Care City will present opportunities for carers to access education, training and employment opportunities in the care sector in Barking and Dagenham and should be explored. DABD also provides a range of services including support with employment, training and welfare rights. Their training courses include basic skills in Maths, English and Computing.

Carers of Barking and Dagenham spoke of contributing to the care market in Barking and Dagenham through their training programme; some carers have gone onto work in the care field as personal assistants. It also runs a volunteer project which engages carers and former carers; currently they have around 120 volunteers.

Carers' finances

There is some correlation between high proportions of carers and higher levels of income deprivation in the population in parts of Chadwell Heath, Parsloes and River. Uptake of Carer's Allowance in the borough correlates with an increase in claims for disability benefits and an increase in the intensity of the caring role.

Social isolation and peer support

The National Carers' Survey revealed that 63% of carers in Barking and Dagenham have little or not enough social contact and feel socially isolated. Carers of Barking and Dagenham offers a wide range of peer support and activities to support carers and reduce isolation. Their day trips always book to capacity and cater to a mix of carers.

The Department of Health identified social isolation as a significant problem for carers of people with dementia.⁹ The Memory Lane Resource Centre is run by Carers of Barking and Dagenham and provides a much needed line of support to a very isolated and historically unsupported group of carers. Professionals spoke of it keeping people with dementia away from going into nursing care.

National research in 2011 showed that carers from some BME groups can experience social isolation due to stigma and language barriers.¹⁰ This research particularly highlighted Pakistani and Bangladeshi carers (of which there are more than 1,200 in Barking and Dagenham). There are also high numbers of carers from Eastern European communities who are not coming forward for support and may be socially isolated due to their caring role.

Carers of Barking and Dagenham offer a number of services which contribute to improving carers' social wellbeing and reducing isolation. As well as day trips and activities, the organisation runs peer support groups for carers of people with mental health conditions, dementia and parent carers. Another group that has proved popular is the monthly 'skill share' group where carers can learn new skills from each other including arts and crafts. This group has encouraged friendships outside of the sessions.

Feedback from the dementia group was that the carers find it hard to find the time to attend activities and pampering sessions; however, they were reassured that someone knew their situation and got peace of mind from the regular telephone contact from Carers of Barking and Dagenham. There was a feeling that more could be done to check that elderly carers are claiming all the benefits they are entitled to.

One carer of someone with a mental health condition said that she had valued the support of a carers' worker at the Hedgecock Centre, and has felt more isolated since that service was stopped.

Long-term family carers in the learning disabilities group spoke of the difference between their quality of life and that of a non-carer who they felt could go about their day as they pleased, and didn't have to plan everything. Generally there was a feeling from carers that caring changes your social life and friends and neighbours may offer to help, but they don't stay for long. One carer described caring as "like being on a desert island".

⁹ The Needs of Informal Carers of Those Living with Dementia (Hull Churches Home from Hospital Services, 2011)

¹⁰ Half a Million Voices: Improving Support for BAME Carers (Carers UK, 2011)

People who attended the peer support groups found them to be a “lifeline” and said they struggled to talk about their caring role to other friends, family members and work colleagues. One carer said that the group helped him to realise, “I’m not absolutely useless....I’m a carer”. Young carers particularly appreciated the support of peers through being part of Carers of Barking and Dagenham; many had had bad experiences with other children at school who would, “take the mick”.

Outcome 6: Carers are supported to cope with changes and emergencies and to plan for the future

Outcome measures	Existing outcome sources
<ul style="list-style-type: none"> • Carers are provided with information and advice at an early stage to prepare them for changes in their caring role and emergency situations • Carers have access to tools and strategies that enable them to prepare for changes in their caring role and emergency situations • Carers who are going through changes in their caring role are offered information, advice and support to help them to cope • Young carers and parent carers are prepared for the transition into adult carers' support services and supported through the process 	<ul style="list-style-type: none"> • NHS Outcomes Framework • CCG Outcomes Indicator Set • Care Act (2014) • Children and Families Act (2014) • Caring for Carers in Barking and Dagenham (2011-15) • Better Care Fund Scheme 2: Improved hospital discharge • Better Care Fund Scheme 6: Support for family carers • Better Care Fund Scheme 11: Dementia Support
Improvement indicators	
<ul style="list-style-type: none"> • The number of carers with an emergency plan recorded (local) 	
Carers most at risk	
<p><u>Older carers</u> Engagement with older carers revealed they worry about the future and are fearful of what will happen to their loved ones if they are no longer able to care for them in the short or long term. The largest proportions of older carers aged 65 and over are in Chadwell Heath, Heath and Parsloes.</p>	
<p><u>Older carers of people with learning disabilities</u> There is a risk within this group of carers who are supporting adult children at home and are getting older themselves and have their own support needs. Both need support with future planning; the older carers need support to 'let go' and the adult children need support to become more independent. A growing number of people with learning disabilities are providing regular and substantial care for their ageing relatives. Without each other's support, neither person would likely be able to remain living independently within their local community.</p>	
<p><u>Carers of people with dementia</u> Identifying people with dementia and their carers early is a key priority of <i>Better Care Fund Scheme 11: Dementia Support</i> and supports people to plan and make decisions for the future.</p>	

Recommendations

Identifying and supporting carers at times of change or crisis

As part of mainstreaming of carer identification and support, the health, social care and voluntary sector could develop joint strategies for identifying and supporting carers at times of crisis or change in their role. This includes social workers, mental health staff, GPs, health staff and voluntary sector staff who may come into contact with a carer in an ongoing or emergency context. As part of *Better Care Fund Scheme 8: Prevention*, offer carers preventative information, advice and training to cope with situations when caring changes; this could be related to carers' own health deteriorating or the health of the person they care for worsening, and should have an aim to sustain carers in their caring role and prevent carer breakdown which leads to costly social care interventions. *Better Care Fund Scheme 2: Improved hospital discharge* is relevant here too; including offering carers in hospital information, training and referral to community support to prepare for and cope with changes to their caring role.

Reviews

Ensure carers receive an annual review where they are receiving ongoing services, or are considered as part of the service user's annual review. This is an opportunity to understand if there have been any changes in the caring situation and to update emergency planning information. This should be timely and carers fully prepared for what it will entail; it should also consider their needs outside of the caring role and related to having a life of their own.

Emergency planning scheme

Consider the development of an emergency/contingency planning scheme for carers. The benefits to health and wellbeing of having a plan in place, written down and securely held, of what carers would like to see happen to the person with care needs in the event of something unexpected happening to themselves is well evidenced. As well as offering peace of mind and reassurance there is an 'invest to save' argument, which suggests these schemes represent value for money.¹¹

Training for future planning

The training programme for carers could include sessions on future planning. Consider commissioning a dedicated piece of work to focus on older carers, including carers of people with dementia and older carers of people with learning disabilities, using an approach that seeks to build trust and confidence in public bodies and supports future planning. This would address a major concern for those older carers, some of whom are experiencing their own serious health issues, and align with a commitment to enable people to become more independent and prevent future crises. Collecting data to measure the level of mutual caring in the borough would be a helpful start, as well as considering the accessibility and availability of information for carers with learning disabilities. Partnerships between learning disability, older people and carers' forums and programmes of work would recognise the interdependency and value of thinking

¹¹ Emergency Schemes for Carers in Britain: Results of a National Survey (H. Elwick and S. Becker, 2011)

systematically about projects.

Supporting young carers and parent carers during transition

Ensure protocols are in place to support young carers and parent carers as they transition to adult social services and adult carers' support. This includes supporting their caring role alongside education and employment ambitions and opportunities.

Summary of key evidence related to this outcome

Changes to a caring role

There are many scenarios which may result in changes to a caring role or even an emergency situation. Common reasons heard from carers include changes in their health or an exacerbation of the condition of their loved one. These changes can result in carers making substantial changes in their life such as giving up work to care or moving house to be closer to the person they care for.

During times of change or crisis, carers said they would usually go to their GP as they don't know where else to seek support; however, carers tend to have a number of interactions with professionals in social care, hospital and the emergency services. A social work professional reported that carers only come into contact with her when a situation has got to crisis point.

Planning for emergencies and the future

Carers voiced their worries about what will happen to the person they care for if they are not able to continue in their role, either in an emergency or ongoing situation. This was a particular concern for carers who had no informal network of support. One carer said that she was completely alone now, with no family or friends left to call on. Another carer, who had already suffered a serious stroke, said she lived in fear of collapsing again with no plan in place for her daughter's care. Carers said that an emergency plan would give them peace of mind and reassurance.

Carers of Barking and Dagenham provides carers with an emergency card to record two contacts that can be called upon if the carer is unable to provide care. If those two people cannot be contacted then the card indicates the police should be called. This card is the only emergency planning tool that is used in Barking and Dagenham and there was no mention of strategies for managing changes in caring situations.

Carers in the learning disabilities group reported finding it difficult to 'let go' and allow greater independence for the adult child who they have been looking after for many years; they were worried for their child's future and what would happen if they weren't around. One carer asked if she could be taught to let go; she feels her daughter is even more reliant now she is getting older and as a family they struggle with respite as they don't want to send their daughter away.

Carers articulated wishes for greater information and support at an earlier stage of their caring role to help prepare them for changes and

emergency situations in the future.

Outcome 7: Carers are supported when their caring role is coming to an end and to have a life after caring

Outcome measures	Existing outcome sources
<ul style="list-style-type: none"> • Carers are provided with the information, advice and support they need when they are looking after someone who is at the end of life • Carers are treated in a sensitive manner and provided with support when their caring role comes to an end • Former carers are supported to transition into mainstream services 	<ul style="list-style-type: none"> • NHS Outcomes Framework • CCG Outcomes Indicator Set • Care Act (2014) • Joint Health and Wellbeing Strategy • Integrated Care in Barking and Dagenham, Havering and Redbridge: The Case for Change • Better Care Fund Scheme 6: Support for family carers • Better Care Fund Scheme 9: End of life care
Improvement indicators	
<ul style="list-style-type: none"> • Bereaved carers' views on the quality of care in the last 3 months of life (NHSOF 4.6) 	
Carers most at risk	
<p><u>End-of-life carers</u> Significantly more people die in hospital in Barking and Dagenham than die at home; for carers to support people at the end-of-life in a home setting, they require a great deal of support and understanding.</p> <p><u>Former carers</u> Some carers' support groups in Barking and Dagenham have a large former carer membership, which can have positive and negative effects on the individuals and groups. Former carers would benefit from a tailored offer and access to other opportunities.</p>	
Recommendations	
<p><i>Supporting carers providing end of life care</i></p> <p>A programme of work to ensure carers are well supported at the end of their loved one's life could help to improve this difficult time for families and to prevent unplanned hospital admissions for people who can be better cared for in other settings. This supports the aims of <i>Better Care Fund Scheme 9: End of life care</i>, This should include ensuring carers' needs and their desire and ability to provide care is assessed when their cared for is approaching the end of their life; and ensuring carers are as involved as they want to be, consulted and treated in a sensitive manner by everyone in every setting. This is a whole system piece of work. It is vital that the right information is available at the right time to help carers to navigate the health and care system and to understand the multitude of professionals they may come into contact with. Continue to offer end of life care training for carers, to prepare them for this time, and refer more carers to this from primary and secondary care. Information for carers regarding end of life care could be provided within GP practices and</p>	

hospitals. Some simple initiatives have included a palliative carers' pack detailing, for example, fast track benefit applications, continuing health care explained, preferred place of care directives and lasting power of attorney.

Research into cultural needs

A discrete piece of work could be commissioned to understand the cultural and faith needs of people providing end of life care at home, including any best practice models.

Supporting carers when their caring role comes to an end and beyond

A tailored, more focused offer to former carers that supports people to consider their life after caring. This could firstly include access to bereavement counselling, available flexibly when the person is ready. Peer support networks may also appeal to some, to reduce isolation; however, a supported transition from carers' groups into mainstream support would be appropriate, as well as support to become a volunteer if they would like to help other carers or former carers. For those former carers who wish to return to the workforce, training and courses such as CV building, computer literacy, confidence building and job searching would help them and could be accessed through the voluntary sector; in the future, this may be something that could be provided through Care City.

Summary of key evidence related to this outcome

Place of death

6 in 10 deaths in Barking and Dagenham occur in hospital (60.6%) and 2 in 10 (19.4%) take place at home. 12.5% of deaths happen in a care home and 4.7% in a hospice. Compared to the England average, significantly more people die in hospital (England average is 50.7%) and significantly fewer die in other places including at home.¹²

Supporting carers with end of life care

Barking and Dagenham scored below the England average regarding the support received by family carers both before and after the death of their loved one; this includes being involved in decisions about end of life care before death, being supported by the health team at the time of death and being dealt with in a sensitive manner after death.

Health professionals expressed concern about end of life care which they said is very good in hospital but is not always supported very well at home. The CCG is interested to research the support carers might need to provide end of life care at home – particularly carers from different cultural and faith groups.

When the caring role comes to an end

Older carers shared their concerns about what will happen to their loved one when they are no longer around to care for them. They also

¹² End of Life Care CCG Profile (Public Health England, 2010-12)

shared that they have faced challenges towards the end of life of the person they care for, or when they move into residential care. One former carer (86) spoke of the loneliness and isolation she felt when her caring role ended, as her loved one moved into residential care and subsequently died. She described positively what she gains from attending a carers' support group, in spite of a journey of up to an hour and a half each way. The carers' group at Memory Lane was dominated by former carers who greatly value the support and friendship they receive from the group whilst in a caring role and also when that caring role comes to an end.

Carers provided examples of the support they would most like to receive when their loved one is no longer around, including bereavement support being routinely available, as well as practical help to look for work and build a CV; "help to get back into society, especially if you've been caring for years".

Appendix 1: Better Care Fund – Mainstreaming Carers

The overall aim for integrated care is to strengthen the community response to people's needs by bringing together health and social care and so reduce the need for hospital care, maximise independence and improve outcomes.

People with caring responsibilities are a fundamental part of any community response to people's needs. They form an integral part, not only of a person's 'natural network', but any 'service' response in place to meet a person's needs. They therefore have an important role to play in supporting the achievement of Barking and Dagenham's Integrated Care Commissioning Strategy and Better Care Fund schemes.

Below is a snap shot view of how each BCF scheme could integrate carer identification, recognition and support as part of its mainstream activity. This is based on evidence and best practice, where available, to suggest the effectiveness both in terms of better service user/carers outcomes and cost-benefit analysis.

Evidence has been drawn from a number of sources including an independent evaluation of the National Carers' Strategy Demonstrator Sites programme. This evaluation concluded that although precise measurement of cost savings was not possible, many of the types of carer support introduced had the potential to result in cost savings within the health and social care sector. Potential savings were identified in the national evaluation study and in the local evaluation reports, relating to:

- Preventing hospital or residential care admissions
- Supporting carers to sustain their caring role
- Earlier identification of physical and/or mental health issues
- Improved health and wellbeing of carers
- Improved partnership working
- Efficiency savings in GP practices
- Assisting carers to return to, or remain in, paid work
- The establishment of informal support networks among carers

Four sites calculated the cost savings of their services, using different approaches; each calculated positive cost savings. Many sites continued to offer all or part of the support services following the end of the demonstrator period.¹³

¹³ New Approaches to Supporting Carers' Health and Wellbeing (Department of Health, 2011)

Scheme 1: Community Health and Social Care Teams

Supporting carers to identify with caring and its impact at the earliest opportunity is an evidenced outcome that promotes health and wellbeing. Primary care is the point of contact for many people when caring changes. This can be as a result of the carers' own health deteriorating and no longer being able to cope, or the cared-for's health worsening.

People who are able to recognise they are caring are more likely to enjoy better health long-term and more able to recognise themselves with some degree of emotional independence from the person they care for and therefore more able to take breaks.¹⁴ One study carried out by Dr Sachin Gupta, the RCGP East of England GP Carers' Lead, concluded a significant reduction in depressive symptoms reported by carers, following a carers' break on prescription; from 39% pre break to 20% post break.¹⁵

Scheme 2: Improved hospital discharge

Hertfordshire County Council, Carers in Hertfordshire and East & North Hertfordshire NHS Trust are piloting a carer friendly community and carer friendly hospital. The aim is to measure the joint benefits – both financial and non-financial – of a carer friendly health and social care system. The hospital is a key trigger point in the caring journey. People may become carers in a hospital setting, or they may see their caring responsibilities increase following a hospital admission as a result of a fall or similar incident.

The impact of caring on health also means that carers are more likely to be admitted themselves; for example, carers caring for someone for over 50 hours a week are at 23% higher risk of a stroke than non-carers. This leaves their cared for alone, vulnerable, with the potential outcome of a double admission to hospital or residential care. The rationale for the carer friendly hospital project is there is significant scope for better outcomes to patients and carers, by improving support to carers in an acute setting. The pilot project ran in tandem with the carer friendly community project, and ran in Lister Hospital until March 2014. It had an initial focus on the carers of stroke survivors, measuring the impact of better support to carers on readmission rates, length of stay, and delayed transfers of care, as well as the carer experience and outcomes for carer and cared for.¹⁶

With the appointment of a dedicated carers' lead officer at the hospital the pilot achieved the following outcomes:

- Initially focusing on the stroke ward, from August 2013 the hospital pilot included elderly care wards where there are higher rates of readmission.

¹⁴ Professor Julia Twigg (University of Kent)

¹⁵ Supporting Carers in General Practice & role of RCGP GP Champions for carers (Dr Sachin Gupta, 2013)

¹⁶ <http://www.enherts-tr.nhs.uk/patients-visitors/our-services/carers-support/carer-friendly-hospital/>

- A Carers' Policy, a trust-wide policy which sets out minimum standards in supporting carers to care in a hospital setting, was drafted and finalised following extensive consultation with staff and the Carer Steering Group. It includes a Carers' Agreement for carers to complete with a member of ward staff at the beginning of their stay, which sets out tasks and boundaries for the carer whilst they are cared for in hospital. The Policy also outlines certain privileges for carers, including discounts on parking, catering and the health shuttle, increasing carers' status in the hospital.
- A carers' leaflet has been produced, guidance for carers is now available on the Trust website, there are dedicated carer information boards and regular carers' coffee mornings are being held. In addition, formal carer awareness training has been attended by 56 members of staff on the stroke unit and elderly care wards over 12 sessions on six days. A further 65 staff have received an informal talk on carer awareness by the Carers' Lead attending team meetings – all with excellent learner feedback.
- The Carers' Lead has helped to expedite discharge and reduce length of stay through specific support to individual carers. The Carers' Lead was in contact with 210 carers from March to December 2013 and varying levels of support were provided depending on the need of the carer.
- During the project, 155 direct referrals were made to Carers in Hertfordshire while there had been no direct referrals from the Lister hospital the year before. The number of carers assessments carried out by the Lister Hospital Team/Integrated Care Team during the pilot was 54% more than the previous year.
- Prior to the project 46 patients were readmitted to the Stroke unit in a 28 day period between April 2012 and March 2013, and of those 10 were admitted due to carer breakdown or where the carer required additional support (142 bed days). During the project period, March 2013 to December 2013, 41 patients from the Stroke unit were readmitted, however all of these patients were readmitted due to medical reasons and none were readmitted due to carer breakdown or where the carer required additional support.

Low level support to carers has also been proven to have an impact on delaying residential as well as hospital admissions. International randomised controlled trials have shown up to 28% reduction in hospital admission compared with the control group when carers are identified soon after admission.¹⁷

The Moffat Project, developed by the former Princess Royal Trust for Carers (PRTC), worked in four Health Board areas in Scotland to promote early identification of carers and to provide support to prevent unnecessary crisis. An evaluation by Glasgow Caledonian University found that the majority of the aims of the Moffat Project had been achieved, including identifying new carers early on; providing

¹⁷ Supporting Carers in General Practice & role of RCGP GP Champions for carers (Dr Sachin Gupta, 2013)

information and support to carers in the hospital setting; creating pathways to refer on carers to carers' centres, other agencies or to social work; and training the paid staff in carer awareness. There was a significant increase in the percentage of carers reporting that discharge plans were put into place.¹⁸

Scheme 3: New model of intermediate care

The following evidence suggests that if carers understand the principles and objectives of reablement and have their training and learning needs taken account of (e.g. moving and handling, health and safety, managing medication), it is more likely to lead to faster recovery rates for the patient and support carers to maintain their caring roles for longer:

- A randomised controlled trial (RCT) evidenced a reduction in depression amongst stroke patients (17% from 27%) and reduced need for physiotherapy by supporting family carers via an information and advice offer in the hospital setting
- Another RCT evidenced a higher proportion of stroke patients achieving independence at an earlier stage when carers were provided with 3-5 sessions of personal care training lasting 30-45 minutes per session. There were also significant reductions in carer burden and improvements in mood and quality of life for carers and care recipients.¹⁹
- Bristol & South Gloucestershire Carers' Centre have dedicated hospital carers' support workers providing advice, information and training for both carers and staff; this has led to reduced bed days either through quicker discharge, or reduced readmission²⁰
- Improving the skills of carers during the rehabilitation of stroke patients was found to reduce the costs for stroke care and improve the quality of life of the stroke patient, without increasing the burden of care to families or transferring the costs to the community.²¹

Scheme 4: Mental health support outside hospital

The Triangle of Care²² project brings together many years of research with carers into what they feel will benefit them when involved with mental health services. It was launched in 2010 to ensure carers are fully included and supported when the person they care for has an acute mental health episode, but has evolved to encompass all areas of mental health service delivery.

¹⁸ The Moffat Project: Preventing Crisis for Carers (PRTC, 2010)

¹⁹ Written evidence from The Princess Royal Trust for Carers and Crossroads Care (Health Committee, 2011)

²⁰ Summary Social Impact Evaluation of the Carers Health Project (Baker Tilly, 2013)

²¹ Training Care Givers of Stroke Patients: Economic Evaluation (British Medical Journal, 2004)

²² The Triangle of Care: Carers Included, A Guide to Best Practice in Mental Health Care in England (Carers Trust, 2013)

The triangle demonstrates true collaboration between the mental health professional, service user and carer. The service is usually defined by the link between professional and patient, the link between patient and carer is already there, and the willingness by the professional and carer to engage completes the triangle and produces the best chance of recovery.

It identifies six key standards that are required to achieve these aims:

1. Carers and the essential role they play are identified at first contact or as soon as possible thereafter
2. Staff are 'carer aware' and trained in carer engagement strategies
3. Policy and practice protocols re: confidentiality and sharing information, are in place
4. Defined post(s) responsible for carers are in place
5. A carer introduction to the service and staff is available, with a relevant range of information across the care pathway
6. A range of carer support services are available

Avon and Wiltshire Mental Health Partnership NHS Trust take an open approach to working with service users and carers, recognising the advantages of fostering three-way working relationships based on Triangle of Care principles. It offers a comprehensive information pack for carers that covers everything from carers' rights and looking after yourself, to advice for carers about how to help someone who has problems with alcohol or drugs. The pack also has a 'Consent to Share Information' form which can be filled out by a service user to give permission for a carer to receive information about their condition and treatment. This form has to be verified by an independent witness.²³

Northumberland, Tyne and Wear NHS Foundation Trust has a Carers' Charter, which was developed in partnership with carers. It sets out what the Trust commits to do to recognise, value, inform, advise and involve carers.²⁴ Involving carers in the care and treatment of the person they care for is guided by a confidentiality policy which provides advice and guidance to carers on how information can be shared. It includes occasions when the patient withholds consent, but the Care Co-ordinator is still able to support the carer. The policy affirms that providing general information about mental illness, emotional and practical support to carers does not breach confidentiality.²⁵

Solidarity in a Crisis is an out-of-hours peer support service in Lambeth, run by Certitude, which offers crisis support and information for service users and their carers during out-of-hours over the weekend. People with lived experience of mental health issues are employed as peer support workers, who can provide support to people over the phone and through face-to-face meetings in public places (always in pairs), as an alternative service to conventional hospital support.

²³ An information pack for relatives and friends who care for people with mental health problems (Avon and Wiltshire Mental Health Partnership NHS Trust, 2010)

²⁴ Carers' Charter (Northumberland, Tyne and Wear NHS Foundation Trust, 2012)

²⁵ Commonsense Confidentiality: A guide for carers, family and friends (Northumberland, Tyne and Wear NHS Foundation Trust, 2012)

In Richmond, a new role has been introduced to integrate a 'chain of care' for informal carers during and post an acute crisis period. The Acute Carers' Recovery Worker gives carers quick access to a dedicated service with specialist advice, support and guidance from a trained family worker. The worker is managed by the local voluntary sector, but seconded to and jointly supervised by the NHS Mental Health Trust. They are able to share risk concerns, address confidentiality barriers and act an advocate for carers. Carers can receive guidance on how to respond to difficult behaviour symptoms and help to navigate health, social care and voluntary sector services.

The role has helped to improve identification and support of carers, particularly those who wouldn't traditionally access a statutory carer support service, and has led to better feedback from carers about the value of the service and their experiences on wards.²⁶

Scheme 5: Integrated commissioning

Commitment to a jointly funded post to support next steps in integrated commissioning makes reference to family carers as an integral part of future commissioning activity.

Scheme 6: Support for family carers

Refer to the work carried out by Carers UK to develop a robust evidence base on carers and this evaluation framework, outlining key recommendations for change.

Scheme 7: Care Act implementation

Preparing for the new duties in the Care Act related to carers is incorporated as part of Scheme 6.

Scheme 8: Prevention

While the theoretical arguments in support of prevention and early intervention are strong, it is also the case that the evidence base for prevention in terms of quantifiable outcomes (including demand reduction and costs savings) has been ambiguous. In part, this reflects the fact that previous approaches to prevention have often been oriented around small, typically grant-funded, pilot schemes, which have not always been embedded and integrated into a 'whole system' of health and adult social care, nor properly evaluated. It is also a consequence of the methodological complexity of proving a causal link between particular interventions and identified outcomes e.g. between carer support and demand reduction or cost savings or avoidance.

Nonetheless, if prevention is about building capacity within communities – enabling individuals, groups and communities to take responsibility for themselves and each other – then supporting carers to build resilience and maintain and improve their own health and

²⁶ Acute Carers Recovery Worker: learning from an initial pilot (Richmond Borough Mind and South West London and St George's Mental Health NHS Trust, 2012)

wellbeing must surely be at the core of any prevention programme of work. Ensuring that carers are included in all of the prevention schemes will help carers to build their own capacity to care now and into the future.

In 2011, a social return on investment analysis evaluated the impact of the support given by five Carers' Centres over a number of years. Looking across the network of 144 Carers' Centres supported by The Princess Royal Trust for Carers, it estimated the gain based on total funding of £57m to be in the region of £814m per year.²⁷

A 2011 report showed how funds to increase support for carers also benefit the people being cared for, as well as reducing demand on other health and social care services. Using evidence from RCTs and peer reviewed journals, the report showed that increasing support for carers not only improves the health and wellbeing of patients and recipients of care, but also improves the health and wellbeing of carers themselves. It also reduces unwanted admissions, readmissions and delayed discharges in hospital settings as well as reducing unwanted residential care admissions and length of stays.²⁸

Scheme 9: End of life care

One London borough has a specific support service for unpaid carers of people with end stage heart failure or severe COPD. The service can fast track access to health and social care services and delivers benefits for patients, carers and commissioners. It has evidenced a significant reduction in hospital admissions, an increase in people dying at home and fewer carers requiring additional bereavement support.²⁹

Scheme 10: Equipment and Adaptations

A study exploring the potential benefits of telecare for unpaid carers in Scotland found that since the introduction of telecare into their caring situation, carers felt they had benefited from more peace of mind; a better night's sleep; an improved relationship with the person(s) they care for; the opportunity to continue with activities they might otherwise have to give up; the ability to remain in paid employment in some cases; and more confidence about the safety and comfort of the person they care for. The carers in the study welcomed the introduction of telecare into their situations.³⁰

Although not tested, the preventative benefits of equipment supporting the caring role but also reducing the burden of caring are anecdotally evidenced. An audit of telephone calls to Essex County Council's Adult Social Care in 2012 discovered the majority of callers (frequently family members) were either unable or struggling to help the person they looked after to get out of the bath.

²⁷ Carers' Centres: What impact do they have? (Baker Tilly, 2011)

²⁸ Supporting Carers: The Case for Change (PRTC and Crossroads Care, 2011)

²⁹ <http://www.carershub.org/content/fast-track-care-and-support-end-life-heart-failure-patients-and-carers>

³⁰ 'A weight off my mind': Exploring the impact and potential benefits of telecare for unpaid carers in Scotland (University of Leeds and Carers Scotland, 2009)

National research suggests it takes on average two years to recognise a shift in relationship and recognition of caring.³¹ It is possible to see the preventative benefits of families being made aware of a range of practical supports, such as equipment that may assist in both maintaining independence and reducing the impact of a caring role, without the necessity to identify with a caring role.

Scheme 11: Dementia Support

A 2005 study looked at the effectiveness and cost-effectiveness of respite services and short breaks for carers of people with dementia. It points to the value of providing a range of respite options for family carers including day care, in-home respite, host-family respite, institutional/overnight respite, respite programmes, multi-dimensional carer-support packages and video respite. Overall, however, the review found that on the basis of the outcome measures used and on the service that was offered, evidence of the effectiveness and cost-effectiveness of respite care and short-term breaks is limited.

In contrast, there was considerable qualitative evidence from carers (and some from care recipients) of the perceived benefits of the use of respite services. It would be wrong to assume that lack of evidence of effectiveness should be interpreted as evidence that respite is ineffective. This is a very complex area; methodologically, undertaking studies of respite services is particularly challenging.³²

As part of a pilot project funded by the Dementia Strategy, two Carers' Support Workers (CSW) were employed by the Worcestershire Carers' Unit to work with the NHS, in Accident and Emergency (A+E) and the Medical Assessment Units (MAU) at Worcester Royal Hospital and the Alexandra Hospital in Redditch. The CSWs are in post to ensure that informal carers of people who may have a dementia and are admitted to A+E or MAU feel supported, listened to and informed right from the start of the hospital journey. The workers can help carers to understand the hospital process, advocate for the needs of the carer and cared for and help the hospital teams to plan effective discharges.

The CSWs work alongside the Integrated Discharge team and utilise the Mental Health Liaison service and the Dementia Nurse Specialist. The workers also help carers by signposting them on to or referring them to support systems in the community. For example, Carers' Action Worcestershire, that offers a 24 hour advice, information and support helpline, regular talk time support, carers groups and training events. The workers also refer carers to services such as Admiral Nurses, Red Cross and, as appropriate, request Carers' Assessments which can lead to statutory services such as the flexible break voucher scheme or carers' direct payments. The practice is to support any informal carers but predominantly carers who look after someone who has dementia. The workers also help to support the staff working in those areas.

³¹ Professor Julia Twigg (University of Kent)

³² Review of Respite Services and Short-Term Breaks for Carers for People with Dementia (NCCSDO, 2005)

Feedback from carers was that the workers have helped to facilitate discharges and that they always listen to and put in place the support that the carer requires to help assist them to continue to look after their cared for person. This in turn may help to reduce re-admissions of the cared for person and may help to prevent potential admissions of the carer. An evaluation by Worcester University captured some of the impact that having CSWs in the hospital has had on the lives of the carers that they made contact with. The workers were praised for their compassion and empathy. Such attributes that underpin a service are difficult to equate into potential savings.³³

The Triangle of Care describes a therapeutic relationship between the person with dementia (patient), staff member and carer that promotes safety, supports communication and sustains wellbeing. The Triangle of Care for Dementia describes how meaningful involvement and inclusion of carers can lead to better care for people with dementia. In an ideal situation the needs of the carer and the person with dementia are both met. Inclusion of people with dementia and support in making decisions is therefore fundamental to its success. This will then complete the triangle.³⁴

³³ A local evaluation of dementia advisers (University of Worcester, 2011)

³⁴ The Triangle of Care: Carers Included, A Guide to Best Practice in Mental Health Care in England (Carers Trust, 2013)

Appendix 2: Building the 'invest to save' argument

Caregiving has ramifications on both the physical and mental health of the carer and can result in carer breakdown, which has significant consequences for the health economy. Carer breakdown is one of the reasons for admission to permanent residential care and hospital re-admission. A national study in 2001³⁵ of almost 2,500 people admitted to residential and nursing care showed that carer-related reasons for admission were common. Reasons including stress on carers and family breakdown were given in 40% of cases overall. Being able to demonstrate both the financial and social return on investment (ROI) of supporting carers is fundamental in ensuring partners prioritise allocating the limited funding that is available into supporting carers. CCGs are focused on Quality, Innovation, Productivity and Prevention (QUIPP) plans and strong business cases are required to ensure that 'spend to save' projects show a true ROI.

Business cases are already being developed elsewhere; Herts County Council and CCG are jointly investing in a test and learn 'carer friendly hospital', part of a broader 'carer friendly community' pilot to collect the data they need in order to test the hypothesis that supporting carers during hospital discharge reduces the risk of re-admission and potentially leads to savings as a consequence.

There is still significant work to do to develop the evidence base around what works well and what does not for carers both in terms of demonstrating positive outcomes and achieving cost savings. It is challenging to show robust evidence on ROI by providing support to carers. The Department of Health National Carers' Strategy Demonstrator Sites programme spent over £15m in 25 sites on a range of interventions to support carers, but concluded that 'precise measurement of cost savings was not possible'. The lesson to learn from their experience is to ensure that measures of success are built into the business case models from the start.³⁶

Investment in carers' support services has also been proven to generate a substantial social return on investment; an investment of £5m in five carers' centres generated £73m in social return. The research looked at the potential financial benefits from improved physical health and the reduced risk of new or pre-existing conditions being exacerbated by the burden of caring. It assumed that a decline in physical health for the carer might result in the need for medical intervention, for example, rehabilitative care. Using a calculated assumption that an average rehabilitation care episode lasts for two week at a cost of £4,254 and the need for residential care for the cared for during this time at a cost of £1,067 per week. The report concluded that the damage avoided by managing a carer's medical condition amounts to £6,388 per annum.³⁷

³⁵ Care Homes for Older People: Volume 2 Admissions, Needs and Outcomes (PSSRU, 2001)

³⁶ Evaluation of the National Carers' Strategy Demonstrator Sites Programme (University of Leeds, 2011)

³⁷ Princess Royal Trust for Carers: Social Impact Evaluation of five Carers' Centres using Social Return on Investment (PRTC & Baker Tilly, 2011)

If there was a cohort of 100 carers and 40 were in danger of suffering a health breakdown due to the impact of their caring role and lack of time away from caring, the above calculation could be used as a proxy measure for the ROI of providing carers with opportunities and time away from their role.

Based on the assumption that an annual carer's break costs £2,500, the following ROI can be demonstrated:

- 40 carers x £6,355 = £255,520
- 40 breaks x £2,500 = £100,000

By spending £100,000 there is the potential to save £155,520 from across the health and social care system.

An example of this in action is in Cambridgeshire, where Crossroads Care, NHS Cambridgeshire and 22 GP practices issue free prescriptions to contact Crossroads Care, who will then visit the carer. Breaks can be booked directly through Crossroads Care. Carer identification increased by 80% across the practices in a six month period and GPs advised that 32% of prescriptions prevented hospital admission.³⁸

Carers' breaks enable carers to maintain a balance between their caring responsibilities and a life outside caring. Time away from the cared for provides an opportunity for carers to pursue hobbies, have relaxation time and tend to their own health needs which in turn enables them to continue in their caring role for longer.

A key finding from a Scottish study of unpaid carers' experiences was that short breaks were considered fundamental to carers to help alleviate the physical and emotional demands of caring and to sustain the caring relationship, preventing admission to residential care. It found that short breaks could be improved by being provided as an early intervention rather than at crisis point and offering carers increased choice and flexibility, including frequency and length of breaks.

As part of next steps the study suggested helping families and communities to support each other. The report highlighted the scope to use online technology and social media to connect families and friends to arrange help with trips to the shops, GP or hospital appointments. An example of this would be Carers UK's Jointly app.³⁹ Linking families in similar circumstances together may provide more opportunities for more informal reciprocal offers of help such as house swapping arrangements for holiday breaks and time banking opportunities to help share the care.⁴⁰

³⁸ GP Carers Prescription Service 6 Monthly Report (Crossroads Care Cambridgeshire and NHS Cambridgeshire, 2010)

³⁹ <https://www.jointlyapp.com/>

⁴⁰ Rest assured? A study of unpaid carers' experiences of short breaks (IRISS, 2012)

The evaluation of the National Carers' Demonstrator sites, noted that carers' perception of how their health and wellbeing was affected by having access to the breaks service showed positive outcomes with regard to health, with a number of carers saying that how they look after themselves and feel about life had improved. In relation to health behaviours, most carers recorded improvements or no change in their ability to relax, deal with stress and take regular exercise. Analysis of breaks in the second wave of the evaluation showed that carers who had not received a break were more likely than those who had done so to show a significant deterioration in their wellbeing scores. Six break sites reported in their evaluation reports that carers were able to sustain their caring role for longer as a result of having a break.

It was not possible for the sites to evaluate an ROI by providing breaks albeit some sites did attempt a broad analysis. The demonstrator sites were encouraged to develop their own definition of breaks and be innovative in how they were provided. This included one off payments for personalised breaks; new ways of making breaks accessible, often without having a carer's assessment; breaks on GP prescription; electronic referral systems for GPs; and online booking of breaks by carers. The evidence suggested that carers preferred to engage with voluntary sector organisations rather than through statutory organisations.⁴¹

⁴¹ Evaluation of the National Carers' Strategy Demonstrator Sites Programme (University of Leeds, 2011)