The Carer's Strategy - Evidence Review
June 2016

The purpose of this evidence review is to provide information to colleagues writing the Carer's Strategy. The scope of work was agreed with the strategy group at the outset. This evidence review is two-fold; firstly it offers a short document with evidence pertaining to specific aspects of being a carer and the impact this has on their own health and wellbeing. Secondly, it aims to provide details of various effective interventions that will improve the carer's own wellbeing. This work focuses on the needs of unpaid carers rather than those employed in a health and social care role. The review provides a variety of literature which can be reviewed in further detail.

This was a rapid review of the evidence, which encompasses research from national and international aspects of carers and caring. The research aimed to answer the following questions:

1. What impacts a carer's health and wellbeing due to being a carer?
2. What do carers' feel would work to improve their own health and wellbeing?

The search was undertaken during May 2016, and incorporates evidence that addressed a carer's needs, what impacted their physical and mental health, as well as their wellbeing, what they needed to continue in their caring role, and how they could be supported to have a life outside of caring. The search was undertaken using an iterative process, this approach included searching of the main academic databases, these being; AMED, BNI, CINAHL, Health Business Elite, HMIC, Medline and PsycINFO. The Healthcare Database Advanced Search (HDAS) was the chosen platform to undertaken a search of the academic publications. In addition, a manual online search was undertaken of the following websites; Social Care Institute of Excellence (SCIE), Age UK, Carers UK and The Kings Fund to ensure all pertinent publications relating to carers was incorporated.

Due to the restricted timeframe, any publications reviewed for inclusion were between the time periods of 2008 – 2016 (present day), similarly a limitation was having only one person undertake the search and appraise the evidence. Therefore, the inclusion criteria was very tight and this was agreed in the 'scope of work'. The search terms used reflected the inclusion criteria, additionally incorporating the use of Boolean operators and truncation helped yield the best results.

The nature of the evidence base is primarily case studies or qualitative data. Where possible, this evidence review has used systematic reviews (A **systematic review** is a type of literature review that collects and critically analyses multiple research studies or papers) or peer reviewed publications (**Peer-reviewed** (refereed or scholarly) **journals** are **articles** that are written by experts and are **reviewed** by several other experts in the field before the article is published in the journal in order to insure the article's quality). When reviewing the data, it became apparent that much of the contents overlapped and could be incorporated into a number of the themes (identified below). Each report has been included in the most relevant heading, however each report had valuable insight and corroborated similar findings. Much

of the research uses self-reported surveys and census data to collate and report on the number of carers in today's society. There is good evidence which focuses on the health and wellbeing of a carer, and what carer's feel impact their health and wellbeing due to their caring role. Similarly, there are reports of what carers feel they need to continue caring and improve their own health, although the majority have focussed on key aspects of the cared for individual; such as caring for a person with dementia or a significant Long Term Condition (LTC) or cancer. Even though these reports focus on a particular aspect of ill health, the learning that can be extracted can still be valuable.

There is very little research which reflects the needs of seldom seen or seldom heard groups, such as BME, LGBT, those with a physical disability or a sensory impairment who are undertaking a carer role. The limited research found, that reflected the needs of carers from these groups, has been included. However, in the time period of this research it was difficult to locate any research that reported on being a disabled carer and the impacts/barriers they face. This may be something to address, as the difficulties they encounter may not be accurately reflected by carers who do not have a disability.

There is less robust evidence in terms of understanding effective interventions, two systematic reviews have been included in the evidence summary. Other areas of effective interventions are based on small studies, which focus on carers reporting their own personal gain and benefits from having support. However, these studies are beneficial for us to learn what has worked well in areas. There needs to be caution when understanding how this could be replicated on a larger scale with other level of need, such as deprivation and rurality.

Summary of Findings

The review of available evidence shows that caring for an older or disabled loved one is having significant impacts on the carer, in terms of their physical and mental health, relationships, ability to socialise and manage their finances.

Ensuring that we answer the questions that were posed at the outset of this evidence review, the findings have been summarised by the two questions.

What impacts a carer's health and wellbeing due to being a carer?

The findings look first at what is reported generally for all carers (this includes young carers, older carers, LGBT and BME carers), then looks at specific findings which are pertinent to certain cohorts of carers.

All Carers:

- Their physical health is impacted by undertaking physical hands-on care, this is physically exhausting and is noted to be combined with sleep deprivation, injury and strain.
- Physical strain and exhaustion links to mental health in terms of the impact of stress, anxiety, worry and depression. Many reports demonstrate the links with mental

health which is impacted by the physical strains of care, worry about who will take care of the person, lack of respite breaks for the carers and financial worry.

- Older age, lower socio economic status and lower levels of informal support were related to poorer health
- Carers reported that their health is impacted when the care recipient has greater needs in terms of controlling their behaviour. In cases where the care recipient has a learning disability or dementia, some noted that aggressive outbursts are difficult to manage. This links to the impact carers feel in terms of their own mental and emotional health
- Carers treat their own health secondary to the person they are caring for. In particular carers would cancel and postpone their appointments because they struggle to get someone to look after the care recipient for their own health appointments. In addition the reliance on transport and costs are important too
- Carers report they find it hard to look after their own health, citing that they undertake less exercise and not eating a balanced diet because of their caring roles and responsibilities. When finances are tight, they will ensure that the care recipient gets plenty of food, and the carer will 'make do'
- It appears that carers most at risk of poorer health and wellbeing are those that undertake care in more complex and demanding situations, and those that provide care over many hours a week, this can be further compounded by existing inequalities
- For those providing more intensive care, this is connected to financial and social issues. It is reported that carers struggle with juggling the role of employment and care duties. However for many carers they need to sustain their employment to be able to undertake a carer role. Many adjust their working and social pattern to accommodate their caring responsibilities. Linked to this, is the increased cost and financial burden associated with caring
- Carers have reported themselves to be isolated, despondent, feel guilty and powerless in their caring role, this created a stress point for them. Carers committed to continuing to care, but felt at an emotional cost to themselves
- Social isolation can be a particular problem for those facing financial difficulties, social activities is reported to be cut or stopped when under financial pressure
- Carers also note that they experience loneliness at work, carers report that colleagues do not understand the impacts of caring and that occasionally they cannot give work their full attention. Disconnection with colleagues is exacerbated by a lack of time to socialise
- Carers report that a lack of appropriate day care/ respite care impacts on the carer being able to take breaks
- Carers also note that the lack of practical support with caring is a factor that contributes to not being able to maintain relationships with family, friends or pursuing interests or meeting new people

Young carers

- Young carers can be reluctant to disclose they are a carer due to the stigma associated with certain illnesses.
- For young carers, they can experience bullying and poor behaviour at school because of their caring role
- Young carers also are at risk of missing school trips, not completing homework and have poor school attendance. This impacts on the young person's education attainment. In later years this impacts on employment outcomes
- Young carers note similar lack of understanding at school, lack of support and flexibility. This is on par with how carers report they feel at work
- Young carers note that when they are caring for someone at home, they find it difficult to locate a quiet place for them to work, or have time for themselves
- Young carers noted that although caring can be challenging, the positive aspects of caring for someone increased their knowledge and understanding about caring

Older Carers

- Most older carers report general satisfaction in their caring role, however hard it is they feel worthwhile and valuable in that role. What is noted which differs from that statement is, carers in the 60-69 age group are not necessarily satisfied with their life and the way caring has impacted upon it - caring is regarded as being important to them and they rarely resent being a carer. This age group is noted to be finding caring responsibilities the hardest – for some they are stull juggling employment and coming to terms with the change of the lifestyle, and the future retirement they had hope for, particularly with their partners. This age group was noted to be more susceptible to risk of depression
- In general, older carers did not feel they were getting all the support they needed in their caring role. The younger age group (60-69) felt this particularly and the difference between age groups is significant
- Many older carers still do not get regular breaks – the reason for this is due to a lack of high quality replacement care available which meets the needs of both the carer and the person they care for. This is noted for all carers in general as well

BME Carers

Very little research for this cohort of carers, however one paper made reference to South Asian carers;
- Language barriers and cultural differences are noted to impact a carer gaining access to support. The cultural differences between communities determines whether they see themselves as a carer, or the fact it is a role they should fulfil.

LGBT Carers

- LGBT carers reported a feeling of 'double isolation' – this being the usual feelings of isolation due to the fact they are a carer, but also because they need to talk to someone openly about the issues that are important and building because they are lesbian or gay.

- LGBT carers noted that it is difficult to decide whether to open up about their sexual identity, and were concerned about the emotional effect this may have on others, rather than their own needs

What do carer's feel would work to improve their own health and wellbeing?

Financial Support:

- Improve financial support so carers and families do not suffer hardship as a result of caring, all reports acknowledge the importance of the carer staying out of poverty and able to provide a steady and regular income
- Provide financial support for carers and ex-carers to attend classes or activities

Workplace Support:

- For carers to be able to remain in work, they noted that more support from paid care workers coming to the home of the person they cared for, support with household chores and help with shopping and support with managing/co-ordinating care
- A workplace culture where caring roles are supported with carer-friendly policies and that they have flexibility of leave, rather than having to use annual leave or having to resign from roles.

Training and Education:

- Carers who need to carry out lifting as part of their caring role should and need to have access to training and be trained in the safe use of the equipment to reduce the impact of strain and physical injury
- Support and training in dealing with difficult behaviour should be available to all carers, and particularly those caring for a person with a condition which is likely to mean their behaviour becomes unpredictable or challenging, as noted in the previous section around carers and caring for people with LD and dementia.
- Providing effective advice, training and guidance to support them through their caring roles, by competent and trained professionals.
- Having timely information throughout the care period, but also during period of change in the care recipients condition is beneficial for managing crisis

Access to Help and Support (including access to health support, social networks, respite breaks and beyond caring):

- Carers need breaks from their caring responsibilities, to allow them to combat stress and anxiety as well as promote mental wellbeing. There is a need for a social connection and increased physical activity to promote both physical and mental wellbeing
- All carers report that leaving a loved one causes worry, especially when the care relief is provided by a person not known to both the carer and the care recipient, carers

need to be encouraged to take breaks and having a consistent stand in carer regularly will build trust and facilitate proactive planned breaks

- For LGBT carers, having a tailored LGBT specific support groups for carers
- For young carers, having a young carers specific support group would enable them to talk openly and not feel intimidated about having a caring role
- Carers find it difficult to visit their own GP, having easier access to GPs would help improve their physical and mental health, in addition GPs providing home visits where appropriate. Understanding how GPs manage carers, such as having a register of carers, offer of flexibility when carers need to attend appointments. When referring a carer to hospital, do they write on the letter that the person has a caring responsibility which will impact their ability to attend at certain times? Having discussions with colleagues in primary care will help address and answer how best to improve access
- Help needs to be provided to support carers re-establish themselves in a social network, particularly when their caring duties end. Life after caring is important for carers to get increased health and wellbeing and reduce the negative impacts of isolation. Carers have to grieve the loss of a loved one, their life long partner and the loss of their role as a carer. Promotion of help groups, activities and volunteering opportunities will help ex-carers be sighted on what is happening and available in their community
- Carers wish to feel respected and appreciated throughout society – bringing a cultural shift towards a society that recognises and understands caring, aging and disability better
- Having an opportunity to talk openly about caring responsibilities, and present that caring is part and parcel of everyday life

This review demonstrated that the needs of the carers are significant, many factors that have been identified are compounding the carers' health and wellbeing. To enable carers to continue and undertake their caring role, more needs to be done to support them. Carers' voices need to be heard to understand what will work best for them, considering access to services and the financial implications of trying to join networks is important. Similarly important to note, the needs of the cared for person. Carers have a strong relationship with the care recipient, and these relationships are closely linked and intertwined. What impacts a carer, will have an influence on the cared for person and vice versa.

There is a complex dynamic that requires greater sophistication in terms of describing the needs of the care recipient, these being, whether they have a mental illness, Long Term Condition, are approaching end of life or are simply frail. Similarly, the needs of the carers can vary in terms of whether they are a young carer, older carer, have their own health issues, are still working or have sensory impairments, as the barriers they face are different. Equally, the additional contextual factors, such as multiple caring demands, financial pressures and the number of hours an informal (unpaid) carer is giving all play a role in significantly affecting the carer's health and wellbeing. There is a need to move away from stereotypes, such as, an older person caring for their partner, as society is aging and more people will have to adopt / support someone in a caring role. Being a carer means they should not be expected to give

up their health, wellbeing or life/retirement ambitions. The evidence strongly shows that society as a whole needs to recognise the role carers' play and offer better support, provision and funding.

All the literature collected as part of this evidence review has been collated under the following themes. Links are available to allow further review of any specific items, should this be required. These can be accessed by clicking on the theme heading and it will connect to that section of literature. Within each section, the research/evidence paper has been provided, this can be accessed by clicking on the title.

Links to other relevant work streams;

- Mental health; significant connections to the carers own mental health, the stress and strain of being a carer impacts their ability to undertake a normal life, and have a life outside of caring. This can lead to significant periods of isolation and a feeling of not belonging.
- Social Isolation and Loneliness; carers feel the impact of being a carer and losing their ability to connect with others either in social activities or whilst at work. Understanding the difference between being isolated and lonely is key here:
  Social isolation is characterised by an absence of social interactions, social support structures and engagement with wider community activities or structures
  Loneliness describes an individual's personal, subjective sense of lacking connection and contact with social interactions to the extent that they are wanted or needed
  Social inaction describes a state where individuals choose, or are unable, to take part in social action and are disconnected from concepts of 'we-ness' and civic society
- End of Life Care; not just supporting the patient in the period prior to death, in turn supporting the carer whom is dealing with their own needs and the needs of the care recipient.
- Living Well; carers will keep going regardless of how they feel themselves. Carers suffer with sleep deprivation and their own ill health, but rarely seek the help they should of health care professionals. Once the carer reaches 'crisis point' this can often result in a period of hospitalisation, where by their health is so poor they are admitted for treatment and recovery. In some cases the care recipient also ends up with a period of admission as there is no-one who can provide interim care. Supporting the carer prior to breaking point, could result in a reduction of hospital admissions.

Health and Wellbeing

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
Welsh Government, Wales	2016	A bulletin on the personal well-being of people who need care and support and carers who need support	Welsh Government, Wales	Summarises findings from the 2014-15 National Survey for Wales and responses to questions designed to measure the personal well-being of people who need care and support and carers who need support. Respondents were shown a list of services offered by care and support services in Wales and were asked whether they had received any help from these services in the last 12 months. 9 per cent of all respondents had received care and support for themselves) or had received help to care for or arrange care for another person.	The report finds that the majority of people who received care and support rated people and services that supported them as "excellent" or "good" and agreed that care and support services have helped them to have a better quality of life. People who received care were more likely to experience lower levels of personal, mental and emotional wellbeing and were at higher risk of isolation. Carers who received support were healthier and experienced higher levels of personal, mental and emotional wellbeing than people who received care and support and were also more likely to feel valued in society	The bulletin provides a picture of the wellbeing of people who received care and carers who received support in relation to: securing rights and entitlements; physical and mental health and emotional well-being; protection from abuse and neglect; education, training and recreation; domestic, family and personal relationships; contribution made to society; social and economic well-being; suitability of living accommodation; and perceptions of social care	Carers Health

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
Scotland. Scottish Government	2015	Scotland's Carers	Scotland. Scottish Government	Brings together statistical analysis and research to provide a picture of carers and caring in Scotland. Drawing from recent population surveys such as Scotland's 2011 Census and the Scottish Health Survey, it looks at who provides care in Scotland.	The report considers the health and wellbeing of carers and the impact that caring can have on wellbeing as well as the nature, purpose and effectiveness of support for carers. Chapters cover: the types of people who provide care in Scotland; health and wellbeing; carers' employment, health and finance; support for carers; and where carers live by local authority, urban and rural area		Carers Health, Wellbeing
Carers UK	2014	Carers at Breaking Point	Carers UK	Based on the experiences of over 5,000 carers, this report examines the experiences of carers who have been pushed to breaking point by caring without the right support.	The analysis examines the causes of carer breakdown, looking at physical health, mental health, inadequate support and financial pressure. It then then discusses the impact of crisis and what support can prevent carers mental and physical health breaking down. The majority of those responding to the survey (84%) were caring, full-time, for more than 35 hours a week. Responses were received from carers from across the UK	Carers UK make 15 key recommendations to address carer breakdown	Carers health, illness

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
					(81% from England, 10% from Scotland, 7% from Wales and 2% from Northern Ireland).		
SCRUTTON Jonathan, CREIGHTON Helen, INTERNATIONAL LONGEVITY CENTRE UK	2015	The Emotional Wellbeing of Older Carers	University College London	This report, the second in a two part series summarising research from the Department of Epidemiology and Public Health at University College London (UCL), focuses on the subjective wellbeing of older carers.	Long term caregiving was associated with declines in quality of life and life satisfaction for carers, and an increased risk of depression; and giving up caregiving was associated with increased depression amongst both male and female carers. The report addresses the wider context of these findings, highlighting how the ageing population could potentially lead to large increases in the number of older carers, with the number of carers over 65 already having risen by 35 per cent since 2001. It also highlights the day-to-day realities faced by many older carers, including a high risk of emotional distress; the loss of friends, either because of a lack of time to socialise or because friends were unable to properly understand the constraints and strains of	The report explores the policy implications of the research, highlighting that few policies and support services are aimed at older carers specifically. The report suggests that more could be done to protect the emotional wellbeing and mental health of older carers, through appropriate support being provided at all stages of the caregiving cycle.	Older carers

Impact of Caring

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
Carers UK	2015	Alone and Caring; Isolation, loneliness and the impact of caring on relationships	Carers UK	Presents the findings from the Carers UK's State of Caring Survey 2014, focusing on isolation and loneliness experienced by carers as a result of their caring responsibilities for a disabled, older or seriously ill loved one	The research reveals that 8 out of 10 carers have felt lonely or isolated as a result of caring and over a third feel uncomfortable talking to friends about being a carer. Key findings include: 57% of carers have lost touch with friends and family as a result of caring and half of carers say they have experienced difficulties in their relationship with their partner because of their caring role; 38% of carers in full-time employment have felt isolated from other people at work because of their caring responsibilities; and carers who have reached breaking point as a result of caring are twice as likely to say that they are socially isolated because they are unable to leave the house and are also	The report outlines the causes of carers' social isolation, loneliness at work, carers' health and what can be done to make a difference	Carers health, carers

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
					more likely to have experienced depression as a result of caring. The report suggests that more must be done to improve public understanding of caring and disability and raise awareness of the emotional and peer-to-peer support available for carers. Key recommendations include: a stronger rights base in the workplace and a statutory right to 5-10 days of paid care leave and an urgent debate on longer-term leave from work to care; a radical improvement in the financial support available to carers and their families to prevent poverty and hardship; and a clear duty on NHS bodies to identify carers and promote their health and well-being		
The Older People's Commissioner for Wales	2016	[Dementia; More Than Just Memory Loss](#)	The Older People's Commissioner for Wales	This report looks at how services across Wales need to improve to ensure that people living with dementia and those who care for them can access the services, support,	The research found a lack of knowledge and understanding of dementia, both amongst professionals and wider society; a lack of flexibility in dementia services; a lack of co-operation between services, which often created	Key themes discussed cover: impact on independence; meaningful activity; impact on carers; awareness within society; diagnosis;	Carers, Carers Health

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
				information and advice that they need. It draws on research carried out by Age Cymru with people living with dementia and their carers, who took part in individual interviews and focus group sessions to share the experiences of their day-to-day lives	barriers for people living with dementia and their carers. Significant variations in the quality of services available across Wales were also identified. The report then identifies what would make a difference to the experiences of living with dementia in Wales and sets out a number of actions. These including work to ensure that primary care services are more dementia supportive; training for staff on working with people with dementia; and greater post-diagnosis support, including a single point of contact to provide information and advice on the services and support available that can be accessed whenever required	relationships with professionals; and health and social services, including post-diagnosis support	
ALDRIDGE Hannah, HUGHES Ceri	2016	[Informal Carers and Poverty in the UK](#)	New Policy Institute	This research uses data from the Family Resources Survey 2013/14 to describe the situation of informal carers in the UK, and how being a carer has implications	The paper shows that people who provide informal care to a disabled or elderly family member or friend are not necessarily at greater risk of poverty than the rest of the population. Much depends on the amount of care provided,		Carers, Carers Health

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
				for employment, income and poverty.	the caring relationship, and whether this has an impact on the capacity of carer households to take on employment. However, the analysis shows that caring is associated with a higher risk of poverty amongst working-age carers who provide long hours of care. Whilst there is a correlation between employment and lower poverty rates for carers, it need not follow that poverty levels can be reduced by supporting more high intensity carers into work. In part, this is because a carer's decision to work and care will depend on a range of factors, including the availability of job opportunities, the scope for flexibility, the availability of social care services and the health of the carer. The analysis points to the important role that the benefit system, in alliance with a carefully targeted employment support package, could play in tackling carer		

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
					poverty. More specifically, it identifies some key policy areas that may be in need of particular attention, including: access to support and quality formal care; working-age carers require personalised and flexible employment support; support carers to improve their qualifications and access training; and changes to disability benefits should consider the impact on carers		
GUEST Carly, CORRIGAN Oonagh, KOFFMAN Ofra	2015	You really do give up your own life once you become a full time carer	Healthwatch Essex	This study places the lived experience of carers at its centre, attending in particular to the day-to-day experience of caring and of formal and informal support provision. It is set in the context of important changes to UK social care provision outlined in the Care Act 2014. To gather in-depth accounts of caring, the study adopted a qualitative	The research demonstrates that caring relationships are already embedded within an existing relationship, such as friendship or family and, as such, the experiences of being a carer are multi-layered and complex. Carers did not primarily identify themselves as carers but used the pre-existing relationship bond to define their identity. Participants' accounts highlighted the profound sense of love, care and commitment they felt towards the person they were caring		Carers, young carers, health wellbeing

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
				methodology, capturing the views of adult and young carers through audio diaries and video interviews and a focus group.	for and it is such feelings that motivate and propel the decision to care. However, this was experienced alongside feelings of guilt, isolation, despondency and powerlessness – feelings that have a negative impact upon carers' own health and wellbeing. The young carers felt that it was more difficult for them to socialise, to complete school work and to find quiet and calm places in the home, in comparison to their peers but they also described their difference from their peers in positive terms, highlighting the knowledge and understanding they gained from their caring responsibilities. Young carer groups were pinpointed as places where they felt understood and did not have to explain themselves to others		
Carers UK	2016	State of Caring	Carers UK	Summarises the findings from the Carers UK annual survey of carers to	The survey explores key aspects of carers' experience, including: access to practical support; experiences of	The report sets out the context, suggesting that the contribution of the	Carers, Carers Health

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
				build a picture of the state of caring in the UK. Over 6,149 people shared their views and experiences on what life is like for carers in 2016.	carers' assessments; experience of hospital discharge; carers' finances; caring and work; and carers' expectations and priorities. The report shows that 1 in 5 of those providing 50 hours or more of care each week are receiving no support with their caring role; only a third of carers who had an assessment in the last year felt that the support they need to look after their own mental and physical health alongside caring was properly considered; nearly 6 in 10 said that they did not feel that they had a choice about providing care to the person following their discharge from hospital; two thirds of carers who are struggling to make ends meet cut back on seeing friends and family to cope; 7 in 10 of working carers have used their annual leave to care and almost half have done overtime to make up hours spent caring. In the next year, half of carers expect their	UK's carers is growing and is now worth £132 billion, which is the equivalent of spending on the National Health Service	

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
					quality of life to get worse, while only 6 per cent think it will get better		
ALZHEIMER'S RESEARCH UK	2015	Dementia in the Family; the impact on carers	Alzheimer's Research UK	Reports on the findings of qualitative research to investigate the experiences of people who are caring for family members with dementia. The report draws on four case studies and diaries completed by carers over the period of one week to record their experiences of providing care	The findings are discussed around the following themes: awareness of dementia, the impact of dementia; changing relationships, social isolation, psychological and physical health and finances.	The report highlights how dementia changes family relationships, leaves people socially isolated, and affects both the physical health, mental health and finances of family carers	Carers, Health, Wellbeing
The Children's Society	2013	Hidden from View; the experiences of young carers in England	The Children's Society	This study draws on government commissioned data on over 15,000 pupils aged 13 and 14. It examines how many of these children had caring responsibilities, the socio-economic characteristics of their families, young carers' educational attainment, and their	This report provides a valuable insight into the daily lives and outcomes for young carers. They can miss out on a huge range of opportunities that so many other children and young people take for granted, from educational opportunities, to spending time with friends and having time and space to do their homework. It also reveals how young carers are gaining fewer	The size of the sample gives us confidence in the findings, many of which confirm earlier research, the data show clearly the differential impact that caring has on young carers compared to other children, including restricting their	Young carers, impact of caring

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
				chances of being in training or paid work	qualifications and are therefore less likely to earn a decent living. We are calling for support for these children, to make sure that they have the same opportunities as other children. We hope to bring about change by influencing policy makers to help prevent these children and young people from caring in the first place. Many young carers come from hidden and marginalised groups, including children caring for family members with mental illness or a substance dependency.	educational attainment in school and the knock-on effect that this can have on employment opportunities, careers and later life	
BIGNALL Tracey RACE EQUALITY UNIT	2015	Young people in a caring role	Engage London	This paper outlines some of the key issues facing young carers' aged up to the age of 24 and the impact caring can have on young people's lives in relation to health, education, employment and training.	While all young carers will experience physical and mental stress, the paper looks at the additional issues facing young carers from a black and minority ethnic backgrounds and 'hidden carers' who are further marginalised because of their personal situation, such as their refugee status, living with HIV, or being lesbian, gay, bisexual or transgender (LGBT). Finally, it	It summarises existing government strategies for supporting young carers, such the assessment of young carers' needs and ensuring young carers are not taking on inappropriate levels of care work.	Young carers

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
					highlights the role of the voluntary sector in proving support		
CLAY Dan, et al	2016	The lives of young carers in England	Department for Education	Reports the findings from a qualitative research to find out more about the characteristics of young carers and their families; the nature of care they are providing; the impacts of caring responsibilities and needs of both young carers and their families; experiences of support; and responses to support propositions developed in consultation with key local and national stakeholders.	The research found that: early interventions are critical in ensuring that children do not take on inappropriate caring tasks; social care, health and education professionals have a crucial role in identifying and assessing the needs of young carers; limited support and a lack of understanding of the parental/sibling condition(s) can exacerbate the adverse emotional effects of caring among children and young people; resistance to disclosure means that children and young people with caring responsibilities, and their wider needs, can go unrecognised and unsupported; the ongoing challenge in identifying and engaging with 'hidden' young carers; the importance of support in helping young carers (and their families) to moderate the impact of their caring responsibilities and to	The results of this study confirm those of other studies in that children and young people with caring responsibilities experience a range of both positive and negative outcomes as a result of their responsibilities, and that these outcomes are directly affected by the level of informal or formal support they receive	Carers, young carers

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
					prepare for adulthood (transition support) should be recognised		
Carers Uk/Age UK	2015	Caring-into-later-life-the-growing-pressures-on-older-carers	Carers UK / Age UK	Draws together and analyses evidence from national data sources and older carers themselves to set out key facts about older carers and identify what steps should be taken to better support them. Information is provided on the numbers of older carers, older carers demographics, the hours and type of support older carers provide, health and wellbeing, and access to NHS and social care services. Quotations from older carers are also included, drawn from Carers UK's State of Caring Survey 2014.	The report found that there are 1.2 million carers aged 65 and over in England, with a growing number of older carers aged over 85 years. Of those carers over 85 years: over half are caring for 50 or more hours each week; 59% are men (whereas only 42% of all carers are men); and 48% of carers aged 85 and over who are providing 20 or more hours of care a week say that they feel anxious or depressed. The report makes a number of recommendations, including: using the new duties of the Care Act to develop advice and information that is accessible to older carers; involving older carers in co-producing and commissioning support services; the provision of good quality care services to support carers who wish to continue working, and for national and local government		Older Carers

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
					to address older carers' emotional health and wellbeing		
INDEPENDENT AGE (in partnership with Carers UK and Carers Week)	2015	You don't stop the worrying; the difficulties in caring in later life	Independent Age	Drawing on findings from focus groups and interviews with older carers, this report explores their experience of caring, what issues most concern them, where they find support in their caring, and what more support is needed	Older carers agreed that caring took a heavy toll on them, and had multiple impacts on their quality of life. It was clear that carers perceived that some of the impacts of caring were exacerbated by their age. Particular impacts affecting older carers included: difficulties keeping up with family and friends; financial constraints; poor health; and stress. They identified a range of gaps in support available to them, problems accessing services and a lack of support from the wider community in their role as carers. 'Former carers' made clear that there were important differences between the experiences of those whose loved ones moved into residential care or supported / independent living, and those who were bereaved	The report sets out older carers' priorities, which include: improving carers' access to support, in particular by ensuring GPs play a part in identifying carers and signposting to support; addressing inadequacies in care and support services available to carers' loved ones; developing a 'carers' friend' service to provide one-to-one practical and emotional support for carers; and improving support for bereaved carers, offering them opportunities	Older people, older carers

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
						to find mutual support among those with similar experiences	

Mental Health

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
Kenny, Patricia, King, Madeleine T., Hall, Jane	2014	The physical functioning and mental health of informal carers: evidence of care-giving impacts from an Australian population-based cohort PDF The physical functioning and me	Health & Social Care in the Community	This study investigated the impact of care-giving on the mental and physical health of informal carers, taking account of contextual factors, including family and work. We examined health changes from before care-giving commenced to 2 and 4 years after, using longitudinal data from the Household Income and Labour Dynamics in Australia survey. The sample comprised 424 carers and 424 propensity score-matched non-carers. Health was self-	The study found that not all carers suffer adverse health impacts; however, the combination of high levels of care-giving with workforce participation can increase the risk of negative physical and mental health effects (particularly in female carers). Working carers providing high levels of care represent a vulnerable subgroup where supportive and preventive services might be focused.	Although study based in Australia. Useful findings which can help aid our understanding and correlate findings from UK based study.	Mental health, impacts of caring, carers health,

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
				assessed, measured with the SF-36 Health Survey Mental Health (MH) and Physical Functioning (PF) scales. Care-giving was classified as non-carer, low (<5 hours/week), moderate (5–19 hours/week) and high (20 or more hours/week). PF and MH change scores were regressed on baseline scores, care-giving, covariates (including work, family and socio-demographic characteristics) and interactions to identify impacts for subgroups.			
McLaughlin, Columba, McGowan, Iain, O'Neill, Siobhan, Kernohan, George	2014	The burden of living with and caring for a suicidal family member The burden of living with and carir	Journal of Mental Health	Eighteen participants were interviewed using a short topic guide. Responses were digitally recorded and transcripts were analysed using thematic analysis. A qualitative design was	One overarching theme: ''Hard work for the whole family'' and four sub-themes: (i) Family burden, (ii) competing pressures, (iii) secrecy and shame and (iv) helplessness and guilt. Caring for a suicidal family member may be euphemistically	The family has a primary role in caring for family members who are suicidal and in the prevention of future suicide. However, the impact that suicidal	Carers; mental health, wellbeing

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
				chosen as it allows the researchers to explore participants' lived experiences as carers of a suicidal family member	summarised as ''hard work'' that impacts heavily on the day-to-day tasks of other family members. Participants spent much time worrying and ruminating about the risk of suicide in their family member. Mental health care professionals ought to acknowledge and address the impact that suicidal behaviour has on family carers	behaviour has on these family members is poorly understood. To explore the lived experiences of participants who cared for suicidal family members.	
Carers Trust	2016	Invisible and in distress: prioritising the mental health of England's young carers	Carers Trust	This report highlights evidence on what is known about the mental health of young carers and shows how caring is a risk factor for children and young people's mental health. Based on discussions from a policy roundtable event attended by young carers, sector leaders and young carers services,	The report makes policy recommendations to improve the awareness and support of young carers' mental health. These include a call for the upcoming Government Carers Strategy to include measures to promote young carers' mental health and improve their access to mental health support; for the NHS England assurance programme for Local Transformation Plans to examine whether the plans include measures to improve young carers' mental health; and for local authority commissioners to increase the sustainability and stability of		Young carers, mental health

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
					young carers services and support partnership working between young carers services and mental health services		

Outcomes for Carers

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
KNOWLES Sarah, et al	2016	Hidden Caring, Hidden Carers; Exploring the experiences of carers of people with LTC	Wiley-Blackwell	Conducted semi-structured interviews with 19 informal carers of people with LTCs recruited from local support groups. Topic guides were designed to encourage participants to provide their retrospective accounts of identifying as a carer or struggling to do so. Data were analysed using the constant comparative method. The study was designed collaboratively with a patient and public involvement (PPI) partner, and we consulted with a PPI	Results showed how participants drew on comparisons with those caring for more dependent relatives in explaining their reluctance to define themselves as a carer, and resisted adopting the label due to concerns that it would threaten the identity of the cared-for person. The data were interpreted in terms of types of 'work' undertaken to manage LTCs, and revealed that carers of patients with LTCs appear to primarily engage in biographical and emotional support, which may be more difficult to conceptualise as legitimate caring 'work'. Participants indicated that health professionals may be in	Makes note to BME groups and how difficult to engage this particular group. States limitation of input is language barrier. BME carers don not get support or signposted for support because of culture differences and breakdown in language and communication.	Carers Health

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
				steering group of people with lived experience of caring during the study.	a unique position to validate their role as carers and encourage support seeking. The study suggests how the greater focus on self-management of LTCs in the community must be complemented by recognition of this group as potentially 'hidden carers', who support the patient to minimise the impact the illness has on their lives and consequently may minimise their own caring role, with negative implications for support seeking		
GILMOUR Alan	2015	How do we ensure that training and information support contributes to positive outcomes for carers	Institute for Research and Innovation in Social Services	The study conducted a semi-structured focus group of 11 carers from a range of backgrounds and experience. Carers were over 18 years of age, had completed an assessment, including identification of training needs; and had completed one or more training programmes to	The research found training played a significant role in enabling and empowering carers. It identified a number of points in the carer's journey where training can provide support such as: at diagnosis; where a condition deteriorates; or where other carers or family become involved. Barriers that prevent attendance or reduce the potential impact of training include: personal illness, lack	The paper was produced as part of the PROP2 (Practitioner Research: Outcomes and Partnership) programme, a partnership between the Centre for Research on Families and Relationships	

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
				support their role as a carer.	of confidence, transport, and flexibility of training provision. Follow up after training was also identified as important to ensure that it has met the needs of the carer	(CRFR) at the University of Edinburgh and IRISS covering health and social care in Scotland	
HAMBLIN Emily	2016	Young people caring for adults with dementia in England	National Children's Bureau	This report explores the available evidence on children and young people who provide regular and ongoing care and emotional support for a person living with dementia. It addresses the prevalence, characteristics, needs and experiences of this group of children and young people, as well as the support available to them.	The findings highlight the difficulties of defining and identifying children and young people who provide care and support for individuals with dementia. Research suggests that young people caring for a loved one with dementia provide a range of practical, emotional and social support. However, in common with many children and young people supporting individuals with other conditions, some do not identify as 'young carers' or feel comfortable with the label.	The report is based on the results of a survey aimed practitioners and managers working in services for young carers, dementia carers and/or carers. Only 12 professionals responded to the survey. They were aware of 51 young people who provided care and support for someone with dementia. The survey was accompanied by internet-based research and searches carried out on the NCB database.	Young carers

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
WAYMAN Sarah, RAWS Phil, LEADBITTER Helen	2016	'There's nobody is there – no one who can actually help?'	Children's Society	This research looks at two key issues in relation to the caregiving responsibilities of children and young people. It asks whether, despite a series of research studies and two Censuses, the current picture of the scale of the phenomenon is accurate. And it assesses how the responsiveness of services to young people with significant caring roles – especially those who may not currently be accessing support – can be improved. The report is based on a literature review, an analysis of the Census data and methodology, and qualitative interviews and focus groups with young carers, service	It summarises key considerations around the support of young carers and their families, highlighting the particular vulnerability of some young carers and their families relative to their individual circumstances, and how services need to be flexible in their responses to adequately meet the variety of needs that can be presented. The overall picture emerging from this study is of services and support being far from what they might be or should be to adequately meet the varying needs of young carer families: professionals and services were often reactive rather than proactive in identifying a need for support; there were problems with how services operated – especially thresholds, catchment areas, and age limits; and services were often subject to change – including staff turnover, or sometimes loss/reduction of funding and	The report sets out the context for the research; looks at competing claims around the number of young carers and how these were generated; uses findings from the interviews to explore how young people experience caregiving responsibilities and the support they themselves had received	Young carers

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
				workers and expert stakeholders.	restriction of services or, at worst, closure		
Reinhard	2008	Chapter 14: Supporting family caregivers in providing care An Evidence-Based Handbook for Nurses	Agency for Healthcare Research and Quality	This chapter summarizes patient safety and quality evidence from both of these perspectives. The focus is on the adult caregiver who provides care and support primarily for adults with chronic illnesses and chronic health problems. The focus is not on those with developmental disabilities. In the first section, we discuss the evidence for protecting the caregiver from harm. The second section addresses research aimed at protecting the care recipient from an ill-prepared family caregiver.	Family caregivers are critical partners in the plan of care for patients with chronic illnesses. Nurses should be concerned with several issues that affect patient safety and quality of care as the reliance on family caregiving grows. Improvement can be obtained through communication and caregiver support to strengthen caregiver competency and teach caregivers new skills that will enhance patient safety. Previous interventions and studies have shown improved caregiver outcomes when nurses are involved, but more research is needed. There is more to be learned about the effect of family caregivers on patient outcomes and areas of concern for patient safety. Nurses continue to play an important role in helping family caregivers become more confident and competent providers as they	Global evidence review although primarily US focussed. Useful in that some evidence is specifically addressing BME or religious patient groups	Carers, impacts, outcomes

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
					engage in the health care process.		
PEEL Elizabeth, McDAID Sam	2015	Over the rainbow - LGBT People and Dementia	University of Worcester. Association for Dementia Studies, Dementia Engagement and Empowerment Project	Reports on the first phase of a project to develop a support and advocacy group for LGBTQ people with dementia. The project facilitated two networking workshops which were attended by a total of 11 LGBT carers of people with dementia.	There was a lack of engagement from LGBT people with dementia, which illustrated the challenge of accessing this hard to reach group. Workshop discussions are summarised under the following themes: reflections on experiences of LGBT people with dementia; identities of LGBT people with dementia; negative experiences with health and social care professionals; and provision of LGBT appropriate support and care home services. The report ends with some suggestions for the Dementia Engagement and Empowerment Project and recommendations for health and social care professionals		Carers, LGBT and Caring

Effective Interventions:

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
Lins S, Hayder-Beichel D, Rücker G, Motschall E, Antes G, Meyer G, Langer G	2014	Efficacy and experiences of telephone counselling for informal carers of people with dementia	The Cochrane Collaboration, John Wiley & Sons, Ltd.	Informal carers of people with dementia can suffer from depressive symptoms, emotional distress and other physiological, social and financial consequences. This review focuses on three main objectives: To: 1) produce a quantitative review of the efficacy of telephone counselling for informal carers of people with dementia; 2) synthesize qualitative studies to explore carers' experiences of receiving telephone counselling and counsellors' experiences of conducting telephone counselling; and	Analysis of both sets of results, i.e. efficacy compared with information about carers' experiences of telephone counselling, revealed needs that so far have not been met by telephone counselling. The studies that examined the experience aspect covered a very limited range of telephone counselling. The results of this review should be interpreted with caution due to the small number of included studies and their moderate quality.	The aim of this review was to investigate whether telephone counselling is an effective way of reducing symptoms of depression and other stresses in the carers of people with dementia. We also investigated which aspects of telephone counselling the people who received it thought could be improved.	Carers, impact of caring, caregiving

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
				3) integrate 1) and 2) to identify aspects of the intervention that are valued and work well, and those interventional components that should be improved or redesigned.			
Candy B, Jones L, Drake R, Leurent B, King M	2011	Interventions for supporting informal caregivers of patients in the terminal phase of a disease (Review)	The Cochrane Collaboration, John Wiley & Sons, Ltd.	To assess the effects of supportive interventions that aim to improve the psychological and physical health of informal caregivers of patients in the terminal phase of their illness	We included eleven RCTs involving 1836 caregiver participants. Nine interventions were delivered directly to the caregiver. Seven of these provided support in the caring role, another involved a family life review, and one grief therapy. None provided practical support. The other two interventions aimed to support caregivers indirectly via patient care. Overall the risk of bias is unclear, as all trials under-reported methods There is evidence that supportive interventions may help reduce caregivers' psychological distress. These findings suggest that	Randomised controlled trials (RCTs) of interventions to support adults who were caring for a friend or relative with a disease in the terminal phase. Interventions could include practical and emotional support and/or the facilitation of coping skills. Interventions could support caregivers indirectly via patient care.	carers

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
					practitioners should enquire about the concerns of caregivers and should consider that they may benefit from additional support. There is, however, a need for further research to explore the benefits identified, and to assess the interventions' effects on physical health, and potential harms. Trials need to report their methods fully.		
G. Livingston, et al	2014	START (STrAtegies for RelaTives) study; a pragmatic randomised controlled trial to determine the clinical effectiveness and cost-effectiveness of a manual-based coping strategy programme in promoting the mental health of carers of people with dementia	The London School of Economics and Political Science	Our START (STrAtegies for RelaTives) study was a randomised controlled trial of an eight-session manual, adapted from an American programme called 'Coping with Caregiving'. It was delivered by psychology graduates to carers individually. We compared it with usual treatment by using a computer program to decide randomly whether or not carers should be in the	We found that START decreased carers' anxiety and depression and improved their quality of life (QoL) in the short term (8 months after the study started) and that it was as effective on these measures in the longer term (2 years after the study started). The intervention was cost-effective at both times but did not improve the person with dementia's QoL. After 2 years, there was a small, but not significant, decrease in the chance		Carers, Carers mental health

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
				intervention or the control group	of people with dementia in the intervention group being admitted to a care home		
Pam Moule et al	2014	An integrated approach for individualised support; carers' views	Emerald Group Publishing Limited	A multi-method evaluation of this integrated service was conducted between August 2012 and October 2013 to explore its impact on carers' health and well-being. This paper presents findings from 40 interviews conducted with carers as part of the evaluation.	Many carers have little respite from very stressful situations; the break enabled them to focus on their own needs. Carers' needs included actual short breaks away with or without those being cared for, as well as items like household equipment or exercise classes. Most carers found the support beneficial, and in some cases reported a positive effect on their own health and well-being. Effective inter-agency communication and collaboration is essential for the success of the integrated service. There is limited research available on the outcomes of integrated approaches to support carers.	The purpose of this paper was to capture carers' views of a service in Bristol funded jointly by the Local Authority and the NHS Clinical Commissioning Group, which offers support to carers in the form of a one-off payment which they can use for anything they choose. The study was centred on an innovation and integrated approach to support carers in one city and provides a snap-shot of the short-term effects. Longer lasting	Carers, caregiving, outcomes

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
						effects are not known.	
MORBEY Hazel, et al	2013	Supporting Older Carers of those nearing the end of life	Lancaster University. International Observatory on End of Life Care	This report presents findings from an independent evaluation of six Age UK pilot projects providing specialist volunteer support services for older carers of an older family member nearing the end of life. It also looks at the potential role of trained volunteer delivered interventions in this area. Interview questionnaires were completed by 58 older carers, 13 cared for family members, and 12 volunteers. Site visits were made to each location and a range of data was analysed.	The findings highlight the perceived benefits of older carers from receiving support services from the Age UK pilot projects and the types of support provided - emotional, practical, information and advice. The service evaluation findings are then presented covering the themes: complex, multiple needs of older carers accessing specialist end of life support services; priorities and responsibilities for volunteer provision of specialist end of life support services; the benefits to users of specialist end of life support services for older carers and their cared-for family members; and the obstacles and challenges faced by local Age UK groups and organisations in establishing and developing specialist end of life support services. Case study examples and direct quotations are included to illustrate key points	Recommendations are provided for organisations providing support services to older carers, to organisations planning provision to meet local needs in this area, and at a national policy and funding level	Older carers

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
NHS England et al	2016	An integrated approach to identifying and assessing Carer health and wellbeing identifying-assessing-carer-hlth-wellbeing	NHS England	Practical resource	This paper builds on the work started by the NHS England Commitment to Carers that was published in May 2014, and which sought to give the five and a half million Carers in England the recognition and support they need to provide invaluable care for loved ones.	This paper addresses changes to the way in which Carer health and wellbeing need is identified, assessed, and supported, as a result of changes introduced by the Care Act 2014 and the Children and Families Act 2014. It is, essentially, a resource to help promote working together between Adult social care services, NHS commissioners and providers, and third sector organisations that support Carers, of all ages, with a specific focus on developing an integrated approach to the identification,	Carers

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
						assessment and support of Carers and their families across health and social care.	
Carers Trust	Not Stated	Commissioning for Carers; Key Principles for Clinical Commissioning Groups commissioning-for-carers-key-principles-f	Carers Trust	Practical Resource	Carers are the largest providers of care and support in each area of the UK. The economic value of the contribution they make is £119bn per year.2 The moral and financial arguments for supporting carers are clear – without support, taking on a caring role can mean facing a life of poverty, isolation, ill health and depression. For the person they care for it can mean costly hospital or care admissions if the caring relationship breaks down. Commissioning well for carers can: Reduce admissions to hospital and residential care. Reduce the costs of delays in transfers of care. Reduce carers' need to access primary care as a result of their caring role. Reduce overall spending on care	Clinical Commissioning Groups (CCGs) across England are under enormous pressure to meet financial targets and priority areas for improvements within the NHS. This document demonstrates how commissioning for carers can help CCGs deliver desired outcomes and make savings across health and social care	

Author/s	Date	Title	Publisher	Study	Key Findings	Applicability	Search Categories
NHS England, Age UK, Carers Trust, Carers UK, Public Health England and older people	2016	A practical guide to healthy caring	NHS England	Practical Resource	The booklet examines a range of support options and themes, including: getting help with common health issues associated with caring; getting an assessment; carers looking after their own health; health and wellbeing, reducing the impact that caring can have on carers' physical and mental wellbeing; taking a break; making better use of technology; multiple health conditions and caring; and preparing for the end of caring	Provides advice, hints and tips on how carers can look after their own health as well as support the person they care for and is particularly relevant for those who are about 65 years or older and are new to caring.	Health and Wellbeing, Carers, Older carers