

Agenda Item 6a)

**Cambridgeshire
Joint Strategic Needs Assessment
(JSNA)**

**Carers
2014**

Contents

1	Executive Summary	8
1.1	JSNA scope and context.....	8
1.1.1	Definitions and scope.....	8
1.1.2	Policy background	8
1.2	Key facts and figures	8
1.3	Issues affecting the health and wellbeing of adult and older carers	9
1.3.1	Health	9
1.3.2	Finance and employment.....	9
1.3.3	Housing, relationships and social isolation.....	9
1.4	Issues affecting the health and wellbeing of young carers and young adult carers.....	9
1.5	Issues affecting the health and wellbeing of specific groups of carers.....	10
1.5.1	Needs of carers of people with mental ill-health	10
1.5.2	Needs of carers of people with dementia	10
1.5.3	Needs of carers of people at the end of life.....	11
1.5.4	Needs of parent carers	11
1.5.5	The needs of carers of people with a learning disability	11
1.6	Cambridgeshire carers' views surveys	12
1.7	Literature review relating to key JSNA questions	12
1.8	Services for carers in Cambridgeshire	13
1.9	What is this telling us about carers in Cambridgeshire?	14
1.9.1	What are the key inequalities?	14
1.9.2	What are the key trends?	15
1.9.3	What are the gaps in knowledge/services?	15
1.9.4	Young carers	16
2	Introduction	18
2.1	Who are our carers? Scope and Aims of the JSNA.....	18
2.2	Background.....	18
2.2.1	The contribution of carers	18
2.2.2	Carers' Policy and legislation	19
2.2.3	Young carers	20
2.2.4	NHS England's commitment to carers	21
2.2.5	Relationship between Carer – cared for	22
2.2.6	Cambridgeshire Carers Partnership Board (CPB).....	22
3	Key Facts: How many people provide informal care in Cambridgeshire?	24
3.1	Overview: What do we know from the 2011 Census?	24
3.1.1	Number and percentage of the population providing unpaid care.....	24

3.1.2	Hours of care provided by carers	26
3.1.3	Carers by sex and age.....	29
3.1.4	Carers by ethnicity	31
3.2	Young carers and young adult carers.....	33
3.2.1	Other information sources on young carers and young adult carers.....	34
3.3	Adult carers.....	34
3.4	Older carers	36
4	Issues affecting the health and wellbeing of adult and older carers	39
4.1	Carers' health	39
4.1.1	What do national surveys tell us about the health of carers?.....	39
4.1.2	What do we know about the health of carers in Cambridgeshire from the 2011 Census?.....	40
4.1.3	What does the General Practice Patient Survey (GPPS) tell us?	42
4.2	Money and employment.....	46
4.2.1	What do national surveys and reports tell us about Money and Employment?	46
4.2.2	What do we know from the 2011 Census about the economic activity of carers in Cambridgeshire?.....	50
4.3	Housing	52
4.4	Relationships and social isolation	53
4.4.1	Rurality and isolation.....	53
4.4.2	Domestic violence.....	53
5	Issues affecting the health and wellbeing of young carers and young adult carers	54
5.1	Key issues affecting the health of young carers	54
5.2	Key issues affecting the health of young adult carers.....	55
5.3	What does the census tell us about the health of young carers and young adult carers?	56
6	Issues affecting the health and wellbeing of specific groups of carers	57
6.1	The needs of carers of people with mental ill-health.....	57
6.2	The needs of carers for people at the end of life	59
6.3	The needs of carers of people with dementia.....	61
6.4	The needs of parent carers	61
6.5	The needs of carers of people with a learning disability	63
6.6	Other specific groups	63
7	Local views.....	64
7.1	Cambridgeshire carers JSNA survey	64
7.2	Young carers – focus group report.....	68
7.3	Carers Connect.....	69
8	What services are available for carers in Cambridgeshire? Services and assets.....	71

8.1	Cambridgeshire County Council.....	71
8.1.1	Service description.....	71
8.1.2	Activity data	75
8.1.3	Service feedback: 2012 Adult Social Care carers survey results.....	79
8.1.4	GP surgeries.....	80
8.1.5	Involving carers in hospital and community-based care	84
8.2	Voluntary organisations	85
8.2.1	Alzheimer’s Society.....	85
8.2.2	Care Network.....	86
8.2.3	Carers Trust Cambridgeshire.....	86
8.2.4	Pinpoint.....	90
8.2.5	Centre 33.....	91
8.2.6	Making Space.....	95
8.2.7	Dementia Carers Support Service.....	95
8.3	Citizens Advice Bureau	96
8.4	Schools.....	96
8.5	Cambridgeshire Carers Assets map	97
9	What keeps carers healthy and well? Evidence and best practice.....	99
9.1	What works? Evidence of effectiveness of interventions to keep carers healthy and well from systematic reviews of the literature	99
9.1.1	Overall summary.....	99
9.1.2	Summary of evidence for particular carer groups.....	104
9.1.3	Other evidence	110
9.2	What improves carers’ health and reduces service use?.....	111
9.2.1	Overall summary:.....	111
9.2.2	More detailed summary	111
9.3	Good practice guidance:	113
10	What is this telling us?.....	114
10.1	What are the key inequalities?.....	114
10.2	What are the key trends?	114
10.3	What are the gaps in knowledge/services?.....	114
10.3.1	All carers.....	114
10.3.2	Young carers	115
11	Appendices	120
11.1	APPENDIX 1: Census question and definitions	120
11.2	APPENDIX 2: Consultation	122
11.3	APPENDIX 3: Glossary of terms used in the literature review	132

Contributors

First name	Last name	Organisation
Liza	Alderman	Hinchingsbrooke Healthcare Library
Eva	Alexandratou*	Cambridgeshire County Council
Zonnetje	Auburn	Cambridgeshire County Council
Trevor	Baker*	Cambridgeshire County Council
Tom	Barden*	Cambridgeshire County Council
Lenja	Bell*	Pinpoint
Helen	Brown*	Carers Trust Cambridgeshire
Claire	Bruin*	Cambridgeshire County Council
Barbara	Cassey	Cambridgeshire County Council
Melanie	DeSmith*	Cambridgeshire & Peterborough Clinical Commissioning Group
Kim	Dodd*	Cambridgeshire County Council
Jill	Eastment*	Cambridgeshire County Council
Madeleine	Eid	Cambridgeshire County Council
Margi	Fosh*	Community Rehabilitation, Chesterton Medical Centre
Elaine	Fleet*	Cambridgeshire County Council
Fe	Franklin	Cambridgeshire and Peterborough NHS Foundation Trust
Beryl	Gillespie	Cambridge Housing Society
Melanie	Gray	Carers Trust Cambridgeshire
Laura	Green*	Cambridgeshire County Council
Sue	Hall*	Cambridgeshire County Council
Richard	Holland*	Cambridgeshire County Council
Tracy	Hyland	Carers Trust Cambridgeshire
Graham	Johnston*	Cambridgeshire County Council
Shaynie	Larwood-Smith	Cambridgeshire County Council
Gill	Lintott	Alzheimer's Society
Meats	Louise	Cambridgeshire County Council
Mansfield	Pauline	Making Space
Andy	McGowan	Centre 33
Jon	Moore	Cambridgeshire County Council
Lynne	O'Brien*	Cambridgeshire County Council
Wendy	Quarry*	Cambridgeshire County Council
Juliet	Snell*	Centre 33
Emily	Steggall*	Cambridgeshire County Council
Anne	Swift	Cambridgeshire and Peterborough Clinical Commissioning Group
Rachel	Talbot	Cambridge and District Citizens' Advice Bureau
Amanda	Warburton	Cambridgeshire County Council

* Members of the JSNA Steering Group

Acknowledgements

Many thanks to the carers who attended the JSNA stakeholder workshop on 4 March 2014.

Demography

The Cambridgeshire JSNA Public Health Atlas has been developed in support of the JSNA programme. This interactive atlas provides the latest available data by local authority district for a number of key indicators relating to the health of the local population and is continually being expanded and updated. A summary of the latest data at the time of this report is presented in the Summary JSNA 2014 available on www.cambridgeshireinsight.org.uk/jsna

For the latest data, including tables, maps, graphs and trend data, and more detailed information on sources and metadata, please visit www.cambridgeshireinsight.org.uk/health/profilesdata.

1 Executive Summary

1.1 JSNA scope and context

1.1.1 Definitions and scope

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

Carers are a valuable asset within our communities, providing not just voluntary, unpaid care to assist the person they care for to remain independent, but also love, friendship, reassurance and connection. Carers have good knowledge of the person they care for and their health issues, often co-ordinating and managing their care. Nationally the 1.25 million carers who provide care for more than 50 hours per week are a full-time workforce greater than the entire NHS!

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

The main question for the JSNA was 'What can we do to support carers to stay healthy and well?' In addition, to support the work around the Better Care Fund, the JSNA has also looked at the evidence for whether supporting carers reduces health and social care service use. The scope of the JSNA is carers across the whole lifecourse.

1.1.2 Policy background

The Care Act 2014¹ recognises carers in law in the same way as those they care for. Carers who are over 18 will be entitled to an assessment of their support needs. There will be a shift to self-directed support and flexibility in fitting services around the family. The act has a key underpinning principle of the prevention of the escalation of need and there is an increased emphasis on integration.

The Children and Families Act 2014² states that local authorities in England must assess whether a young carer within their area has needs for support and, if so, what those needs are.

1.2 Key facts and figures

In the 2011 census 60,176 people in Cambridgeshire self-identified themselves as carers in response to the question 'do you look after, or give any help or support to family members, friends, neighbours or others because of long term physical or mental ill-health/disability or problems related to old age'. Overall 70% provide 1-19 hours per week of unpaid care, 10% provide 20-49 hours and 20% said that they provide 50 hours or more per week. There are more female carers than male. Around 60% of carers are aged over 50. Carers over 65 are more likely to provide informal care for more than 50 hours per week than younger carers and are also more likely than other age groups to report their own health as 'bad' or 'very bad'. The percentage of the population providing unpaid care is highest in Fenland (11.1%); this is the only district in Cambridgeshire with a higher percentage than the national average.

¹ <http://services.parliament.uk/bills/2013-14/care.html>

² <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

According to the 2011 census, 4,208 young people under 25 years in Cambridgeshire provide unpaid care. 385 young people aged 0-24 provide 50 or more hours care per week (including 92 under 16's). 1.3% of young carers reported 'bad' or 'very bad' health over the year prior to the census. The figures from the census for young carers or young adult carers are likely to under-represent the true number since census forms are completed on behalf of the household by an adult.

The number of people, who reported caring responsibilities, increased by 9,500 between the 2001 Census and the 2011 Census. This 19% increase was greater than the overall population increase, which was 12%. The highest proportional increase was in Fenland.

1.3 Issues affecting the health and wellbeing of adult and older carers

1.3.1 Health

The percentage of carers reporting bad or very bad health status in the 2011 census was 5.3% in Cambridgeshire, higher than the percentage for non-carers (3.8%), reflecting the pattern for England. Carers UK found that 84% of carers surveyed said that caring has a negative impact on health. Carers tend to neglect their own health.

The GP patient survey for Cambridgeshire and Peterborough Clinical Commissioning Group showed that the proportion of carers who reported a long standing health condition increased by number of hours care provided.

It is recommended that carers receive an annual influenza vaccination.

1.3.2 Finance and employment

Families taking on caring responsibilities often face lasting financial pressure as a result of loss of earnings and rising household costs relating to the extra costs of ill-health or disability. A national survey found that one in five carers is forced to give up work as a result of their caring responsibilities.

In the 2011 census, the percentage of people providing unpaid care varied with economic activity status. 10.6% of economically active Cambridgeshire residents (in work or actively seeking work) provide unpaid care compared with 13.5% of economically inactive residents (eg retired, looking after home/family, permanently sick or disabled).

4,430 people across Cambridgeshire received Carers Allowance in May 2013.

1.3.3 Housing, relationships and social isolation

The cared for person may require adaptations and aids or may need to move into new accommodation. Relocation may be stressful for both the cared-for person and carer. It is important that appropriate aids and adaptations are available to prevent injury to carers whilst moving and handling.

Carers report that caring restricts their social activity resulting in social isolation and smaller social networks. Caring may also result in a deterioration of relationships with other family members

1.4 Issues affecting the health and wellbeing of young carers and young adult carers

Young carers are significantly more likely to grow up in poverty. They have significantly lower attendance and attainment at school and may be victims of bullying. Young carers may be at higher risk of poorer health and risk-taking behaviour as they move into adulthood. The Longitudinal Survey of Young People in England found that young carers are 1.5 times more likely to have a disability, long-term illness or special educational needs, 1.5 times more likely to be from

a black, Asian, or minority ethnic community and twice as likely to not speak English as their first language. Young carers of someone with a mental health issue may suffer significant stigma.

Young carers in Cambridgeshire have identified:

- They want time to have fun and socialise, getting breaks from caring.
- They want more help for the person they care for.
- They need to be less isolated and have people they can turn to.
- They need more money in their families.
- They need help at school with attendance, homework, course work and bullying.
- They need to be helped to get the best from learning and work towards an independent future.
- They need to be meaningfully involved in the planning for their cared for person, and given information and knowledge about the practicalities of caring.
- They need emotional support with worry, anxiety and low self-esteem.
- They need help planning for and dealing with family crises.

Young adult carers are carers over the age of 18 who may be looking at moving out of the home, going into higher education or juggling working lives with continuing to be a carer. Their needs may sometimes be different to those of other carers. For young adult carers caring roles often increase and result in strained family relationships and caring responsibilities resulting in little time for themselves. Young adult carers are more likely to be not in employment, education or training (NEET).

1.5 Issues affecting the health and wellbeing of specific groups of carers

1.5.1 Needs of carers of people with mental ill-health

The fluctuating nature of poor mental health may make the need for support by their carers unpredictable. Carers may be less willing to seek support because of the stigma surrounding mental ill-health.

1.5.2 Needs of carers of people with dementia

Carers of people with dementia need and value information and support at a number of critical points along their caring journey. These are:

- When dementia is diagnosed.
- When the carer takes on an active caring role.
- When the capacity of the person with dementia declines.
- When the carer needs emotional support and/or a break from caring.
- When the person with dementia loses their mobility.
- When the person with dementia has other health problems.
- When the carer has to cope with behaviour problems.
- When the carer's own circumstances change.
- When the person with dementia becomes incontinent.
- When decisions about residential care and end of life have to be made.

What is key, at these points, is that the carer knows where to go to for advice, knows what support is available, that the professionals they are in contact with are knowledgeable regarding dementia and that they engage with both the carer and the person with dementia and they understand the carers needs and issues, not just those of the person with dementia.

1.5.3 Needs of carers of people at the end of life

Carers for a person approaching the end of his or her life share many of the positive and negative aspects of any other form of caring. However, there are additional challenges faced, including rapidly changing care needs, the need to understand complex and often uncertain medical information around prognosis and symptom control, and the prospect and reality of death and bereavement. The impact on health and wellbeing of caring for someone who is dying includes the physical and psychological impacts of any caring role but with the additional strain of bereavement. The most valuable ways for palliative care services to support carers may be to:

- Offer opportunities and permission for the carer to express his or her needs.
- Provide practical help with nursing and symptom control.
- Equip them with information on the likely course of the illness and the dying phase.
- Allocate time for the carer to have respite from their role.

1.5.4 Needs of parent carers

Parent carers look after one or more children with a learning difficulty, a disability and/or an additional need. The role of parent carers blurs between being a parent and being a carer, as parents naturally 'care' for their children. However, parent carers are those that have children that need additional support 'to live ordinary lives' as a matter of course. Similar to other carers, parent carers are not always identified as they are parents first. This is especially true for parents of children that have additional needs who are not eligible for social care, short breaks or a statement of educational need. These are the carers that get the least support and often feel very alone. We don't know how many there are as they are usually unknown to services. However these parents can get support from the voluntary sector, especially parent support groups. Parent carers need:

- A break from their caring responsibilities.
- Access to continuous emotional support including out of hours, weekends and during school holidays. Support is needed from when a concern is first identified to diagnosis (and if there is no diagnosis) through to adulthood.
- Support from professionals and other parents.
- Support for their wellbeing and a safe place to show their feelings.

1.5.5 The needs of carers of people with a learning disability

The 2013 Cambridgeshire Physical and Learning Disability through the Life Course JSNA³ identified that

“Growing numbers of people (with a learning disability) experience a mid-life transition when their parents or family carer’s who they have lived with since childhood become too ill to care for them or they die.

It is important that carers of adults with a learning disability are supported both emotionally and practically to plan early for this transition.”

In addition to this it is important the person with the learning disability's rights to care for their loved one is recognised. Services for the older person and the person with the learning disability providing the care need to be joined up to ensure the needs of both are met.

³ Available at www.Cambridgeshireinsight.org.uk/jsna

1.6 Cambridgeshire carers' views surveys

An internet/phone survey of Cambridgeshire carers was carried out as part of the JSNA. 85 carers responded and were predominantly parent carers. Findings were similar to national survey findings, including that around a third had given up work to care and carers reporting prioritising the health of the person they care for above their own. Only a small proportion had received advice on finance or knew where to get one. Most reported access to support, out of hours, is difficult and a third had not made plans should they be unable to care. Caution is needed, given small numbers, in generalising the results to all Cambridgeshire carers and in making comparisons to national survey results.

Focus groups involving children and young people aged 8-18 were held across Cambridgeshire. Questions asked related to how being a young carer affects friendships, hobbies and school. Findings for 8-11 year olds included difficulties in seeing friends out of school and worries about being made fun of at school. Issues for the older groups included limited time to themselves, difficulty at school because of worrying about the person they care for and worry about meeting deadlines and managing revision. 11-15 year olds spoke about their peers not understanding their caring role. Young carers valued going to young carer groups and making friendships there.

For information on feedback relating to specific Cambridgeshire services, see Section 8 of the main report.

1.7 Literature review relating to key JSNA questions

A review of the literature was carried out to try to answer the question: 'what is effective in helping carers to stay healthy and well?' Reviews of multiple smaller studies were used to provide the highest level of evidence. The key findings are summarised below

- No consistent evidence was found that interventions for carers improve carers' wellbeing or quality of life. The reason for this is likely to be that many of the individual studies on which the reviews were based are small and variable in quality. The outcomes being measured in studies were often not standard across studies eg ways of measuring emotional wellbeing. There were very few (particularly UK based) studies which measured cost effectiveness of interventions. This is not the same as saying that there is evidence that interventions for carers do not have benefits or are not cost effective.
- There was contradictory evidence for the impact of any type of intervention on carers' burden. However, many interventions resulted in carer satisfaction. The best evidence was that education, training and information for carers (particularly when targeted at a particular parent group) improved knowledge and caring 'abilities'.
- The relationship between breaks from care and carers' emotional wellbeing is not straight forward. Many of the studies in reviews are small and of variable quality. There was some evidence of respite having a negative effect in some groups (because of feelings of guilt). There was suggestion that it is important that interventions are tailored to the individual family situation.
- Cognitive reframing (aims to reduce carers' stress by changing certain of their beliefs, such as beliefs about their responsibilities to the person with dementia, their responsibilities to the person with dementia, their own need for support, and why their relatives behave as they do) may be useful when used alongside other interventions for carers of people with dementia (reduced carer depression, anxiety and stress, but did not impact on coping or burden).

A second brief literature review, as part of the JSNA, (again focussing on reviews of multiple studies) aimed to answer the question ‘does supporting carers result in reduced service use by the cared for person?’ The review found that there are gaps in the limited UK-based evidence that supporting carers reduces service use in those they are caring for. This is not the same as saying there is evidence that these services are not effective. Modelling work such as in the Social Return on Investment modelling work on behalf of carers trust⁴ indicate that support given or received has the potential to reduce service use. A report on the UK National demonstrator sites⁵ identified that looking at cost effectiveness in the context of service delivery can be challenging. The evaluation identified the potential for cost-savings and the need to build tools for measuring cost-effectiveness into programme design. Locally the GP prescription service for carers has identified potential financial savings as a result of identification and support for carers

Good practice guidance:

The Triangle of Care - Carers Included: A Best Practice Guide in Acute Mental Health Care. Available at <http://static.carers.org/files/caretriangle-web-5250.pdf>

Commissioning for carers. Royal College of General Practice 2013. Available at <http://www.rcgp.org.uk/clinical/clinical-resources/~media/Files/CIRC/Carers/RCGP-Commissioning-for-Carers-2013.ashx>

1.8 Services for carers in Cambridgeshire

The carers JSNA has taken an assets mapping approach to services in Cambridgeshire. Services identified how many carers were in contact with them or received a service in the financial year 2012/13. The results are shown in the diagram below. The diagram is intended to be indicative of Cambridgeshire assets for carers and has several limitations:

- Many assets for carers cannot be counted, for example the support provided by friends, family, local community networks and religious groups. Other assets are more challenging to count, for example the services provided by many voluntary and community services in Cambridgeshire.
- Where there are numbers, these may underestimate the number of contacts because of the way data are recorded; for example for social care, information may be recorded against the record of the carer or the cared-for person.
- The categories are not mutually exclusive, so carers are likely to be in contact with several of the assets shown.
- Some services are commissioned by one organisation and provided by another.

Key to the diagram:

- The diagram shows assets provided in one financial year (2012/13; unless marked with an asterisk, in which case the data are from 2013/14). Of the 60,000 informal carers in Cambridgeshire, not all will need to access services in a given year. The challenge is knowing how far we are meeting need with existing assets – this requires a range of information sources, most importantly feedback from carers themselves.
- The diagram is colour coded. Services provided by Cambridgeshire County Council Social care are coloured red, benefits and citizen’s advice services in yellow, commissioned voluntary organisations in orange and primary care in green. Other community assets are

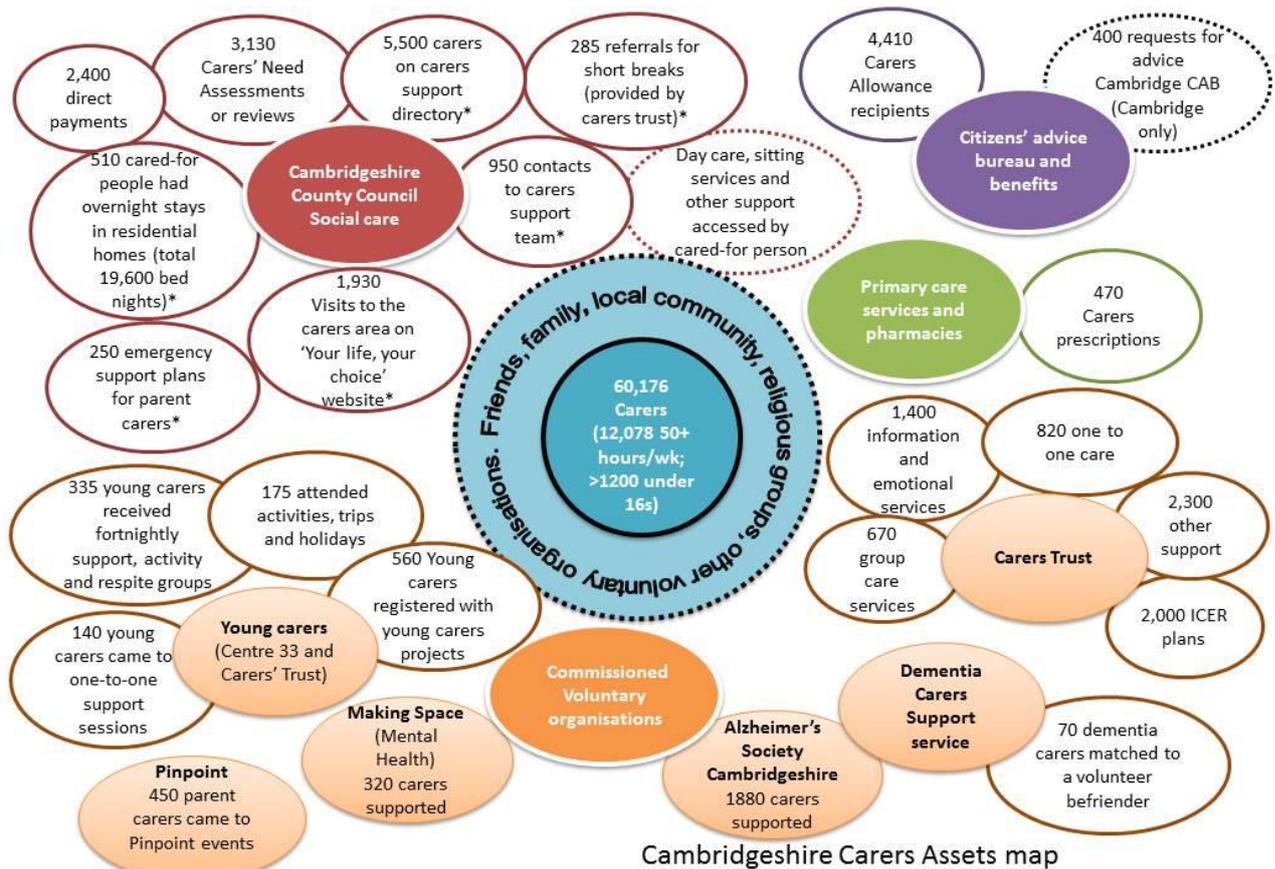
⁴ The Princess Royal Trust for Carers (2011) Social Impact Evaluation of five Carers’ Centres using Social Return on Investment.

⁵ Circle (2011) New approaches to Supporting Carers’ Health and Well-being: evidence from the National Carers’ Strategy Demonstrator Sites programme.

shown as a blue ring around the central bubble, which shows some information about the number of carers in Cambridgeshire.

Where the numbers presented are unknown, uncertain or likely to underestimate assets, a dotted line has been used in the diagram. Numbers of service provisions have been rounded to the nearest 5.

See Section 8 in the main report for more detail on individual services and a larger version of this diagram.



1.9 What is this telling us about carers in Cambridgeshire?

1.9.1 What are the key inequalities?

National survey data tells us that carers report that caring has an impact on their physical, emotional and economic wellbeing. Carers may also not prioritise their own health for and may miss routine health appointments like influenza vaccinations or check-ups with doctors or dentist.

Carers may give up work as a result of their caring responsibilities. This is significant given the importance of 'meaningful activity' (such as employment) to maintaining an individual's positive mental health. Such activity also reduces social isolation.

Cambridgeshire asset mapping has identified the importance of local community networks and services in supporting the health and wellbeing of carers. Carers in new communities may therefore be at risk of having fewer opportunities for support.

In addition, young carers are more likely to grow up in poverty, have poorer school attendance and attainment, to be not in education, employment or training (NEET) and to be bullied and see physical aggression at home. All of these issues may impact on future life chances into adulthood.

Carers from BME groups are likely to be under-identified in Cambridgeshire. Services for carers are not necessarily culturally sensitive in relation to the Gypsy and Traveller community. This community is at particular risk of missing out on Carers Allowance because of the impact of travelling and may be forced to move away from established community networks to be able to access equipment and adaptations.

1.9.2 What are the key trends?

The number of carers in Cambridgeshire increased between 2001 and 2011, the proportionate increase was greater than for the general population. There will be further population growth in Cambridgeshire, including new developments, which means the number of carers are expected to increase. The population in Cambridgeshire is ageing, which will result in a larger number of adults with care needs.

1.9.3 What are the gaps in knowledge/services?

1.9.3.1 All carers

The Care Act 2014 requires services to prevent and reduce future needs through the early identification and support of carers. Considering the large number of carers identified in the census work, it is needed to understand how best to support carers who do a small amount of caring, especially those who are likely to go on to care more intensively for someone whose needs are increasing over time, with staying healthy and well. Given the low level of evidence available on what works best to keep carers healthy and well, building in evaluation of interventions will be crucial.

The survey carried out as part of the JSNA process yielded some useful information, but further work is needed to systematically capture the views of carers. This could include use of reference groups or known distribution groups (for example receiving carers' magazine) or better use of information collected at contact points with carers (eg carers' assessment, carers' prescription). The best response was achieved with parent carers, suggesting that there are good networks within this particular group of carers. This further suggests that there may be learning from models like Pinpoint for other carer groups.

NICE guidance and good practice documents recommend that carers involved in patient care are identified as soon as possible and supported appropriately. This includes having information sharing and confidentiality protocols in place. In addition, national carer policy points to the need to take a holistic approach to assessing the needs of the carer and cared-for person together. It is important that carers are recognised and supported within acute hospitals and that their needs are identified at hospital discharge. Work in Addenbrooke's Hospital has shown the capacity to recognise and support carers and link to community based support, emergency planning and referral to GP carer registers where they exist. It is currently not possible to measure whether carer status is being recorded in the multidisciplinary team record at discharge across Cambridgeshire.

Asset mapping of services in Cambridgeshire suggests that not all carers providing high intensity care (as identified in the 2011 census) have a plan in place to deal with an unexpected emergency that stops them being able to carry out their caring role. However, this information does not include carers who have nominated a friend or family member in this role. It is also important to ensure services and the wider community are able to support carers with lower level, 'urgent' issues, including supporting carers out of hours. Planning is also important for transitions in care eg child to adult, death of carer.

Accurate data are not available on the number of carers registered in primary care in Cambridgeshire. The GP surgery is often the first point of call for carers and most want to use surgeries as a source of support or referral. The Cambridgeshire carers' prescription service has resulted in the identification and referral for support of carers not in receipt of any other support and linked many to emergency support and ICER plans. National surveys suggest that GPs could do more to support carers. A survey carried out as part of this JSNA suggests that some carers in Cambridgeshire are not registered as carers with their GP and where they are, do not receive practice services tailored to their needs eg flexible appointments. The prescription service shows that some surgeries are providing very good support for carers but this is variable. Further work is needed to understand the provision of services to carers in Primary care in Cambridgeshire and include in a Cambridgeshire carers assets map.

Most carers who are recently bereaved do not require specific 'bereavement counselling'. However, education is needed for GPs and other primary care professionals in identifying when a referral is needed. Whilst support services for the bereaved have been mapped by Cambridgeshire and Peterborough Clinical Commissioning Group, the availability and quality of services for bereaved carers in Cambridgeshire is not known. Support for carers both during a terminal illness and following death is variable and there are inequalities in provision on the basis of the diagnosis, place of death and socio-economic status.

In addition to the key findings above, a carers JSNA stakeholder event identified a general need for joint working and joint training across organisations.

1.9.4 Young carers

Joint working between services specifically working with young carers and mainstream preventive services for children and young people is needed to ensure that young carers are seen as a vulnerable group, their needs identified early and seen in the context of the whole family (for example through ensuring good parenting support)

National data tells us that young carers have poorer educational outcomes than their peers. Information from local focus groups tells us that children are worried about meeting deadlines and managing homework at school. However, at a population level it is not possible to identify numbers of young carers in Cambridgeshire schools or to look at local educational outcomes for this potentially vulnerable group. Support at transition to adulthood (from age 14) is needed to ensure young carers continue in education or training and to ensure good health outcomes. A multidisciplinary approach is needed to ensure each child or young person is able to access education and fulfil their educational potential.

Data on the referrals of young carers to organisations like Centre 33 and Carers Trust Cambridgeshire suggest that adult services need to do more to identify young carers and take action to support their needs, particularly mental health, drug and alcohol services. There is poor take up of young carers services by black and ethnic minority communities.

There are few dedicated services for young adult carers in Cambridgeshire although The Carers Trust Cambridgeshire has funding for a new project this year in Huntingdon and Fenland. This suggests that this group of carers may be missing out on advocacy, information and advice on issues such as finance and employment as well as emotional support and opportunities to socialise. However, currently the way data on service use by young adults, is recorded makes it difficult to identify the support this group is receiving from adult services. With a lack of engagement, young adult carers have no voice. They need mechanisms to be heard and involved in the planning, review and evaluation of Carers Services.

Cambridgeshire young adult carers have identified the following gaps:

- Poor access to Information and Advice for young adult carers.
- Poor access to Carers Assessments for young adult carers.
- Poor access to support to access social and leisure activities for young adult carers.

- Poor access to participation opportunities and chances to be heard for young adult carers.

2 Introduction

2.1 Who are our carers? Scope and Aims of the JSNA

A person can become a carer at any age, may care for more than one person at any one time and may become a carer at several points in their lives. Carers come from many different backgrounds, reflecting our local population. Many people do not recognise themselves as carers and may prefer not to be labelled as such, preferring to be identified as 'husband' or 'wife', 'daughter' or 'son', 'parent' or 'friend'. (Royal College of General Practitioners, 2013)

Young carers are children and young people who look after someone in their family who has an illness, a disability, a mental health problem or a substance misuse problem, taking on practical and/or emotional caring responsibilities that would normally be expected of an adult. (Royal College of General Practitioners, 2013)

The scope of this JSNA is carers across the whole lifecourse. The aim of the JSNA is to identify the current and future health and wellbeing needs of people providing informal care in Cambridgeshire and to answer the question:

'What can we do to support carers to stay healthy and well in Cambridgeshire?'

In addition, to support the work around the Better Care Fund, the JSNA has also looked at the evidence for whether supporting carers reduces health and social care service use.

2.2 Background

2.2.1 The contribution of carers

Carers are a valuable asset within our communities, providing not just voluntary, unpaid care to assist the person they care for to remain independent, but also love, friendship, reassurance and connection. Carers have good knowledge of the person they care for and their health issues, often co-ordinating and managing their care. Nationally the 1.25 million carers who provide care for more than 50 hours per week are a full-time workforce greater than the entire NHS! (Royal College of General Practitioners, 2013). Carers may be at risk of poor physical, emotional and financial health themselves. It is, therefore, morally, ethically and financially vital that we support carers to stay healthy and well.

Without involvement, information and support, the carers own health may deteriorate and they may no longer be able to cope with their caring role.

Moriarty (2005) identified that looking after another person affects people's lives in many and various ways. Support to carers needs to reflect individual differences. The impact of caring may have a detrimental effect on the carer's life in many different ways and many carers report difficulties in having their needs met. Carers at particular risk are:

- Spouse carers.
- Live-in carers.
- Those caring for someone with a mental health problem.
- Those caring for someone whose behaviour is changing.
- Those caring for someone who cannot be left alone.
- Those who have a poor relationship with the cared-for person.
- Those who do not have someone in whom to confide.

Moriarty (2005) also found that carers feel it is important to:

- Be included in decision making.
- Have their expertise valued.
- Know whom to contact if needed.
- Have a service which is responsive to their needs.

2.2.2 Carers' Policy and legislation

2.2.2.1 Carers Strategy

The refreshed Carers Strategy of 2010⁶ set out the Government's priorities for carers and identified the actions to be taken to ensure best outcomes for carers, including:

- Supporting those with caring responsibilities to identify themselves as carers at an early stage.
- Recognising the value of their contribution and involving them from the outset, both in designing local care provision and in planning individual packages of care.
- Enabling those with caring responsibilities to fulfil their educational and employment potential.
- Personalised support both for carers and those they support, enabling them to have a family and community life.
- Supporting carers to remain mentally and physically well.

Local authorities and clinical commissioning groups are required to have local carers' strategies and plans, and budgets for supporting carers. The NHS Outcomes Framework for 2013 placed specific emphasis on the provision of carers breaks and support.

2.2.2.2 The Care Act

The new Care Act 2014⁷ recognises all of these priorities and gives more rights to carers and duties to statutory services in relation to carers.

The overarching aims and principles of the Care Act 2014 are to modernise social care legislation and for the first time treat carers as equal to those they care for. The Care Act 2014 simplifies, consolidates and improves existing legislation; "putting carers on an equal legal footing to those they care for and putting their needs at the centre of the legislation".

The Act has a key underpinning principle of the prevention of the escalation of need and there is an increased emphasis on integration in the Act. Local authorities will be under a duty to provide services through the integration of health services and other care and support providers where it would:

- Improve the wellbeing of the adults or carers needing care and support.
- Contribute towards the prevention or development of needs.

⁶ Recognised, Valued and Supported: Next steps for the Carers Strategy. HM Government 2010.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213804/dh_122393.pdf

⁷ <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>
<http://services.parliament.uk/bills/2013-14/care.html>

- Improve the quality of care and support provision.

The Act places an overarching duty to promote wellbeing. It aims to prevent and reduce needs through early identification, the provision of information and advice, integration, assessments and family based support (including Family assessments and care planning). Local Authorities have a duty of market shaping, to offer more choice; and are expected to adopt an asset based approach of taking into account what individuals, family and community have to help people meet their own needs.

The Duty and Power to Meet a Carer's Need for Support strengthens carers' rights, although if they or the person they care for have financial resources over the limit they will still have to request that the local authority meets their needs and they will have to pay for any costs. The impact assessment of the Act found that the new duties would result in an increase in the numbers of carers being assessed and becoming eligible for support. The Government's analysis shows that, whilst this would lead to an increase in demand for resources, and a need to commission further carer's support, it would be cost effective to meet carers' needs as a preventative measure.

The focus on information and support follows studies and consultation with carers showing that involving carers provides better outcomes for the person with care needs; and provides peace of mind for carers that the person they care for is receiving the best and appropriate treatment; together these result in better health for carers. This is the basis for much of the Triangle of Care work. See <http://professionals.carers.org/health/articles/triangle-of-care,6802,PR.html>

The Act places a duty for accessible information and advice that meets the needs of its population. Information and advice must be open to everyone who would benefit from it. People access information and advice from a wide variety of sources:

- Breaks from caring.
- The health and wellbeing of carers themselves.
- Caring and advice on wider family relationships.
- Carers financial and legal issues.
- Caring and employment.
- A carer's need for advocacy.

Carer's assessments should establish not only the carer's needs for support but the sustainability of the caring role itself, which includes both practical and emotional support the carer provides to the person they are caring for. The assessment should take into consideration the carers activities beyond their caring role and the impact of caring on those activities. It should particularly consider whether the carer works, or wishes to work, and what obstacles their caring responsibilities present to their ability to do so.

2.2.3 Young carers

- The Children and Families Act (2014) states that:
 - (1) A local authority in England must assess whether a young carer within their area has needs for support and, if so, what those needs are, if—
 - (a) It appears to the authority that the young carer may have needs for support, or .
 - (b) The authority receive a request from the young carer or a parent of the young carer to assess the young carer's needs for support.

- The refreshed Carers Strategy of 2010⁸ states that: *‘Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive and to enjoy positive childhoods.’*
- The United Nations Convention on the Rights of a Child (UNCRC) (1989) identifies that *‘Every child has the right to participate fully in family, cultural and social life. It is an integral part of the role of all health and social care services to uphold this convention.’*
- General Medical Council Guidance for Doctors (2007)⁹ requires that *‘Doctors should be aware of the needs and welfare of children and young people when they see patients who are parents or carers, or who are cared for by children or young people.’*

The Cambridgeshire Young carers Strategy group set out eight priorities for the years 2011-2014:

1. Improving identification and assessment of young carers.
2. Improving young carers awareness amongst all young people and tackling bullying.
3. Improving support in schools.
4. Improving support to families to reduce levels of inappropriate care.
5. Improving access to out of school and leisure activities for young carers.
6. Sustaining young carers services and ensuring good use of resources.
7. Ensuring that young carers make good transitions to adulthood.
8. Improving access to young carers support for all communities.

2.2.4 NHS England’s commitment to carers

NHS England has carried out engagement with carers to identify what is important for carers. The key themes were:

- Recognise me as a carer (this may not always be as ‘carers’ but simply as parents, children, partners, friends and members of our local communities).
- Information is shared with me and other professionals.
- Signpost information for me and help link professionals together.
- Care is flexible and is available when it suits me and the person I care for.
- Recognise that I also may need help both in my caring role and in maintaining my own health and wellbeing.
- Respect, involve and treat me as an expert in care.
- Treat me with dignity and compassion.

Based on these themes, NHS England has developed 37 commitments¹⁰ around the following priorities:

1. Raising the profile of carers.
2. Education, training and information.
3. Service development.
4. Person-centred, well-coordinated care.
5. Primary care.
6. Commissioning support.

⁸ Recognised, Valued and Supported: Next steps for the Carers Strategy. HM Government 2010.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213804/dh_122393.pdf

⁹ General Medical Council (2007) 0-18 years guidance for all doctors. Available at: http://www.gmc-uk.org/static/documents/content/0-18_years_-_English_0414.pdf

¹⁰ NHS England’s commitment to carers (2014). Available at: <http://www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf>

7. Partnership links.
8. NHS England as an employer.

2.2.5 Relationship between Carer – cared for

Support for carers cannot be viewed or provided in isolation. Carers often are not identified at an early stage or their contribution to care and impact on themselves is not recognised or valued, even though many will be known to health professionals, particularly in primary and community care.

Carers frequently put their own needs behind the needs of the cared for and this increases the risk of their own physical and mental wellbeing deteriorating. This also applies to young and young adult carers, who may adversely affect education and employment chances.

Carers need, and the Care Act 2014 seeks to put in place, mechanisms to enable them to care effectively and safely – both for themselves and the person they are supporting, eg timely interventions or advice on moving and handling safely or avoiding falls in the home, or training for carers to feel confident performing basic health care tasks; to look after their own physical and mental health and wellbeing, including developing coping mechanisms; and to make choices about their own lives, for example, managing care and paid employment.

The holistic approach, addressing carer and cared for needs together, is an option encompassed in the Care Act 2014. For example, rather than services which support a stroke survivor physically, with separate services for depression and no recognition or planning for the increased risk of carer depression, could be planned for in a family care and support plan ideally with integrated support services available. Working with families from a very early stage to teach and encourage them to be involved in care provision as valued partners reduces the risk of carer ill mental health and improved outcomes for cared-for.

The importance of involving carers in patient care:

- "Carers are an integral part of the patient's support system. They are the ones with the day-to-day experience of the patient's condition and they carry the most intimate responsibility for the patient's welfare. The carer's voice in decision making about admission and discharge is ignored at everyone's peril and yet so often is." Dr Mike Shooter, Past-President, Royal College of Psychiatrists.
- Carers are already involved, and will continue to be involved following any medical or other intervention. It is essential they are aware of different strategies, especially behaviour management strategies, to ensure they are not exacerbating the mental health condition. It is really important that they are aware of early warning signs to help the person they are caring for keep their condition under control.
- Good diagnosis and treatment is dependent on background information that the carer may be in a perfect position to provide. Carers are the ones who know the most about what the person they care for is like when they have good mental health. They may also know what strategies have already been tried. Without their involvement, vital information may be missed.
- Involving carers will also give the carer confidence in the services that are being provided.

2.2.6 Cambridgeshire Carers Partnership Board (CPB)

The Carers Partnership Board's aim is to maintain a strategic overview of the support provided for Family Carers across Cambridgeshire. The Board meets bi-monthly at venues around the county. Since 2013 the Board has been facilitated by the Cambridgeshire Alliance for Independent Living. The posts of chair and vice chair are held by carers. Membership of the board includes: Clients, Service Users, carers and staff from the county council; social care; National Health Service, voluntary organisations and HealthWatch. Carers are an important part of all the partnership

Boards, but the CPB has a number of carers with different caring experiences – parent carers, young carers (represented by Centre 33), individuals caring for people who have learning disability, physical disability, mental health and for older people. The Carers Partnership Board provides valuable feedback on various policies and proposals from CCC and partners. Representatives from the various partnership boards also sit on the Adult Social Care Forum which takes an overview from the Boards and links in with Adult Social Care management.

3 Key Facts: How many people provide informal care in Cambridgeshire?

3.1 Overview: What do we know from the 2011 Census?

The 2011 Census was the second Census to include a question on the provision of unpaid care. The question asked ‘Do you look after, or give any help or support to family members, friends, neighbours or others because of long-term physical or mental ill-health/disability or problems related to old age? (Do not count anything you do as part of paid employment).’ Respondents were also asked to state the number of hours care provided per week (Figure 1). See Appendix 1

Figure 1: Question on provision of unpaid care from the 2011 Census

14 Do you look after, or give any help or support to family members, friends, neighbours or others because of either:

- long-term physical or mental ill-health/disability?
- problems related to old age?

↪ Do not count anything you do as part of your paid employment

No

Yes, 1 - 19 hours a week

Yes, 20 - 49 hours a week

Yes, 50 or more hours a week

Source: 2011 Census form, Office for National Statistics

3.1.1 Number and percentage of the population providing unpaid care

At the 2011 Census, 60,176 people in Cambridgeshire (9.7%) reported they were providing some level of unpaid care. This is a similar percentage of the population to the national average of 10.2% (Table 1 and Figure 2). This percentage varied a little by district within the county: the lowest percentage providing unpaid care was in Cambridge City (7.9%) and the highest in Fenland (11.1%), the only district with a percentage higher than the national average.

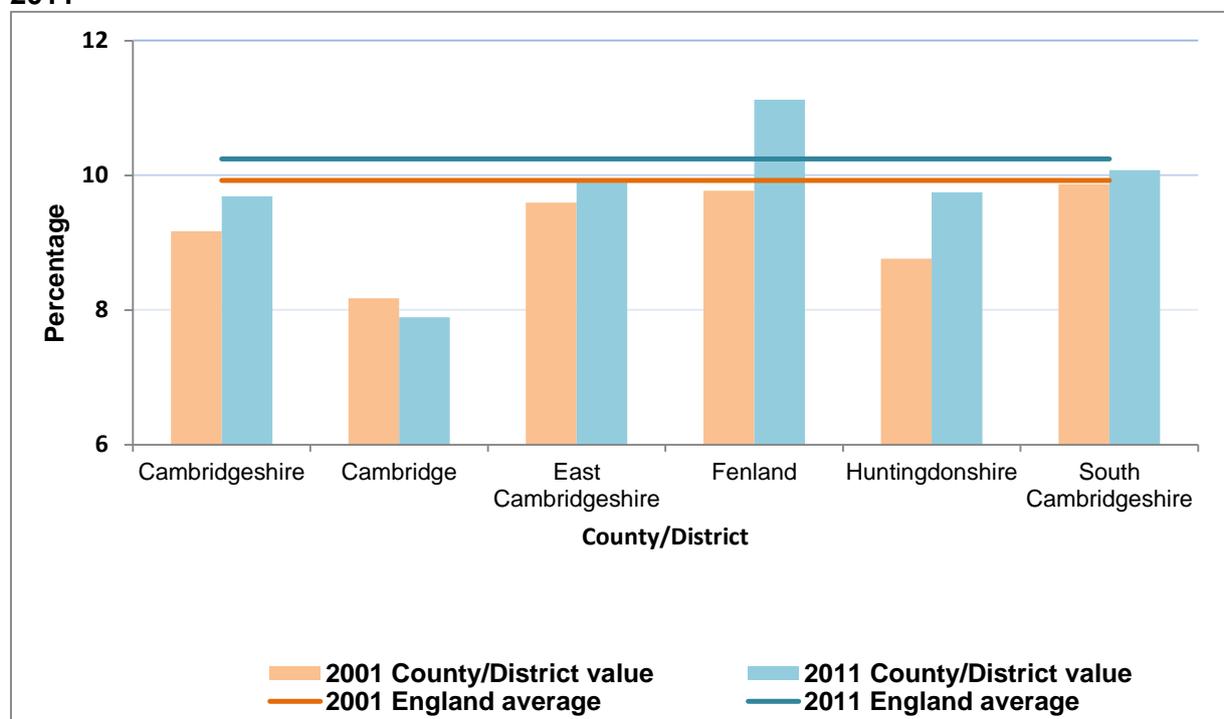
An additional 9,500 people reported that they provide unpaid care in Cambridgeshire in 2011 compared with 2001 (an increase of 19%); the increase in numbers of carers is greater than the general population growth (12%). The percentage providing unpaid care was also slightly higher in Cambridgeshire in 2011 compared to 2001 (9.7% v 9.2%), in line with the national trend. The percentages increased in 2011 compared to 2001 in all districts except for Cambridge City, though the numbers did still increase, consistent with population growth and/or ageing. In 2001, there was less variation by district in the percentage of the population reporting that they provided unpaid care than in 2011. The percentage providing care increased markedly in Fenland from 9.8% to 11.1% of the population.

Table 1: Number of people and percentage of population providing unpaid care, Cambridgeshire, 2001 and 2011

	2001			2011		
	Number	%	Population	Number	%	Population
Cambridge	8,901	8.2	108,863	9,777	7.9	123,867
East Cambridgeshire	7,026	9.6	73,214	8,289	9.9	83,818
Fenland	8,159	9.8	83,519	10,594	11.1	95,262
Hunts	13,750	8.8	156,954	16,525	9.7	169,508
South Cambridgeshire	12,837	9.9	130,108	14,991	10.1	148,755
Cambridgeshire	50,673	9.2	552,658	60,176	9.7	621,210
England	4,877,060	9.9	49,138,831	5,430,016	10.2	53,012,456

Source: 2011 Census, Office for National Statistics

Figure 2: Percentage of the population providing unpaid care, Cambridgeshire, 2001 and 2011



Source: 2011 Census, Office for National Statistics

Table 2 shows the increase in the number of people reporting that they provide unpaid care at Census 2001 and at Census 2011 by age group. The largest increases have been in older people, people aged 65 and over, and in the younger age groups. In 2011, an additional 4,700 people aged 65 and over reported that they provide unpaid care in Cambridgeshire compared with 2001 (an increase of 50%) in line with the national trend. An additional 1,000 young adults, and 300 children aged 15 and were identified as providing unpaid care, increases of 56% and 36% respectively.

Table 2: Number of people that provide unpaid care, by age group, Cambridgeshire 2001 and 2011

Age group	2001	2011	Change	% change
0 - 15	900	1,227	+327	36%
16 - 24	1,916	2,981	+1,065	56%
25 - 34	4,104	4,354	+250	6%
35 - 49	14,184	14,838	+654	5%
50 - 64	19,464	22,563	+3,099	16%
65+	9,469	14,189	+4,720	50%
All ages	50,673	60,176	+9,503	19%

Source: 2001 and 2011 Census, Office for National Statistics

3.1.2 Hours of care provided by carers

Numbers and percentages among those that provide care, for Cambridgeshire, its districts and England, are presented in Table 3 and

Table 4. Among those that provide unpaid care, the percentage providing 50 or more hours of care per week in Cambridgeshire was 20.1%, lower than the England average of 23.1% (

Table 4 and Figure 2). This varied by district within the county with 27.8% of those that provide care in Fenland providing 50 or more hours per week but just 16.3% in both Cambridge and South Cambridgeshire.

Greater percentages of the population are providing 20 or more hours of care per week in 2011 compared with 2001 – this is true for Cambridgeshire as a whole and each district, and is in line with the national trend.

Table 3: Hours of care provided among those that provide unpaid care – number of people, Cambridgeshire, 2001 and 2011

Local authority	2001				2011			
	Hours provided per week			Total	Hours provided per week			Total
	1-19	20-49	50 or more		1-19	20-49	50 or more	
Cambridge	6,889	763	1,249	8,901	7,146	1,042	1,589	9,777
East Cambs	5,249	575	1,202	7,026	5,725	927	1,637	8,289
Fenland	5,272	893	1,994	8,159	6,154	1,496	2,944	10,594
Hunts	10,009	1,223	2,518	13,750	11,150	1,911	3,464	16,525
South Cambs	10,220	960	1,657	12,837	11,138	1,409	2,444	14,991
Cambs	37,639	4,414	8,620	50,673	41,313	6,785	12,078	60,176
England	3,347,531	530,797	998,732	4,877,060	3,452,636	721,143	1,256,237	5,430,016

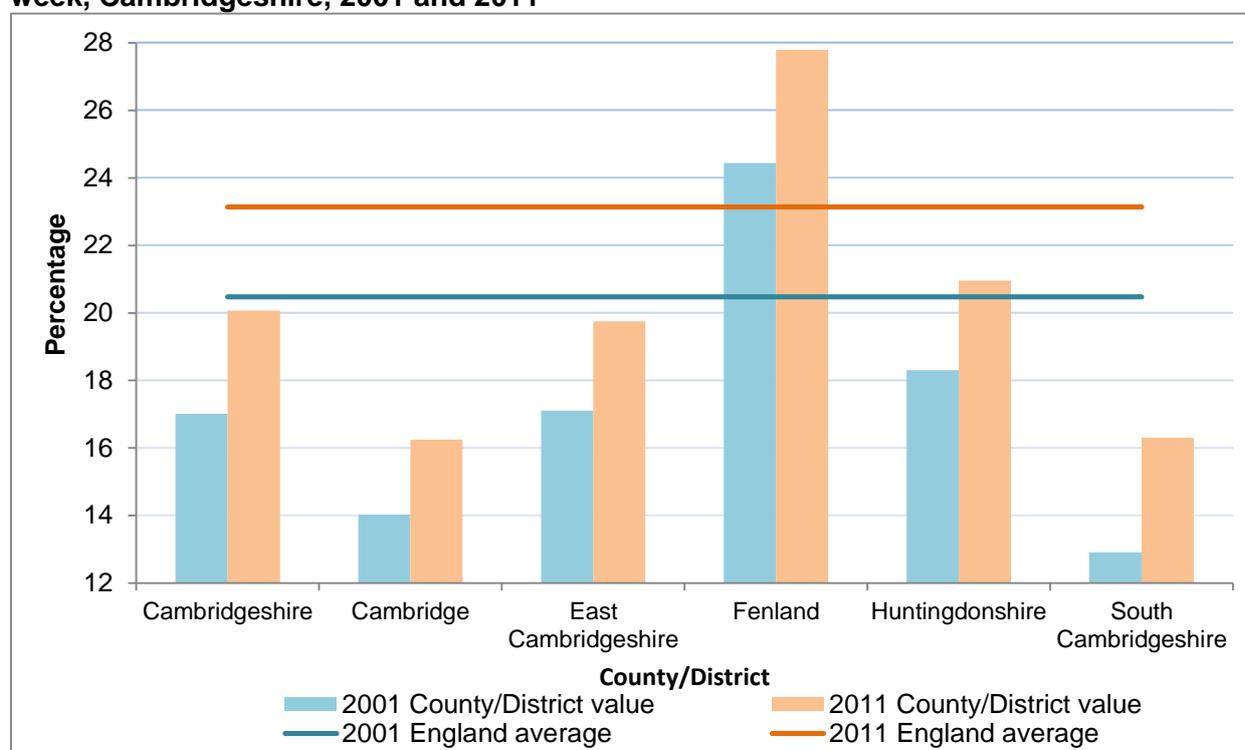
Source: 2011 Census, Office for National Statistics

Table 4: Hours of care provided among those that provide unpaid care – percentage of population, Cambridgeshire, 2001 and 2011

Local authority	2001				2011			
	Hours provided per week			Total	Hours provided per week			Total
	1-19	20-49	50 or more		1-19	20-49	50 or more	
Cambridge	77.4	8.6	14.0	100.0	73.1	10.7	16.3	100.0
East Cambs	74.7	8.2	17.1	100.0	69.1	11.2	19.7	100.0
Fenland	64.6	10.9	24.4	100.0	58.1	14.1	27.8	100.0
Hunts	72.8	8.9	18.3	100.0	67.5	11.6	21.0	100.0
South Cambs	79.6	7.5	12.9	100.0	74.3	9.4	16.3	100.0
Cambs	74.3	8.7	17.0	100.0	68.7	11.3	20.1	100.0
England	68.6	10.9	20.5	100.0	63.6	13.3	23.1	100.0

Source: 2011 Census, Office for National Statistics

Figure 3: Percentage of the population providing 50 or more hours of unpaid care per week, Cambridgeshire, 2001 and 2011



Source: 2011 Census, Office for National Statistics

3.1.3 Carers by sex and age

In Cambridgeshire, 57.3% of carers are female. The sex ratio of carers in Cambridgeshire differs noticeably compared with England where the split is more even (50.8% of carers are female). This pattern compared with the England average is seen across all age groups, except for those aged 65 and over, where 51.4% of carers in Cambridgeshire are female compared to 55% in England. Cambridgeshire's general population breakdown by sex and age is very similar to England (data not shown).

The age group with the highest percentage providing unpaid care in Cambridgeshire was those aged 50-64 years (19.9%, 22,563 people), followed by those aged 65 and over (14.6%, 14,189 people), consistent with the pattern for England (Table 5 and Table 6). Around 60% of carers in Cambridgeshire are over 50.

At district level, the percentages providing unpaid care were consistently higher in Fenland compared with the other districts across all age groups up to 49 years (

Figure 3). However, in the 50-64 year age group, the percentages were more even across the districts, and in those aged 65 years and over a greater percentage of Cambridge and South Cambridgeshire residents provide unpaid care compared with the other districts.

Table 5: Number of people providing unpaid care by age group, Cambridgeshire, 2011

Local Authority	Age group (years)						Total
	0-15	16-24	25-34	35-49	50-64	65+	
Cambridge	178	869	1,045	2,304	3,267	2,109	9,777
East Cambridgeshire	155	328	519	2,054	3,212	2,021	8,289
Fenland	222	506	747	2,631	3,786	2,702	10,594
Huntingdonshire	402	738	1,119	4,258	6,313	3,679	16,525
South Cambridgeshire	270	540	924	3,591	5,985	3,678	14,991
Cambridgeshire	1,227	2,981	4,354	14,838	22,563	14,189	60,176
England	111,423	302,356	473,891	1,420,318	1,929,420	1,190,520	5,430,016

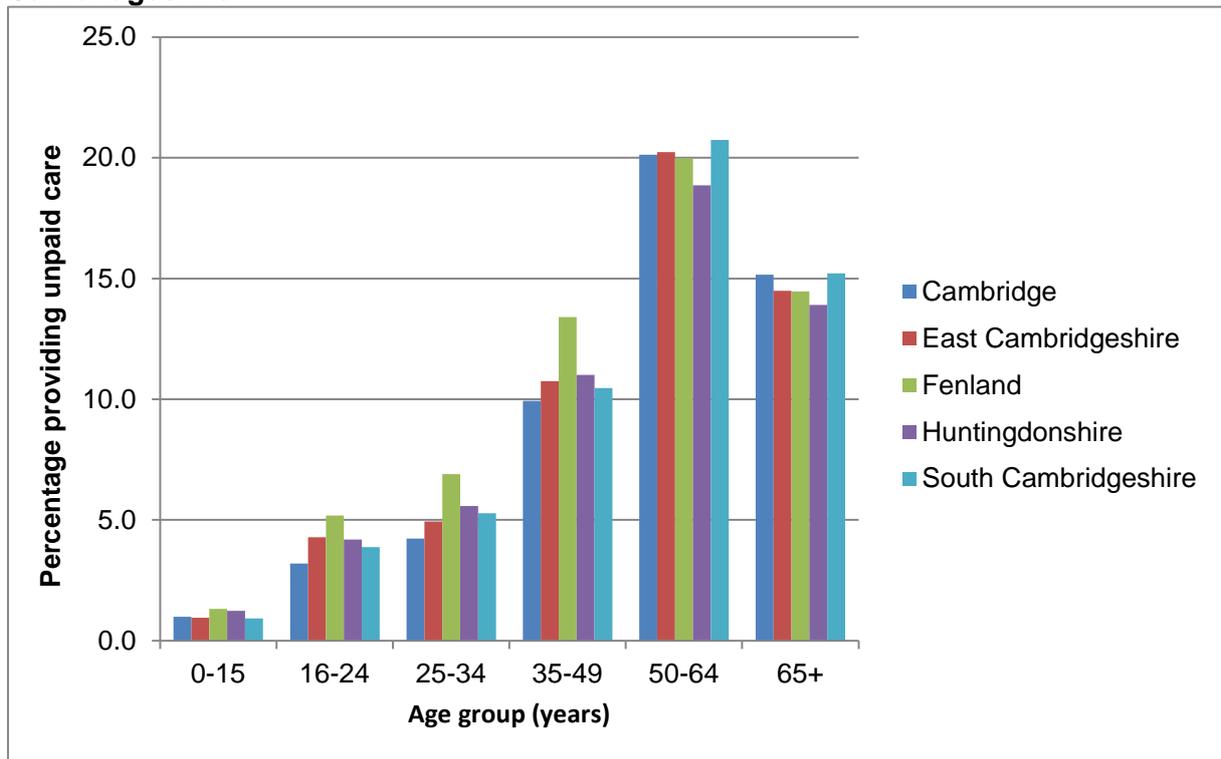
Source: 2011 Census, Office for National Statistics

Table 6: Percentage of the population providing unpaid care by age group, Cambridgeshire, 2011

Local Authority	Age group (years)						Total
	0-15	16-24	25-34	35-49	50-64	65+	
Cambridge	1.0	3.2	4.2	9.9	20.1	15.2	7.9
East Cambridgeshire	0.9	4.3	4.9	10.7	20.2	14.5	9.9
Fenland	1.3	5.2	6.9	13.4	20.0	14.5	11.1
Huntingdonshire	1.2	4.2	5.6	11.0	18.9	13.9	9.7
South Cambridgeshire	0.9	3.9	5.3	10.5	20.7	15.2	10.1
Cambridgeshire	1.1	3.9	5.2	11.0	19.9	14.6	9.7
England	1.1	4.8	6.6	12.6	20.2	14.3	10.2

Source: 2011 Census, Office for National Statistics

Figure 4: Percentage of the population providing unpaid care by age group and district, Cambridgeshire



Source: 2011 Census, Office for National Statistics

3.1.4 Carers by ethnicity

The percentage of people providing unpaid care varies with ethnic group. The ethnic group with the highest percentage providing unpaid care was the white – English/Welsh/Scottish/Northern Irish/British/Irish group (10.5%) followed by the white – Gypsy or Irish Traveller ethnic group (9.8%) (

Table 7). The percentages providing care by ethnic group were fairly similar in Cambridgeshire to the England average but with a notably lower proportion of the Asian/Asian British ethnic group providing unpaid care compared to England (5.5% v 8.5%).

In Cambridgeshire, 96% of carers are from a white ethnic group, slightly higher than the percentage of the total population than are from the white ethnic group (93%). The other white ethnic group represents 7.1% of the total population but 3.2% of carers.

Variation in the proportion of carers, among different ethnic groups, may be as a result of differences in their respective age profiles. For example, 30% of Cambridgeshire's white population is aged 50 or over whereas among the Asian/ Asian British population, only 14% are aged 50 and over. Since people are more likely to be carers later in life this is likely to have an impact on figures. Also, people from BME backgrounds may be less likely to self-identify so resulting in under-reporting of carers in BME groups.¹¹

¹¹ **Improving support for black and minority ethnic (BME) carers IRISS Insights, no.7**
<http://www.iriss.org.uk/sites/default/files/iriss-insight-7.pdf>

Table 7: Provision of unpaid care by ethnic group, Cambridgeshire and England, 2011

Ethnic group	Cambridgeshire		England	
	Number	%	Number	%
White English/Welsh/Scottish/Northern Irish/British/Irish	55,569	10.5	4,705,577	11.0
Gypsy or Irish Traveller	148	9.8	5,870	10.7
Other White	1,936	4.4	128,157	5.3
Mixed/multiple ethnic group	595	5.4	67,192	5.6
Asian/Asian British	1,404	5.5	353,301	8.5
Black/African/Caribbean/Black British	332	5.5	131,356	7.1
Other	192	5.5	38,563	7.0
Total	60,176	9.7	5,430,016	10.2

Source: 2011 Census, Office for National Statistics

3.2 Young carers and young adult carers

In Cambridgeshire, in 2011, 1,227 children aged 15 and under reported as providing unpaid care in the 2011 census, representing 1.1% of the population (

Table 8). This is the same proportion as in England as a whole. Of the population aged 16 to 24, 2,981 people (3.9%) reported providing unpaid care (Table 9) lower than the average of 4.8% in England as a whole.

Table 8: Young people aged 0-15 years providing unpaid care, Cambridgeshire, 2011

Local Authority	Population (0-15 years)	% population providing unpaid care	Provides unpaid care			
			Total	1-19 hrs/wk	20-49 hrs/wk	50+ hrs/wk
Cambridge	17,860	1.0%	178	143	17	18
East Cambridgeshire	16,337	0.9%	155	128	16	11
Fenland	16,780	1.3%	222	173	27	22
Huntingdonshire	32,351	1.2%	402	340	35	27
South Cambridgeshire	29,413	0.9%	270	234	22	14
<i>Cambridgeshire</i>	<i>112,741</i>	<i>1.1%</i>	<i>1,227</i>	<i>1,018</i>	<i>117</i>	<i>92</i>
<i>England</i>	<i>10,022,836</i>	<i>1.1%</i>	<i>111,423</i>	<i>90,171</i>	<i>11,142</i>	<i>10,110</i>

Source: 2011 Census Table LC3304EW

Table 9: Young people aged 16-24 years providing unpaid care, Cambridgeshire, 2011

Local Authority	Population (16-24 years)	% population providing unpaid care	Provides unpaid care			
			Total	1-19 hrs/wk	20-49 hrs/wk	50+ hrs/wk
Cambridge	27,236	3.2%	869	752	61	56
East Cambridgeshire	7,661	4.3%	328	259	38	31
Fenland	9,768	5.2%	506	336	92	78
Huntingdonshire	17,637	4.2%	738	546	107	85
South Cambridgeshire	13,936	3.9%	540	437	60	43
<i>Cambridgeshire</i>	<i>76,238</i>	<i>3.9%</i>	<i>2,981</i>	<i>2,330</i>	<i>358</i>	<i>293</i>
<i>England</i>	<i>6,284,760</i>	<i>4.8%</i>	<i>302,356</i>	<i>219,853</i>	<i>47,962</i>	<i>34,541</i>

Source: 2011 Census Table LC3304EW

3.2.1 Other information sources on young carers and young adult carers

The Health Related Behaviour Survey (HRBS) was conducted in Cambridgeshire schools with Year 8 (13/14 year olds) and Year 10 (15/16 year olds) in June/July 2012. Questions on caring were included and are shown below.

83 a) Are you a 'young carer'? Please tick one answer ✓

A young carer is someone whose life is in some way restricted because of the need to take responsibility for the care of a person, on a regular basis. This person may have a long-term illness, a physical or sensory impairment or learning difficulties, or they may be experiencing mental distress or be affected by drug or alcohol misuse. This person may be a parent, brother, sister or close friend. You may have help with the caring role from another family member or you may be the only carer.

No 0

Don't know 1

Yes 2

b) If you are a 'young carer', who do you look after? e.g. mum, dad, grandma, brother, stepdad

84 If you are a 'young carer', how much of your time does it take up each day?

Please tick one answer ✓

Less than 1 hour 0

1-2 hours 1

More than 2 hours 2

Some time, but I don't do this every day 3

Of the 7,325 Year 8 and 10 school pupils who answered the question about being a young carer in the 2012 Health Related Behaviour Survey, 452 self-identified as Young carers. Other findings from the survey were:

- Higher proportion of female carers than male.
- Girls care for more hours each day than boys.
- The person being cared for was more often mother or siblings (although the percentages of the total sample were small).

The proportion of young people reporting that they have caring responsibilities in the 2012 HRBS (6% of those answering the relevant question) is higher than the proportion of Cambridgeshire's children and young people identified as caring by the 2011 census. This finding suggests that the census, which is completed on behalf of the child or young person by their parent, may underestimate the number of young carers in Cambridgeshire. This finding is supported by a BBC and University of Nottingham survey of 4000 UK secondary school children, which found that 1 in 12 reported caring responsibilities.¹²

3.3 Adult carers

In Cambridgeshire, in 2011, 5.2% of the population aged 25 to 34 years were providing unpaid care (Table 10). This is a slightly lower figure than in England as a whole.

¹² <http://www.bbc.co.uk/newsbeat/11758368>

Table 10: Adults aged 25-34 years providing unpaid care, Cambridgeshire, 2011

Local Authority	Population (25-34 years)	% population providing unpaid care	Provides unpaid care			
			Total	1-19 hrs/wk	20-49 hrs/wk	50+ hrs/wk
Cambridge	24,725	4.2%	1,045	755	141	149
East Cambridgeshire	10,524	4.9%	519	341	70	108
Fenland	10,821	6.9%	747	422	122	203
Huntingdonshire	20,044	5.6%	1,119	732	141	246
South Cambridgeshire	17,525	5.3%	924	671	114	139
<i>Cambridgeshire</i>	<i>83,639</i>	<i>5.2%</i>	<i>4,354</i>	<i>2,921</i>	<i>588</i>	<i>845</i>
<i>England</i>	<i>7,160,102</i>	<i>6.6%</i>	<i>473,891</i>	<i>300,162</i>	<i>74,098</i>	<i>99,631</i>

Source: 2011 Census Table LC3304EW

In Cambridgeshire, in 2011, 11% of the population aged 35-49 years were providing some form of unpaid care (Table 11), compared to 10.0% in people of all ages. This is a slightly lower figure than in England as a whole.

Table 11: Adults aged 35-49 years providing unpaid care by District and hours provided, 2011

Local Authority	Population (35-49 years)	% population providing unpaid care	Provides unpaid care			
			Total	1-19 hrs/wk	20-49 hrs/wk	50+ hrs/wk
Cambridge	23,207	9.9%	2,304	1,645	278	381
East Cambridgeshire	19,118	10.7%	2,054	1,433	249	372
Fenland	19,625	13.4%	2,631	1,574	389	668
Huntingdonshire	38,690	11.0%	4,258	2,832	539	887
South Cambridgeshire	34,310	10.5%	3,591	2,659	369	563
<i>Cambridgeshire</i>	<i>134,950</i>	<i>11.0%</i>	<i>14,838</i>	<i>10,143</i>	<i>1,824</i>	<i>2,871</i>
<i>England</i>	<i>11,314,865</i>	<i>12.6%</i>	<i>1,420,318</i>	<i>917,535</i>	<i>199,118</i>	<i>303,665</i>

Source: 2011 Census Table LC3304EW

In Cambridgeshire, in 2011, 19.9% of the population aged 50-64 years were providing some form of unpaid care (Table 12), compared to 10.0% in people of all ages. This is a slightly lower figure than in England as a whole.

Table 12: Adults aged 50-64 years providing unpaid care by District and hours provided, 2011

Local Authority	Population (50-64 years)	% population providing unpaid care	Provides unpaid care			
			Total	1-19 hrs/wk	20-49 hrs/wk	50+ hrs/wk
Cambridge	16,238	20.1%	3,267	2,565	310	392
East Cambridgeshire	15,871	20.2%	3,212	2,469	306	437
Fenland	18,949	20.0%	3,786	2,452	507	827
Huntingdonshire	33,486	18.9%	6,313	4,716	653	944
South Cambridgeshire	28,869	20.7%	5,985	4,909	474	602
<i>Cambridgeshire</i>	<i>113,413</i>	<i>19.9%</i>	<i>22,563</i>	<i>17,111</i>	<i>2,250</i>	<i>3,202</i>
<i>England</i>	<i>9,569,364</i>	<i>20.2%</i>	<i>1,929,420</i>	<i>1,341,380</i>	<i>237,760</i>	<i>350,280</i>

Source: 2011 Census Table LC3304EW

3.4 Older carers

In Cambridgeshire, in 2011, 14.6% of the population aged 65 and over were providing some form of unpaid care (Table 13), compared to 10.0% in people of all ages. These figures compare to 14.3% of people aged 65 and over in England as a whole. Cambridgeshire, therefore, had a slightly higher proportion of people aged 65 and over providing unpaid care.

Of the 14,189 people aged 65 and over in Cambridgeshire providing unpaid care, 51.4% were female and 48.6% male. Despite a higher proportion of carers being female, carers actually made up a slightly higher proportion of the male population aged 65 and over. The proportion of female carers is higher in Cambridgeshire than in England as a whole where 45% of carers are female and 55% male.

Table 13: Number of carers providing unpaid care in Cambridgeshire residents aged 65 and over, by time spent.

Local Authority	Population (65+ years)	% population providing unpaid care	Provides unpaid care			
			Total	1-19 hrs/wk	20-49 hrs/wk	50+ hrs/wk
Cambridge	13,912	15.2%	2,109	1,282	234	593
East Cambridgeshire	13,945	14.5%	2,021	1,095	248	678
Fenland	18,684	14.5%	2,702	1,197	359	1,146
Huntingdonshire	26,460	13.9%	3,679	1,975	435	1,269
South Cambridgeshire	24,182	15.2%	3,678	2,228	369	1,081
<i>Cambridgeshire</i>	<i>97,183</i>	<i>14.6%</i>	<i>14,189</i>	<i>7,777</i>	<i>1,645</i>	<i>4,767</i>
<i>England</i>	<i>8,343,008</i>	<i>14.3%</i>	<i>1,190,520</i>	<i>582,572</i>	<i>150,731</i>	<i>457,217</i>

Source: 2011 Census Table DC3301EW and DC3303EW

As shown in

Figure 5 and Figure 6, older carers aged 65 and over are more likely to provide informal care for more than 50 hours per week than in other age bands. 34% of carers aged 65 and over provide informal care for more than 50 hours per week, compared to 16% of carers across other age groups.

Figure 5: Carers living in households in Cambridgeshire by age and hours of care

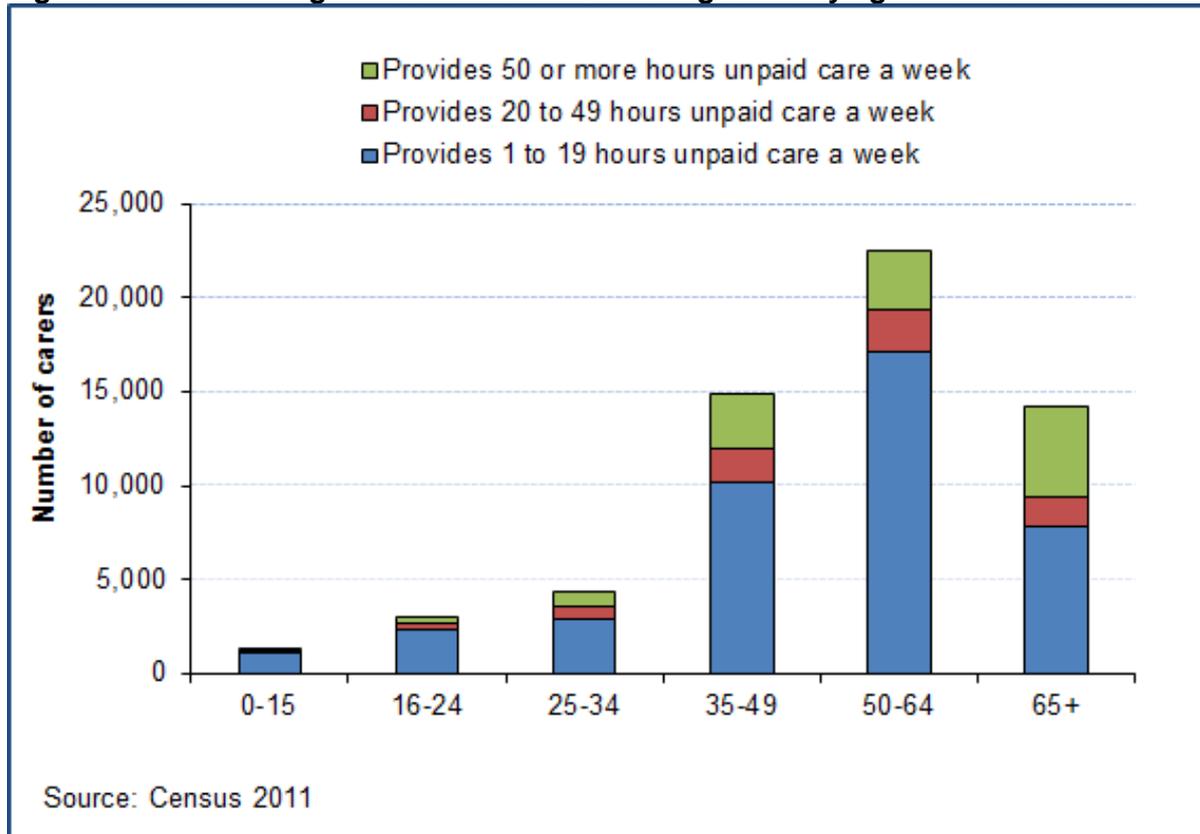
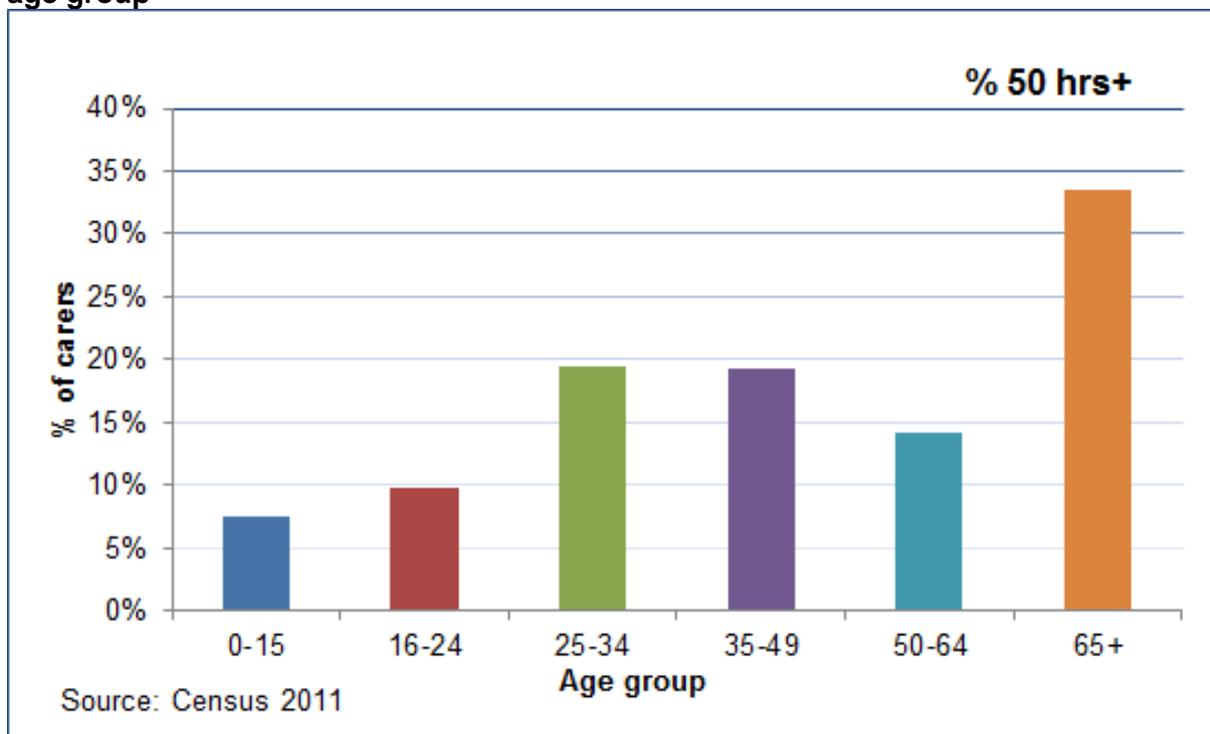


Figure 6: Percentage of carers in Cambridgeshire providing 50+ hours of care per week, by age group



4 Issues affecting the health and wellbeing of adult and older carers

4.1 Carers' health

4.1.1 What do national surveys tell us about the health of carers?

Carers UK found that 84% of carers surveyed said that caring has a negative impact on health. Nine in 10 (92%) of carers said that their mental health has been affected by caring with only 1% saying that caring has improved their mental health. 67% of carers said their GP is aware of caring responsibilities but gives them no extra help. (Carers UK, 2013).

Carers not receiving respite are more likely to have mental health problems (36%), compared with those in receipt of respite (17%) (Hirst, 2004).

The health of carers deteriorates more quickly than that of non-carers due to the lack of support (often due to a lack of awareness of support available). 64% reported a lack of practical support and 50% a lack of financial support. (Carers UK, 2012)

The Royal College of General Practitioners (RCGP) 2013 have identified (from various sources) that:

- Carers tend to neglect their own health. The impact on a carer's own physical and mental health is worsened if they are unable to attend their own health-related appointments. They may fail to notice their own health deteriorating and miss routine appointments or check-ups with doctors or dentists. Information from Carers UK shows that two in five carers postpone their own treatments due to lack of support. Care and support is also relied on to take the cared for to appointments if the carer works.
- Caring can limit carers' ability to take exercise.
- 40% of carers experience psychological distress or depression, with those caring for people with behavioural problems experiencing the highest levels of distress.
- 33% of those providing more than 50 hours of care a week report depression and disturbed sleep.
- Those providing more than 20 hours of care a week over an extended period have double the risk of psychological distress over a two year period compared to non-carers. Risk increases progressively as the time spent caring each week increases.
- 44% of carers suffer verbal or emotional abuse; 28% endure physical aggression or violence from the person they care for.
- Older carers who report 'strain' have a 63% higher likelihood of death in a four year period.
- Providing high levels of care is associated with a 23% higher risk of stroke.

4.1.2 What do we know about the health of carers in Cambridgeshire from the 2011 Census?

The percentage of carers reporting 'bad' or 'very bad' health status was 5.3% in Cambridgeshire, higher than the percentage for non-carers (3.8%), reflecting the pattern for England (Table 14). However, the percentage of carers in 'bad health' in Cambridgeshire was lower than in England as a whole. The percentage of carers in bad or very bad health was noticeable higher in Fenland (7.8%).

Table 14: Number and percentage of carers and non-carers in bad or very bad health, Cambridgeshire, 2011

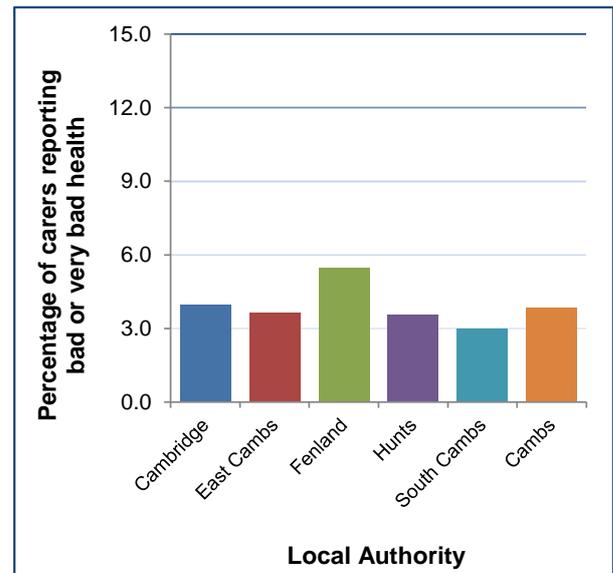
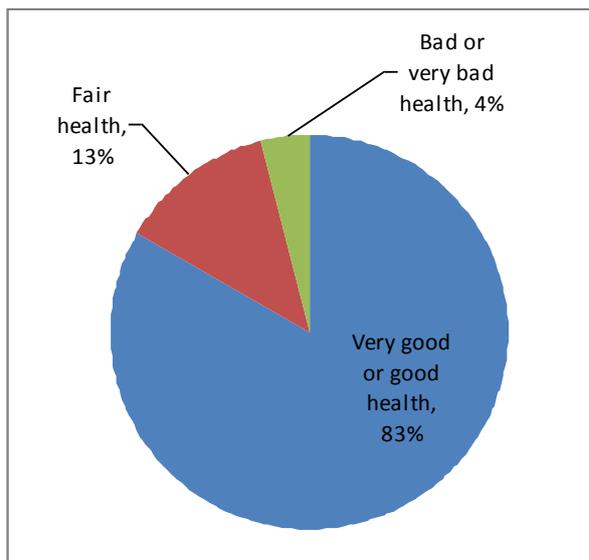
Local authority	Carers		Non-carers		Total	
	Number	%	Number	%	Number	%
Cambridge	487	5.2	3,668	3.7	4,155	3.9
East Cambridgeshire	445	5.4	2,736	3.7	3,181	3.8
Fenland	796	7.5	4,839	5.8	5,635	6.0
Huntingdonshire	801	4.9	5,438	3.6	6,239	3.7
South Cambridgeshire	618	4.1	3,970	3.0	4,588	3.1
Cambridgeshire	3,147	5.3	20,651	3.8	23,798	4.0
England	355,960	6.6	2,413,496	5.2	2,769,456	5.3

Source: 2011 Census

4.1.2.1 The health of adult carers

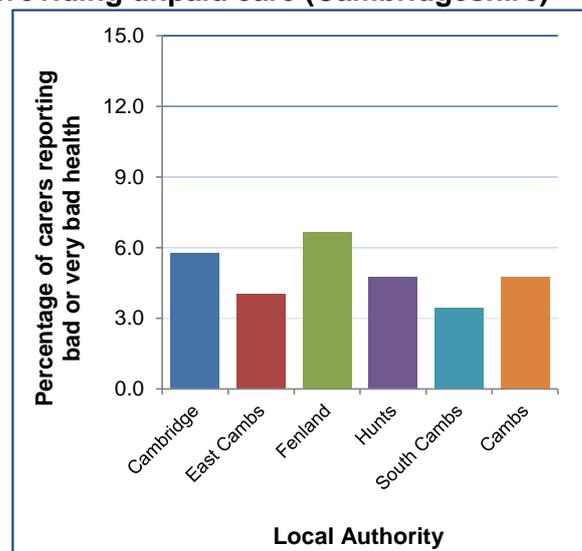
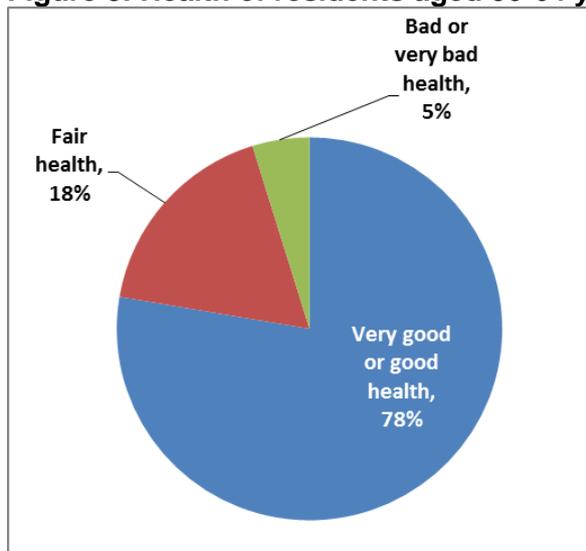
Of the 19,056 residents in households aged 25-49 in Cambridgeshire that provided unpaid care, 3.8% reported having experienced 'bad' or 'very bad' health over the year prior to the Census compared with 2.4% of the overall population (Figure 7). Of the 22,517 carers in households in Cambridgeshire aged 50-64 years, 4.8% reported having experienced 'bad' or 'very bad' health over the year prior to the Census compared with 5.8% of the overall population (Figure 8). Adult carers reported less 'bad' or 'very bad' health than in the total population of Cambridgeshire.

Figure 7: Health of residents aged 25-49 years providing unpaid care (Cambridgeshire)



Source: Census 2011 DC3301EW

Figure 8: Health of residents aged 50-64 years providing unpaid care (Cambridgeshire)



Source: Census 2011 DC3301EW

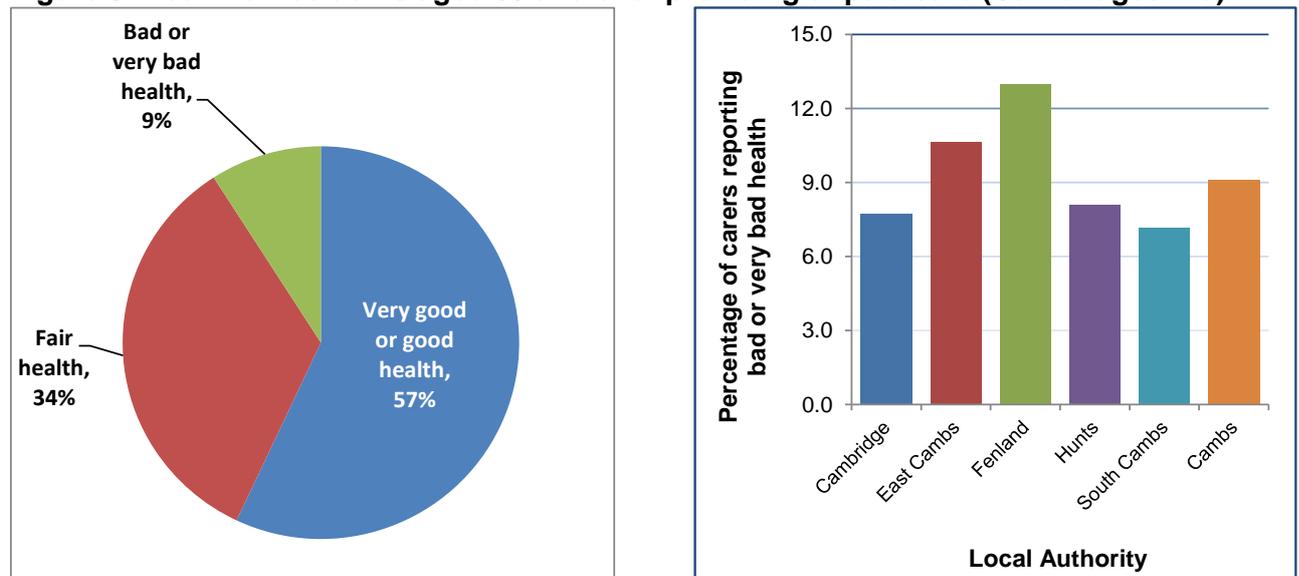
The health of older carers

As

Figure 9 shows, of the 14,189 people aged 65 and over in Cambridgeshire providing unpaid care, 9.1% reported having experienced 'bad' or 'very bad' health over the year prior to the Census. Carers reported less 'bad' or 'very bad' health compared to the total population over 65 of Cambridgeshire (11.3%).

Figure 9 also shows how the proportion of people aged 65 and over providing care who had experienced 'bad' or 'very bad' health in the year preceding the Census varied by district. Levels were highest in Fenland, where 13.0% of older carers described their general health as 'bad' or 'very bad'.

Figure 9: Health of residents aged 65 and over providing unpaid care (Cambridgeshire)



Source: Census 2011 DC3301EW

4.1.3 What does the General Practice Patient Survey (GPPS) tell us?

The General Practice Patient Survey (GPPS) is a national survey conducted by Ipsos MORI. Questionnaires are sent out twice a year to a randomly selected group of patients aged 18 or over who have been continuously registered with a general practice in England for at least six months. The latest survey results were published in December 2013.

All general practice results are available to the public on the GPPS website www.gp-patient.co.uk/surveyresults/. Several general practices in Cambridgeshire have produced their own reports on the survey available on their practice websites.

Carers in the GPPS

This analysis for the JSNA has taken an extract of the Cambridgeshire and Peterborough Clinical Commissioning Group (CCG) results in order to produce a figure on carers for Cambridgeshire GP practices alone. The overall response rate to the survey was 40% for the CCG (ie including Peterborough) and was slightly higher for Cambridgeshire GP practices alone at 42.0%. This compares well with the national response rate (35%) and varies by GP practice within the CCG (range 25% to 54%).

Carers are identified within the GPPS by responses to the question below:

Q56 Do you look after, or give any help or support to family members, friends, neighbours or others because of either:

- long-term physical or mental ill health / disability, or
- problems related to old age?

Don't count anything you do as part of your paid employment

- No
- Yes, 1-9 hours a week
- Yes, 10-19 hours a week
- Yes, 20-34 hours a week
- Yes, 35-49 hours a week
- Yes, 50+ hours a week

For Cambridgeshire GP practices, 9,440 completed surveys were returned and 1,822 people aged 18 and over responded positively to Q56 so 19.9% of people reported they 'looked after or provided support to friends or family for physical/mental ill-health or problems in older age.

This is a higher proportion than responded positively to the question in the 2011 Census. Reasons for this could include:

- The questions asked are the same in the GPPS and the Census, however 'response bias' could have affected this result in that people who return the GPPS survey may differ in some way from the general population who complete the Census.
- For example, people may be more keen to let their GP practice know they are caring or supporting as it may have a more direct impact on them than the more 'faceless' Census survey.

Results¹³ from both the Census and GPPS are shown below, but it must be noted that this is not intended as a direct comparison but to illustrate the impact of the different survey results on an estimate of the number of carers.

Table 15: Number of carers identified by 2011 Census (all ages) and estimate of carers in Cambridgeshire if GPPS estimate is applied to local population figures

Cambridgeshire (County)	Population	% population reporting they provide support/care	Provides unpaid care			
			Total	1-19 hrs/wk	20-49 hrs/wk	50+ hrs/wk
<i>Census (all ages)</i>	621,210	9.7%	60,176	41,313	6,785	12,078
<i>GPPS (18+)</i>	502,933	19.8%	99,694	64,247	15,657	19,790
			100%	69%	11%	20%
			100%	64%	16%	20%

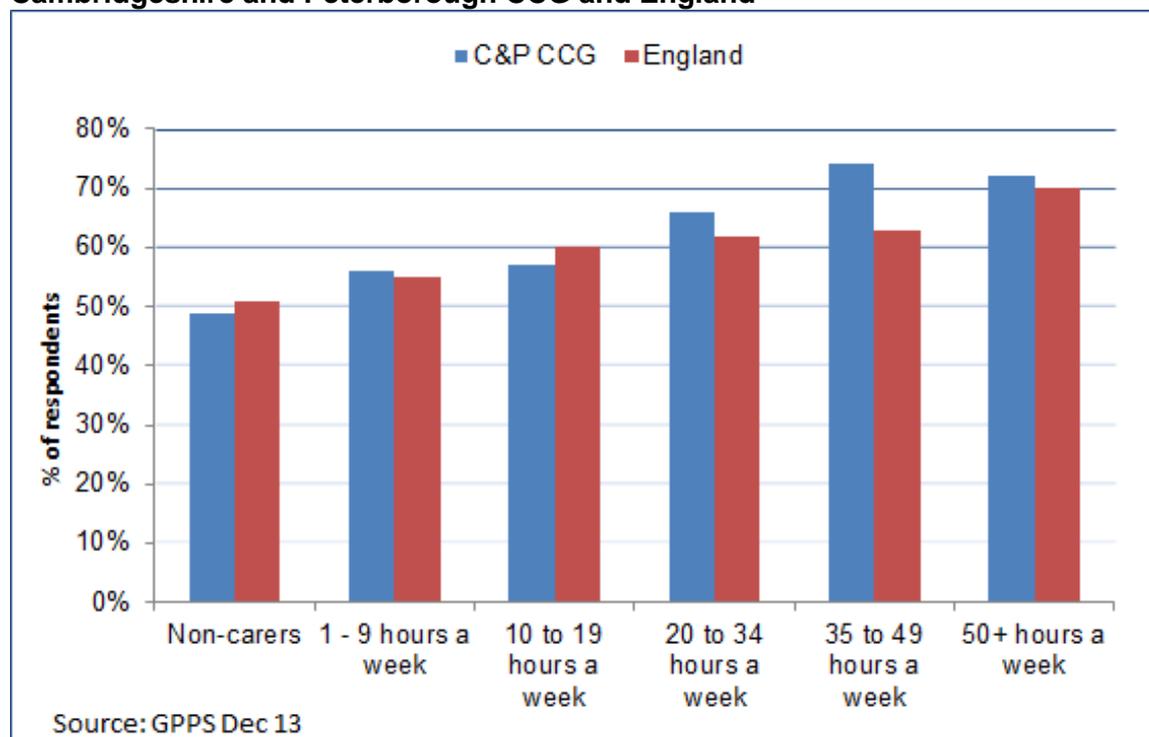
Source: GPPS and Census 2011

Other local analysis of the GPPS in this JSNA uses the 'cross tabulation' tool on the website to identify some key facts from the survey in relation to carers across the CCG area. This tool can only produce this level of results at CCG level.

¹³ Estimated figure from GPPS obtained by applying the survey responses (%) to the registered population at April 2013 (Source: FHS Registration System, Exeter). In order to obtain a figure for Cambridgeshire alone, it was necessary to use the practices data. This is not broken down by age group. A better estimate would be obtained that way but that would be for C&P CCG.

Figure 10 shows that the proportion of carers who report a 'long standing health condition' increases as hours of support increase. In the CCG, 57% of non-carers report that they had a long standing health condition whereas overall, 65% of carers reported a long standing health condition. This increased to 78% of those providing 35-49 hours a week and 74% of those providing 50+ hours a week.

Figure 10: Carers who report a long standing health condition by hours of care provided. Cambridgeshire and Peterborough CCG and England



4.1.3.1 GPPS Health related quality of life for carers

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

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

The EQ-5D survey asks questions on mobility, self-care, usual activities, pain/discomfort and anxiety which together, are used to produce the 'Health Related Quality of Life' score for Carers. This is one of the Improvement areas in the NHS Outcomes Framework Domain 2 *Enhancing quality of life for people with long-term conditions*.

National results are shown below by age and sex (Figure 11) and for those with and without long term conditions (Figure 12). The graphs show that carers health and wellbeing declines as hours of care provided increase. Comparison with the EQ-5D scores for non-carers (ie the cared for in GPPS) show that carers have better quality of life scores than the cared for, across all age groups (data not shown). In the GPPS, the EQ-5D score is only measured for people with long term conditions.

Figure 11: Health Related Quality of Life for Carers by sex and age band (national)

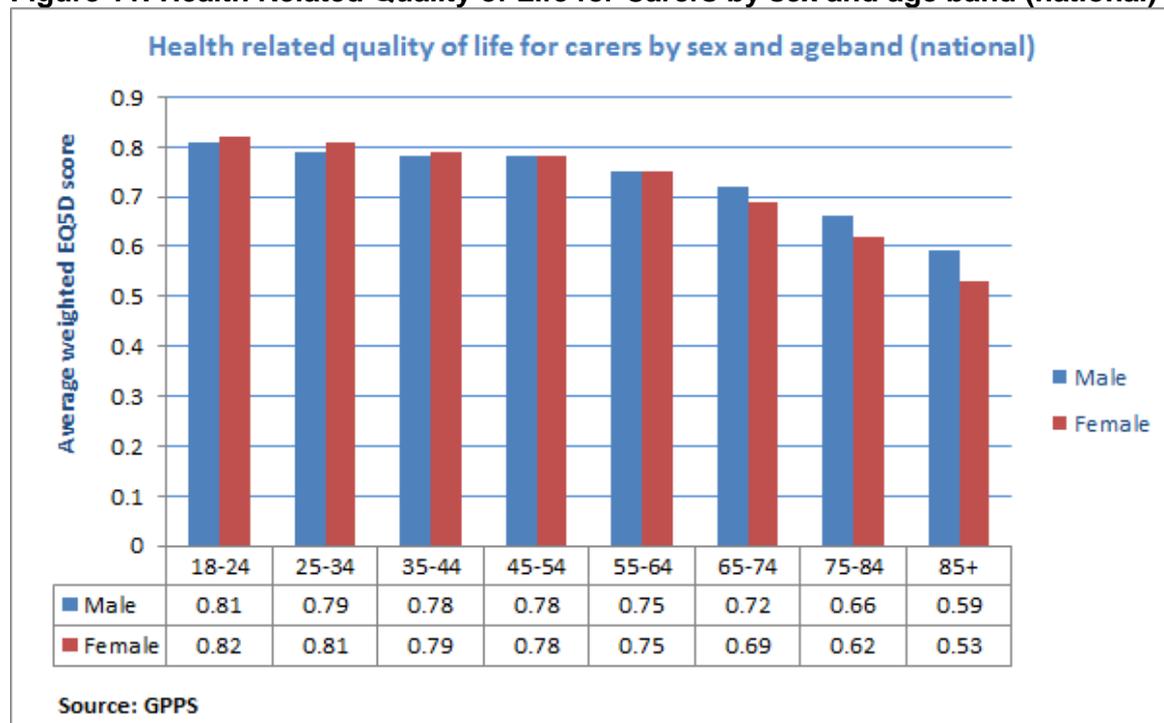
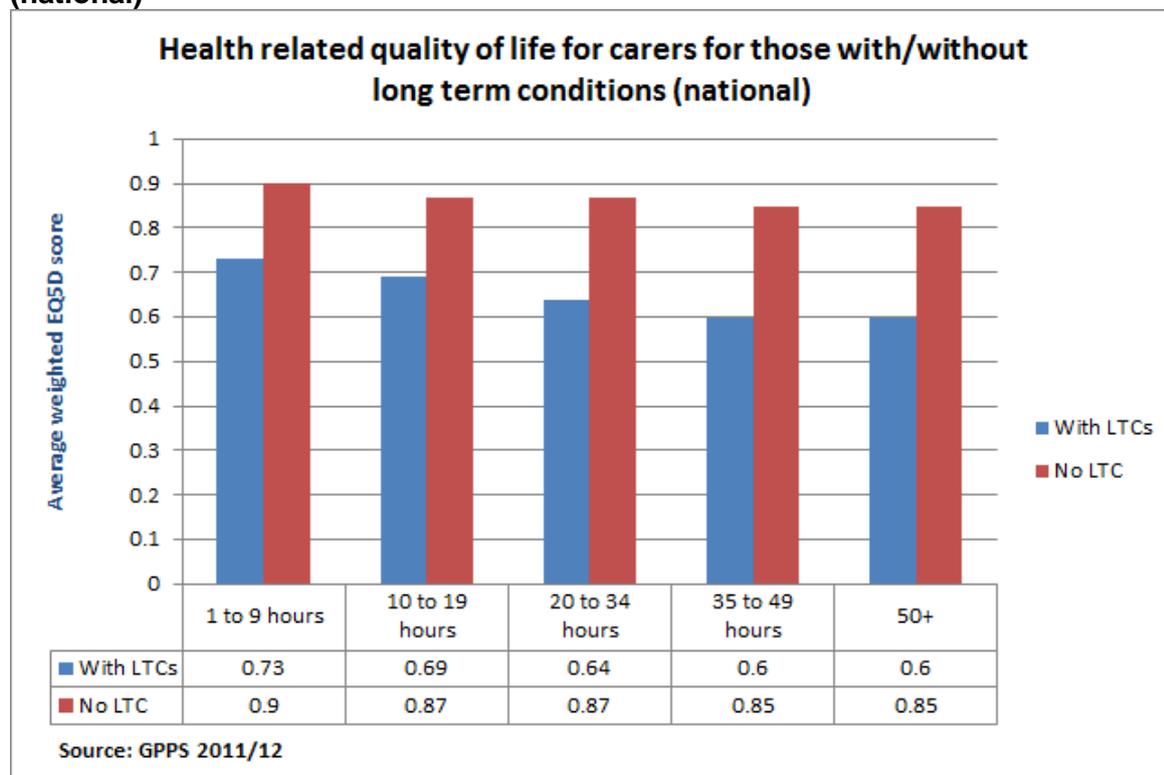


Figure 12: Health Related Quality of Life for Carers with/without long term conditions (national)



4.2 Money and employment

4.2.1 What do national surveys and reports tell us about Money and Employment?

A UK report on the impact of caring on family finances (Carers UK, 2014) found that families taking on caring responsibilities often face lasting financial pressure as a result of loss of earnings and rising household costs relating to the extra costs of ill-health or disability.

Carers UK (2013) found that:

- Four in 10 (44%) of carers surveyed have been in debt as a result of caring.
- Nearly one in four (58%) carers spend at least 10% of their income on energy bills. Up from 54% in 2011/12.
- 36% of carers are struggling to afford utility bills like electricity, gas, water or telephone bills.
- 52% of carers say that financial concerns are affecting their health.
- 41% of those struggling are cutting back on essentials like food and heating.

4.2.1.1 Employment

Many carers struggle to combine work with caring responsibilities and, as a result, may have to leave work, reduce their hours or take lower paid or part-time jobs. A Carers UK/YouGov survey in 2013 found that of 2,073 UK adults surveyed, 4% had given up work to care for an elderly parent, or an ill or disabled loved one at some point¹⁴. Being in employment is beneficial for health and wellbeing and reduces social isolation.

Carers UK (2013) found that:

- Nearly two thirds (65%) of carers in work have used annual leave to care while, nearly half (47%) have done overtime to make up for taking time off to care.
- One in seven (15%) have taken a less qualified job or turned down promotion because of caring responsibilities.
- A further one in six (17%) continue to work the same hours but find their job is negatively affected by stress, tiredness or lateness. Over half (56%) of carers who gave up work to care spent or have spent over five years out of work as a result.
- One in five carers is forced to give up work as a result of their caring responsibilities. This is significant given the importance of 'meaningful activity' (such as employment) to maintaining an individual's positive mental health. Such activity also reduces social isolation.

There are multiple pieces of legislation which are relevant to the rights of carers in employment. Since April 2007 the **Work and Families Act 2006** (The Work and Families (Northern Ireland) Order 2006 in Northern Ireland) has given carers, as well as parents, the right to request flexible working such as changing hours or working from home. The Employment Rights Act 1996, as amended by the **Employment Relations Act 1999**, gives carers rights to help them manage work and their caring responsibilities. People who are looking after someone who is elderly or disabled are now protected against direct discrimination or harassment because of their caring responsibilities under the **Equality Act 2010**.

¹⁴ http://www.carersuk.org/northernireland/news-ni/research-reveals-over-2-million-quit-work-to-care#_ftn1

A recent report on supporting working carers (HM Government, Carers UK and Employers for Carers, 2013) highlights the economic benefits of supporting carers to stay in work. Its recommendations include the importance of effective joint working between Local Authorities and care providers to support the development of services that meet carers' needs using Local Enterprise Partnerships and Health and Wellbeing Board to promote this agenda.

4.2.1.2 Benefits

The only benefit specifically for carers is the Carers Allowance. In the 2014/15 financial year it is worth £61.35 per week. A carer must provide at least 35 hours care per week to a person who receives one of the major disability benefits. Unfortunately the qualifying conditions mean that many carers cannot qualify for the benefit. It is not payable to people who have net earnings of more than £102 per week. Nor is it payable to people in full time education, which affects many younger carers.

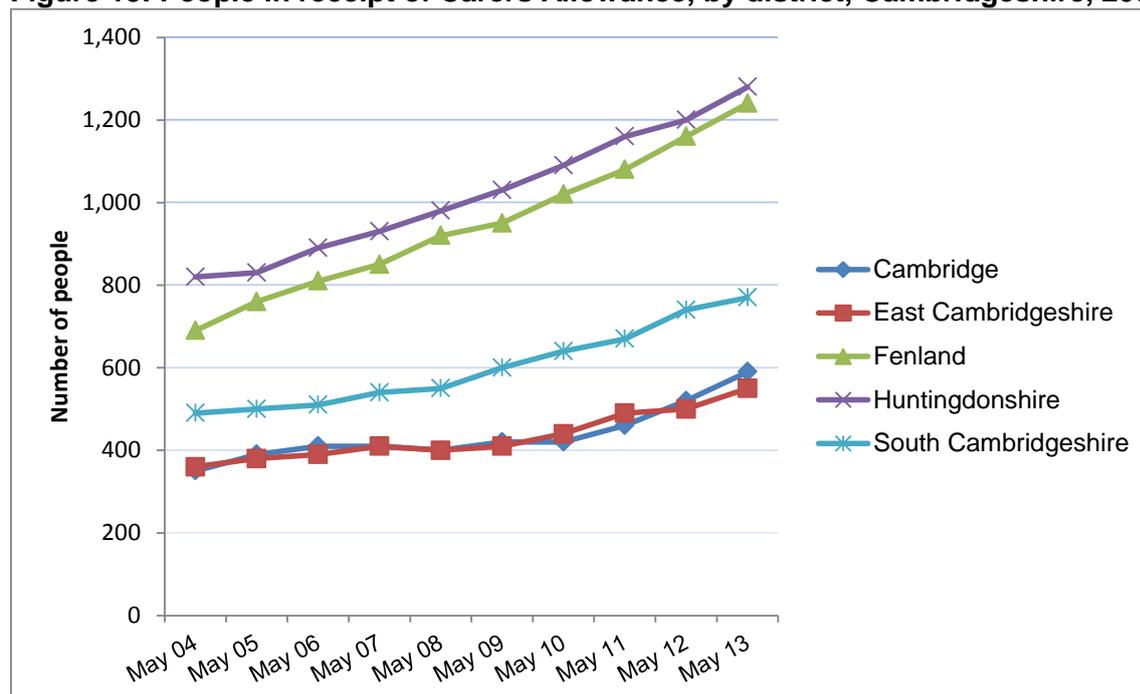
Even where people would otherwise qualify for the Carers Allowance, many fail to receive it because they already receive a benefit that 'overlaps' with it. This affects the State Retirement Pension so many older carers cannot receive the Carers Allowance. However, if they qualify for means tested benefits like Pension Credit it is advisable to claim the Carers Allowance and establish an underlying entitlement to it, as this can increase the means tested benefit. The system is complicated and difficult to explain.

Carers UK estimate that carers in the UK are missing out on over £1 billion in unclaimed Carers Allowance. Some of the recent Welfare Reform changes like the Housing Benefit social housing reduction (bedroom tax) may have affected some carers.

Carers from Gypsy and Traveller communities have different experiences than others. A family will often jointly care for a family member but only one person is recognised as the carer and receive carers allowance. The other family members will still provide significant amounts of care but this goes unrecognised as often the family will live in caravans on the same shared yard and they will also have the same address. They are, in fact, in separate accommodation. This presents a challenge to claiming Personal Care Budgets. The personal care budget also does not recognise their way of life, in that if the family goes away travelling for more than a fortnight their payments are stopped.

Figure 13 shows the number of people in receipt of Carers Allowance by district for the period 2004 to 2013. In May 2013 there were 4,410 people across Cambridgeshire in receipt of Carers Allowance.

Figure 13: People in receipt of Carers Allowance, by district, Cambridgeshire, 2004-2013



Source: NOMIS. Data set is based on all claims (ie 100% processing of records) so is not subject to sampling error.

The largest numbers of people in receipt of carers allowance benefit is in Huntingdonshire and Fenland and those in the age groups 35 to 64 years (Table 16).

Table 16: Number of people in receipt of Carers Allowance by district and age group, May 2013, Cambridgeshire

Local Authority	Age group (years)					Total
	18-24	25-34	35-49	50-64	65+	
Cambridge	20	120	250	170	20	580
East Cambridgeshire	20	80	240	200	20	560
Fenland	60	190	520	440	30	1,240
Huntingdonshire	40	210	600	400	20	1,270
South Cambridgeshire	20	110	350	260	20	760
Cambridgeshire	160	710	1,960	1,470	120	4,410

Source: NOMIS (May 2013)

Table 17 shows the number of people in receipt of Carers Allowance in 2011 as a proportion of those who self-identified as Carers at Census 2011. There are higher percentages of people in the age groups 25 to 49 years in Fenland and Huntingdonshire and in the age group 50-64 years in Fenland. Unfortunately the 'hours of care' in the Census do not allow further comparison with these benefits data since the criteria (16+ and 35+ hours of care) are not the same as in the census.

Table 17: Number of people in receipt of Carers Allowance as a percentage of those identified as carers at Census 2011, by district and age group, May 2011, Cambridgeshire

Local Authority	Age group (years)					Total
	<24	25-34	35-49	50-64	65+	
Cambridge	2%	9%	8%	5%	1%	5%
East Cambridgeshire	2%	13%	11%	5%	1%	6%
Fenland	5%	19%	18%	10%	1%	10%
Huntingdonshire	4%	15%	13%	6%	1%	7%
South Cambridgeshire	2%	9%	9%	4%	1%	4%
Cambridgeshire	3%	13%	12%	6%	1%	6%

Source: NOMIS (May 2011) and Census 2011

4.2.2 What do we know from the 2011 Census about the economic activity of carers in Cambridgeshire?

The percentage of people providing unpaid care varies with economic activity status. Of economically active Cambridgeshire residents, 10.6% provide unpaid care compared with 13.5% of economically inactive residents (

Table 18). The biggest percentage providing unpaid care were the economically inactive – looking after home or family (21.4%) followed by the retired (15.8%). The percentages providing care in Cambridgeshire by economic activity status were very similar to those for England as a whole.

Of Cambridgeshire's carers, 40% are economically inactive, slightly lower than the percentage for England (42%). The percentage of carers in employment (57%) is slightly higher than the England average (53%); 31% of Cambridgeshire's carers are in full-time employment.

The economically inactive provide greater numbers of hours of care per week compared to the economically active (34% report providing 50 hours or more of unpaid care per week compared with 11%) (Figure 14). Of the 1,648 people who describe themselves as 'long-term sick or disabled' and who reported providing unpaid care for others; 39% of these (647) provide 50 or more hours per week of care.

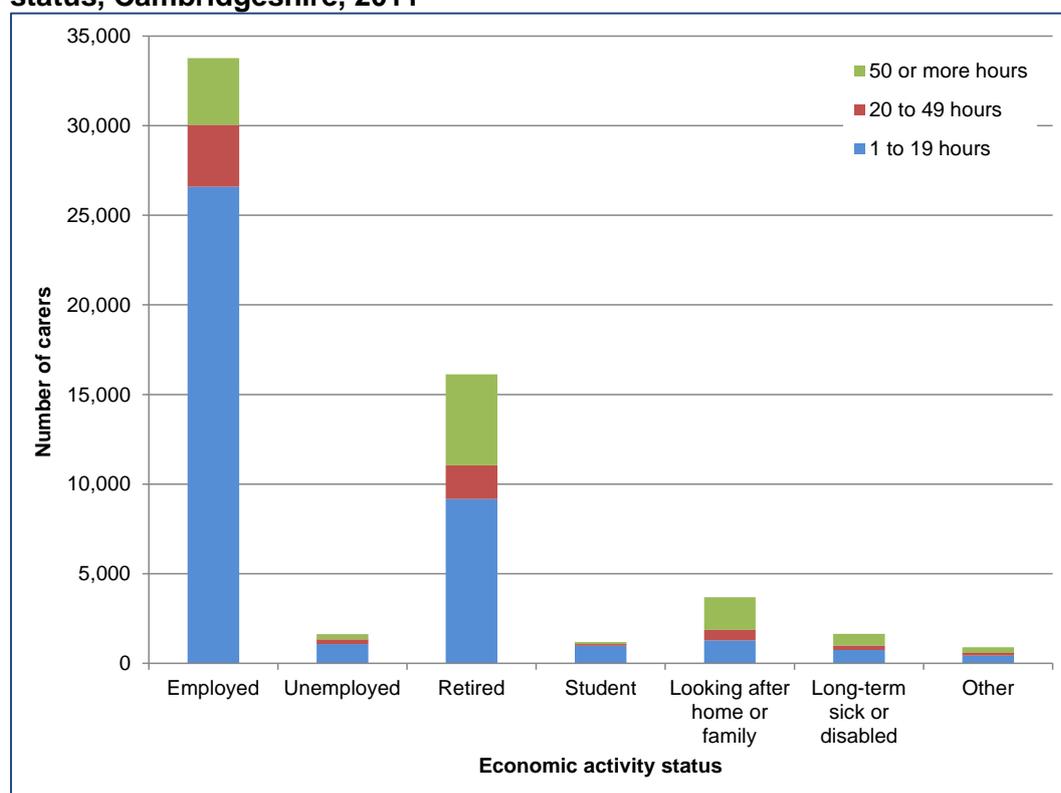
Table 18: Provision of unpaid care by economic activity status, Cambridgeshire and England, 2011

Economic activity status		Cambridgeshire		England	
		Number	%	Number	%
Economically active	In employment	33,772	10.6	2,880,279	11.4
	Unemployed	1,636	10.1	198,682	9.8
	Total	35,408	10.6	3,078,961	11.3
Economically inactive	Retired	16,122	15.8	1,412,271	15.5
	Student	1,187	3.5	104,805	4.6
	Looking after home or family	3,684	21.4	420,057	24.6
	Long-term sick or disabled	1,648	12.9	196,461	12.0
	Other	900	11.0	106,038	11.3
	Total	23,541	13.5	2,239,632	14.3
	Total	58,949	11.6	5,318,593	12.4

Note: Data in the table above are limited to people aged 16 and over

Source: Census 2011

Figure 14: Numbers providing unpaid care by hours of care provided and economic activity status, Cambridgeshire, 2011



Source: Census 2011

4.3 Housing

The cared for person may require adaptations and aids or may need to move into new accommodation. Relocation may be stressful for both the cared-for person and carer.

It is important that appropriate aids and adaptations are available to prevent injury to carers whilst moving and handling. Housing Associations review individual needs, for those living in social housing, including disability, and are involved if adaptations are needed. At present, housing reviews may not be carried out with the carer in mind. Housing associations across

Cambridgeshire are beginning to work more closely together to ensure need is met, including centralised information about what accommodation is available.

Carers from the Gypsy Traveller communities have different experiences from others. Decisions about adaptations may not be culturally sensitive with families being encouraged to move out of their homes and into housing rather than adaptations being made to a caravan site. This has a negative impact on the carer and cared-for person, being moved away from social and family networks.

4.4 Relationships and social isolation

Carers report that caring restricts their social activity resulting in social isolation and smaller social networks. Caring may also result in a deterioration of relationships with other family members (Royal College of General Practitioners, 2013).

4.4.1 Rurality and isolation

Carers living in rural parts of Cambridgeshire often tell the Cambridgeshire County Council Carers Support Team about the difficulties they face as a result of isolation. For those without access to a private vehicle or are no longer able to drive, public transport is often inadequate to enable them to access community resources. The Carer's Support Team regularly offer the Community Transport Guide and Voluntary Driver scheme which helps but does not cover all areas. This difficulty is not limited to those living in the countryside, carers in the city have also reported difficulties using public transport to travel across the city (where voluntary schemes do not operate) both as a result of the availability of transport and because illness and disability can make access more difficult.

This is also a major issue for Young Carers, many of whom are excluded from school and after-school based activities due to lack of transport or income to fund it (see section 5).

4.4.2 Domestic violence

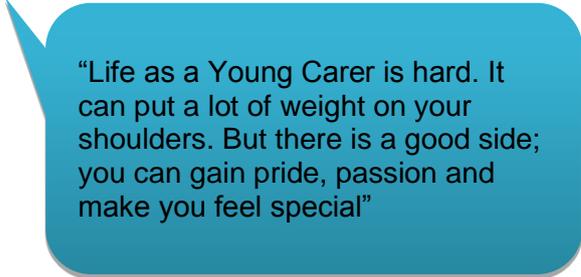
There is very little research about domestic abuse against carers, the most recent research on the subject was carried out by the Queen's University in Belfast in 2010. Their report, 'Older Women's Lifelong Experience of Domestic Violence in Ireland', includes case studies from women who experienced domestic abuse from their husband for a number of years then, in later years, became the main Carer for their abuser. This potential switch of control in the relationship can lead the Carer to experience emotional conflicts such as anger versus feelings of love and sympathy for the abuser. If the abuse continues, this can cause further conflict for the Carer between wanting to protect themselves, and any dependent children, versus knowing the abuser is dependent on them for day to day support.

Findings from a study focusing on older female Carers (Phillips, 2000) supported the need for awareness that ageing caregivers can be placed at risk by verbally and physically abusive behaviours of the elders for whom they provide care.

Both these pieces of research indicate that carers need specialised support if they are in an abusive relationship as the emotional conflict they may experience about being the main, or sometimes only, care giver to their abusive spouse brings with it a raft of additional complexities. In such cases, it is imperative that services work together to support the carer and to ensure safeguarding of the vulnerable perpetrator.

In Cambridgeshire, the issue of adult safeguarding is taken very seriously. In the coming year the Cambridgeshire County Council Carers Support Team are planning to look into the experiences of carers around domestic abuse to ensure that processes and services for carers are delivering the best possible support.

5 Issues affecting the health and wellbeing of young carers and young adult carers



“Life as a Young Carer is hard. It can put a lot of weight on your shoulders. But there is a good side; you can gain pride, passion and make you feel special”

5.1 Key issues affecting the health of young carers

- Young carers often take on practical and/or emotional caring responsibilities that would normally be expected of an adult. The tasks undertaken can vary according to the nature of the illness or disability, the level and frequency of need for care and the structure of the family as a whole.
- The Longitudinal Survey of Young People in England found that young carers are 1.5 times more likely to have a disability, long-term illness or special educational needs, 1.5 times more likely to be from a black, Asian, or minority ethnic community and twice as likely to not speak English as their first language (The Children's Society, 2013)
- Young carers are significantly more likely to grow up in poverty, with all the associated needs and risks that this brings. The average annual income for families with a young carer is £5,000 less than families who do not have a young carer.
- Young carers have significantly lower attendance at school and educational attainment at GCSE level, *the equivalent to nine grades lower overall than their peers* eg the difference between nine B's and nine C's. In Cambridgeshire, young carers are not identified in routine data on educational performance. This means that the educational performance of young carers cannot be measured.
- Young carers may be at higher risk of poor health and risk-taking behaviour as they move into adulthood. Data from the 2012 Cambridgeshire Health Related Behaviour Survey tell us that young carers are more likely than their peers to be worried about or to have experienced bullying, to have seen physical aggression at home and to report receiving free school meals. Survey respondents who reported being a young carer were also less likely to report that they had had eight hours sleep in the night before the survey, more likely to report smoking a cigarette in the last seven days and more likely to describe themselves as unfit.
- Transitions to adulthood: There is currently a pilot underway in Cambridgeshire which addresses the specific needs of young carers as they move to adulthood. Early findings from this pilot suggest that young carers are not getting enough support about careers and education options, are experiencing challenges at school and are struggling with their caring role in particular between the ages of 14 and 18.
- Approximately 30% of the young carers supported by young carers Cambridgeshire projects care for a parent where mental health is one of the contributing cared for needs. This is not usually in isolation but is a symptom of the presenting problem. It is a higher proportion where the parents have a substance dependency. The stigma of having a parent with a mental health problem is usually greater than having the issues around parental substance misuse. The experience of Carers Trust is that young carers are happier to discuss drink/drug related alcohol problems than mental health.

What do young carers need?

For over a decade, there has been considerable consultation of the needs of young carers and their families, nationally and within Cambridgeshire. The messages have been very consistent:

- They want time to have fun and socialise, getting breaks from caring.
- They want more help for the person they care for.
- They need to be less isolated and have people they can turn to.
- They need more money in their families.
- They need help at school with attendance, homework, course work and bullying.
- They need to be helped to get the best from learning and work towards an independent future.
- They need to be meaningfully involved in the planning for their cared for person, and given information and knowledge about the practicalities of caring.
- They need emotional support with worry, anxiety and low self-esteem
- They need help planning for and dealing with family crises.

For further information see:

- Hidden from view: The experiences of young carers in England, Children's Society
http://www.childrenssociety.org.uk/sites/default/files/tcs/hidden_from_view_-_final.pdf

5.2 Key issues affecting the health of young adult carers

Young adult carers are carers over the age of 18 who may be looking at moving out of home, going into higher education or juggling working lives with continuing to be a carer. Their needs may sometimes be different to those of other carers.

- Young adult carers are more likely than the national average to be not in education, employment or training (NEET) between the ages of 16 and 19; one in four carers between the ages of 16 and 25 are NEET. Specific information on NEET for young carers in Cambridgeshire is not currently available because young carer status is not recorded alongside these data.
- Caring roles often increase and result in strained family relationships in this age group. Half of young adult carers are constantly busy with little or no time for themselves, particularly those providing high levels of emotional support, or caring for more than one person. Young adult carers find it harder to make friends and feel different from their peers in that they cannot be spontaneous or carefree.
- Many young adult carers are unaware of what help may be available to support them and their relatives, how to access this and who supplies it.
- Most young adult carers experience financial hardship as a direct consequence of caring and just under a third of youth adult carers had recently or were currently engaged in part-time employment as a means to getting additional money for themselves or their family.

Carers Trust Cambridgeshire provides a support group for young adult carers. In 2012/13 the group was used by 32 people.

There are very few dedicated services provided to young adult carers in Cambridgeshire and adult services may be inappropriate for their needs. For information about a new service for young adult carers, see section 8.3.3. Young adult carers are entitled to the same support as other adult carers. There are concerns that they are not accessing these entitlements, or appropriate support.

The Cambridgeshire Young Carers Strategy Group has identified the following gaps in provision for young adult carers, putting this group at risk of poor outcomes and increased need of more costly support in later years:

- Poor access to Information and Advice.
- Poor access to Carers Assessments.
- Poor access to support to access social and leisure activities.
- Poor access to participation opportunities and chances to be heard.

Further information is available from:

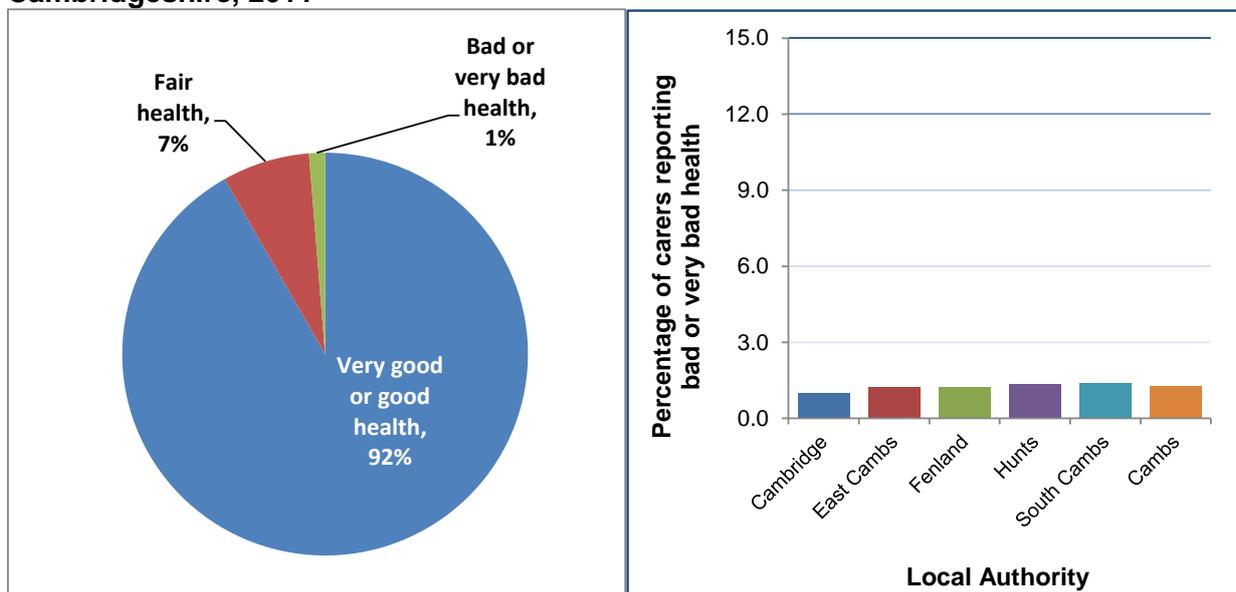
- Sempik, J, Becker, S. Young Adult Carers at School: Experiences and Perceptions of Caring and Education. Carers Trust. 2013. http://www.carers.org/sites/default/files/young_adult_carers_at_school-8_11_13-1_proof_4_final.pdf
- Niace; Working for more and different adult learners: <http://www.niace.org.uk/current-work/young-adult-carers>
- Young Adult Carers in the UK; Experiences, Needs and Services for Carers aged 16-24. Becker and Becker; <http://static.carers.org/files/yac20report-final-241008-3787.pdf>

5.3 What does the census tell us about the health of young carers and young adult carers?

Of the 4,208 young people aged under 25 years in Cambridgeshire providing unpaid care, 1.3% reported having experienced 'bad' or 'very bad' health over the year prior to the Census (

Figure 15), a higher percentage than in non-carers (0.6%). The percentages of carers under 25 years reporting 'bad' or 'very bad' health were similar across the districts but with a slightly lower percentage in Cambridge.

Figure 15: Health status of residents aged 0-24 years providing unpaid care, Cambridgeshire, 2011



Source: Census 2011

6 Issues affecting the health and wellbeing of specific groups of carers

6.1 The needs of carers of people with mental ill-health

Caring for someone with mental health needs presents different challenges for their carer compared with a physical illness or disability. These include^{15,16,17,18,19,20}:

- The fluctuating nature of poor mental health. The need for, and levels of, support may therefore be unpredictable. Dependence on the carer can be really intense and prolonged at times yet minimal at others.
- Poor mental health is not necessarily as evident as a physical health problem or disability, therefore may be less understanding or support forthcoming for the carer as there is with other health conditions.
- Because of the stigma surrounding mental ill-health, carers may be less willing to seek support or share with family members and friends. This may mean they have less of a social network to draw on themselves with a resulting risk of poor mental health in the carer themselves.
- Many people say dealing with the stigma surrounding mental health is worse than coping with the condition itself.
- Carers play a key role in the recovery of people with poor mental health conditions. This is a significant level of responsibility.
- Often mental ill-health is associated with other conditions, so this is not the only condition the carer is required to deal with.
- There are a number of legal and ethical issues surrounding mental health that can make the role of caring even harder.
- Carers need information, advice and support about carrying out their caring role, but also about understanding and coping with mental health conditions. Carers of people with poor mental health are dealing with taking on a caring role as well as learning how to respond to the behaviours and emotions associated with the condition.

As a result of these issues, caring for someone with mental health needs may be even more emotionally draining than any other caring role.

Family and friends bereaved by a suicide, or affected by those at risk of suicide, are at increased risk of mental health and emotional problems and may be at higher risk of suicide themselves. Keeping family and friends informed and providing the relevant advice and support in a timely manner can prevent this. (Qin, Agerbo, & Mortenson, 2002; Beautrais, 2004). Suicide prevention research and recommendations all cite the need to include, support, identify and listen to carers. (Department of Health, 2012)

¹⁵ <http://www.carers.org/help-directory/key-facts-and-asks-mental-health-carers>

¹⁶ <http://www.rethink.org/carers-family-friends/caring-for-yourself-guide>

¹⁷ <http://www.rethink.org/about-us/commissioning-us/carers-support>

¹⁸ <http://www.carers.org/help-directory/mental-health-factsheets>

¹⁹ <http://rcpsych.ac.uk/campaigns/partnersincare.aspx>

²⁰ <http://www.rcpsych.ac.uk/healthadvice/parentsandyouthinfo/parents/carers/parentalmentalillness.aspx>

Relevant policy/guidance/legislation

- The Royal College of Psychiatrists and The Princess Royal Trust for Carers (now Carers Trust) campaigned for carers of all ages. Consequently 'Partners in Care' was launched in January 2004 by Her Royal Highness, the Princess Royal, and aimed to:
 - Highlight the problems faced by carers of people with different mental health problems and learning disabilities.
 - Encourage true partnerships between carers, patients and professionals.

- Triangle of Care report

<http://static.carers.org/files/the-triangle-of-care-carers-included-final-6748.pdf>

The Princess Royal Trust for Carers (now known as Carers Trust) and the National Mental Health Development Unit first published the Triangle of Care guide and launched it in the Houses of Parliament in 2010. Recently Carers Trust has been working with the Royal College of Nursing to adapt the Triangle of Care to meet the needs of carers of people with dementia when that person is admitted to a general hospital.

The Triangle of Care emphasises the need for better involvement of carers and families in the care, planning and treatment of people with mental ill-health with the purpose of supporting recovery and sustaining wellbeing of both service user and carer. It was developed to address the clear evidence from carers that they need to be listened to and consulted more closely. The guide outlines key elements to achieving this as well as examples of good practice. Key elements include:

- The carers involved in patient care are identified as soon as possible.
- Professionals are 'carer aware' and equipped to involve carers effectively.
- Protocols are in place regarding the sharing of information and confidentiality.
- Specific professional roles are identified with carer responsibility.
- Carers are able to meet with staff and are provided with information throughout the care and treatment pathway.
- A range of support services are provided for carers.

Fundamental to the Triangle of Care approach is the importance of understanding what carers need to carry out their role effectively: skills, information, advice, support, regular breaks. Not just focusing on the impact of the caring role, but the causes of the stresses in the first place. If the right information, advice, support and services are not available then a detrimental effect from the caring role will still ensue.

For a good practice example of enhancing working relationships between an NHS Foundation Trust and carers, see

http://www.sompar.nhs.uk/content/26210/93094/Good_Practice_Compndium_Cards.pdf

- CG178 Psychosis and schizophrenia in adults: NICE guideline <http://guidance.nice.org.uk/CG178/NICEGuidance/pdf/English> includes recommendations on the need for mental health services to offer carers of people with psychosis or schizophrenia an assessment of their own needs, provide information about the condition (including negotiation with service users about how their information will be shared), include carers in decision making if the service user agrees and, in addition, advise carers about their statutory right to a formal carer's assessment. The guidance recommends that all carers of people with psychosis and schizophrenia should be offered a carer-focused education and support programme, which may be part of a family intervention, as early as possible.

- There is often a link between mental health and alcohol dependence. NICE clinical guideline 115 recommends that families and carers, involved in supporting a person who misuses alcohol, should have the opportunity to discuss concerns about the impact of alcohol misuse on themselves and other family members.

<http://www.nice.org.uk/guidance/qualitystandards/alcoholdependence/familiescarers.jsp>

6.2 The needs of carers for people at the end of life

It is estimated there are around half a million people in the UK at any one time providing care for someone with a life-limiting illness. While the needs of these carers will in many ways be similar to those of other groups of informal caregivers, there are specific issues that face people caring for someone at the end of their life, such as:

- Possible sudden diagnosis and onset of the caring role.
- Uncertainty as to the length of time until death.
- Likely rapidly changing care needs.
- Information needs on the dying process and associated complex medical and nursing care.
- Psychological and emotional strain of knowing that they will face bereavement.
- Practical and emotional issues at the time around the death, and in the months and years following bereavement.

In common with other groups, people caring for those at the end of life may not identify themselves as 'carers' and so may be unaware of, or reluctant to access, available support.

The National Palliative Care Policy is based around a strong preference for death at home. In order to achieve this supporting the needs of family carers is paramount.

Literature review

From the literature, carers in the end of life context describe three priority areas of need:

1. Practical help as a co-worker eg with turning bed-bound patients, or with symptom relief.
2. Information as to what is likely to happen as the illness progresses and the likely consequences.
3. Allocated professional time for attending the patient to allow the carer to have respite from their role.

More personal support, such as addressing spiritual, psychological and emotional needs is reported to be less valued. Qualitative data suggest that carers often find it difficult to focus on their personal needs, as they perceive that such focus will take professional time and resources away from the person cared for.

The Department of Health End of Life Care Strategy (Department of Health, 2008) highlighted the importance of considering carers' opinions and needs, and commissioned national surveys (Office for National Statistics; VOICES (views of informal carers for the evaluation of services) survey, completed in 2011 and 2012 to investigate carer perceptions of the quality of end of life care. Data from these surveys place Cambridgeshire and Peterborough in the top 20% of CCGs for providing support for carers while patient was at home and for carers being able to discuss worries with the GP. The survey however highlighted significant inequalities in the standard of care and support provided, both by geography/socio-economic status and by cause of death of the loved one.

Analysis of data from a recent local pilot survey based on the VOICES model is currently underway, but early qualitative findings indicate a mixed picture across the local health system that broadly reflects the national findings.

The impact on carers' health and wellbeing

Caring for a loved one, who is dying, carries with it the same risks to the carer's health and wellbeing as in other care situations, but with the additional strain of coping with an impending death. This is likely to have an impact on the physical health and wellbeing of the carer; Whittingham, Barnes, & Gardiner (2013) report that elderly carers for heart failure patients who have pre-existing health problems of their own, are more likely to experience deteriorating health. In addition, there is a suggestion that the greater the strain and burden reported, the more likely the carer's physical and mental health will have deteriorated. It should not be forgotten that there are positive aspects to a caring role; caring for a loved one when they are most vulnerable can be a valuable experience, potentially boosting self-esteem, confidence and assertiveness and reinforcing relationship bonds.

There is little evidence that discrete 'carer support' services within palliative care are necessary; instead, repeated checking of carer needs by those providing 'usual care' in an end of life context is thought to be helpful. The evidence base for specific interventions to improve the health and wellbeing of carers is weak.

Bereavement

Inevitably, carers of people who are dying will have to face bereavement and a change in their role. Bereavement has long been recognised as a risk factor for poor psychological and physical health. Stroebe, Schut, & Stroebe (2007) concluded that there is an early increased risk of death from a variety of causes, including suicide and 'dying from a broken heart' – meaning the psychological distress, loneliness and secondary consequences of loss such as changes in eating habits, economic status and social support. A few authors have found this risk to persist after six months.

The recently bereaved are also more likely to have physical health problems; widowed people in general consult with their GP more frequently than the non-widowed, but also may be less likely to consult when they need to. This indicates that there is likely to be significant met and unmet need in terms of the physical and mental health of the recently bereaved, particularly those bereaved of spouses.

Interventions

The evidence suggests that it is neither necessary nor desirable for all bereaved people to undergo 'bereavement counselling'. Around 85% of bereaved people will manage their own path through grief using existing social support. 5% will need specialist help to manage their extreme grief reactions, and the remaining 10% need something in between, such as a befriending or counselling service. However there are no reliable tools for identifying which group an individual falls into and so a network of universally available first-line services is necessary to allow people to access care if they feel they need it.

At present such a network does not exist in Cambridgeshire. There is a need for:

- Wider publicity and awareness of local services able to provide bereavement support.
- A network of such services to improve co-operative working, pool risk and raise the profile of the carer support and bereavement agenda.
- Education for GPs and other primary care professionals in identifying and supporting people in 'normal' grief and understanding when and how to refer to a support service.
- A commitment from practices to keep track of those left behind when someone dies, and to acknowledge their loss and offer support if it is wanted.

6.3 The needs of carers of people with dementia

One in three will care for a person with dementia in their lifetime (Carers Trust, 2013).

“A Road Less Rocky: Supporting People with Dementia” (Carers Trust, 2013) identified a number of critical points along the caring journey where information and support is most valued and needed by carers and what professionals can do to help at these times. It should be noted that these may be quite different to the critical points experienced by the person with dementia in their journey.

The critical points for the carer are:

- When dementia is diagnosed.
- When the carer takes on an active caring role.
- When the capacity of the person with dementia declines.
- When the carer needs emotional support and/or a break from caring.
- When the person with dementia loses their mobility.
- When the person with dementia has other health problems.
- When the carer has to cope with behaviour problems.
- When the carer's own circumstances change.
- When the person with dementia becomes incontinent.
- When decisions about residential care and end of life have to be made.

What is key at these points is that the carer knows where to go to for advice, knows what support is available, that the professionals they are in contact with are knowledgeable regarding dementia and that they engage with both the carer and the person with dementia and they understand the carers needs and issues not just those of the person with dementia.

This research is being cited by Public Health England as a means of mapping the needs of carers of people with dementia

6.4 The needs of parent carers

Parent carers look after one or more children with a learning difficulty, a disability and/or an additional need. The role of parent carers blurs between being a parent and being a carer, as parents naturally ‘care’ for their children. However, parent carers are those that have children that need additional support ‘to live ordinary lives’ as a matter of course. Similar to other carers, parent carers are not always identified as they are parents first. This is especially true for parents of children that have additional needs who are not eligible for social care, short breaks or a statement of educational need. These are the carers that get the least support and often feel very alone. We do not know how many there are as they are usually unknown to services. However these parents can get support from the voluntary sector, especially parent support groups. ‘Disabled children and their families have the same human rights as others, including the right to the same quality of life as those who do not live with disability.’²¹

A lack of support will result in parent carers having mental health issues, physical health issues, and relationship difficulties. A parent summarises “If we are not well we cannot look after the kids”.²²

A parent carer participation network in Cambridgeshire, involved 59 parent carers to identify what constitutes good emotional support. In summary the groups identified:

- Support around diagnosis.
- Before, during (assessment) and after.

²¹ Cambridgeshire County Council Short Break Duty Statement 2013

²² Pinpoint Parent Network Meetings March 2013 – **Emotional Support for Parents**

- When there is no diagnosis.
- Support after child turns five, in school.
- Continuous and out of hours support.
- Through peaks and troughs.
- Weekends and evenings.
- Not just during term time.
- Consistency across organisations, practices and professionals – not ‘luck of the draw’.
- Communication: open and transparent, value what parents have to say.
- Specialist and group support:
 - Parent to parent.
 - For family (siblings, dads etc) and relationships.
 - For specific conditions.
- Support for parent’s wellbeing
 - A safe place to show feelings.
 - ‘Having to battle creates emotional needs and problems for parents; parents drained by fighting the system’.
 - ‘Positive feedback from professionals helps to improve parental mood and wellbeing’.
 - Someone to support with meetings, reading statements, and to speak up for you.

Further feedback has been gathered from parents at pinpoint parent network meetings, events, etc between October 2011 and December 2012. Parent carers said that they need:

- Advice on what services are available (including information on financial help) and signposting to other services.
- Timely access to accessible, welcoming and local services including through schools, GP and school nurse.
- Needs-led services.
- Child-friendly services which are coordinated across health and education.
- Continuity of staff.
- Good communication; staff listen to parents who know their child best.
- Honest and sensitive support for parents and family at diagnosis and also when no diagnosis found. On-going support as the child gets older.
- Support from other parents.
- Family therapy and support for siblings.
- Respite.
- Support with managing behaviour eg Early Birds.

6.5 The needs of carers of people with a learning disability

The 2013 Cambridgeshire Physical and Learning Disability through the Life Course JSNA²³ identified that:

“Growing numbers of people (with a learning disability) experience a mid-life transition when their parents or family carer’s who they have lived with since childhood become too ill to care for them or they die.

It is important that carers of adults with a learning disability are supported both emotionally and practically to plan early for this transition.”

In addition to this, it is important the person with the learning disability's rights to care for their loved one is recognised. Services for the older person and the person with the learning disability providing the care need to be joined up to ensure the needs of both are met.

The recent Winterbourne Concordat placed a duty on Clinical Commissioning Groups to review hospital placements with a view to moving people back into the county in more local, community-based services. In Cambridgeshire, the local authority, as lead commissioner, is required under the concordat to review the care of all people currently in hospital placements who have a learning disability and who may be on the autistic spectrum and demonstrate behaviour that challenges. A care plan should be agreed for each individual, based on their needs and agreed outcomes, enabling community-based care arrangements to be put in place, as appropriate. This work will involve family carer's whose requirements, in terms of the choice of location and the type of care arrangements, will be taken into account. In the year to June 2014, Cambridgeshire has settled the majority of people, who were previously in hospital, back into the community and has plans to do the same for all of the remaining people unless there is a clinical reason for them to remain in hospital.

6.6 Other specific groups

This chapter is not exhaustive, only having picked out a few specific groups of carers. Other groups not covered in any detail in this JSNA may have needs which are different from others because of their caring situation, for example so-called ‘Sandwich’ Carers’ who care for people of different generations, for example, caring for a disabled child (of whatever age) and also an elderly parent.

²³ Available at www.Cambridgeshireinsight.org.uk/jsna

7 Local views

7.1 Cambridgeshire carers JSNA survey

An online survey was carried out as part of the JSNA. Carers could also complete the survey by telephone. The survey questions were focused around areas relating to health and wellbeing. Questions used in other local and national surveys, which had therefore been validated for use in this type of survey, were used. The survey was piloted first with a small number of carers.

85 carers responded to the survey. The characteristics of those responding to the survey included that most were aged between 35-54 years and most were female. The majority of respondents provide more than 100 hours per week and the most common group that respondents are caring for was someone with a learning disability. Most respondents reported caring for a child. Given that this does not reflect the demographics of carers across Cambridgeshire and represents only small numbers, caution is needed in generalising the results to Cambridgeshire as a whole.

Key findings included:

- Respondents highlighted having prioritised the health of the person they care for and their family above their own.
- 35% given up work to care and 26% took a less qualified job or turned down promotions to fit around their caring responsibilities.
- Whilst many respondents worried about finances and being able to cover all costs associated with caring either sometimes or all the time, only a very small % had had a review of finances or knew where to get one.
- 27% had had a carers' assessment and 64% reported that their GP is aware of their caring responsibilities. (71% of those caring for 100 hours or more).
- 32 carers who had registered with their GP as a carer responded that "(my GP) knows I'm a carer but doesn't do anything different as a result".
- 37% had made no preparations if unable to care.
- Most carers who had tried to access care and support out of hours reported finding it very difficult to do so.

The full analysis of the survey is attached at Appendix 2.

The final question in the JSNA survey asked carers to identify things which would make life easier in their caring role. The key themes are identified below:

Financial Support

Further financial support which may enable carers to give up work, work less hours, to attend support groups and to prevent worry about money and bills all the time. Comments were made about the benefits system and not receiving correct payments or not receiving the full amount that the carer feels he/she is entitled to.

- "A proper respectful carers income"
- "Guarantee that DLA /Carers' Allowance benefits wouldn't be stopped"
- "Being able to claim carers allowance even though I earn more than £100 per week. I have my own bills and need to balance an income with caring. It's hard and causes most stress/guilt"
- "Money is tight, but I feel that I would be at risk of benefits fraud if I claim carer's allowance because I work 4 days and care 3 days"

- “After filling out a multi-pull choice form to work out our needs we scored about 65 percent and we only get half of the money that could be allocated to us.”

Respite

Respite seems to be important to many of the carers and they would like it to be more accessible, flexible and be available for all including the hard to place. It was felt that the carer would like to have time to themselves and also time with other family members but that well trained support workers are needed to step into the carer’s role. It was felt that free family short breaks should be offered or someone to provide cover to allow carers’ to have a holiday and that childcare should be provided for children who needed special care.

- “Qualifying for respite. Parents of violent autistic teenagers need breaks even if the children are hard to place!!”
- “More accessible, flexible respite.”
- “Consistent well trained dependable support workers who can genuinely step into our caring role and allow us a genuine break.”
- “It would be reassuring to have a week in the summer holiday where she could access a holiday club all week during the day-this was taken away and if i want to put her into a mainstream holiday club she has to have support so i have to use the 8hrs for that week which gives me one day.”
- “Special childcare provision during school holidays - not access normal kids clubs”

Support Group/Counselling

It was felt that more support groups/phone counselling/helplines are required. Agencies should work collaboratively. There should be a main keyworker for each person who is being cared for.

- “The NHS, social services and charities working together more to support Carers”
- “A keyworker for my son”
- “More local support groups re: future for my daughter”
- “One key worker that I can contact if I need support, information, advice.”

Groups for children

More social activities such as days out are required for the cared for child.

- “More social activities for my daughter to attend with better transport links”
- “Social activities for my child - especially social opportunities with other ASD children”
- “Perhaps money off vouchers for local days out - zoo's, tea rooms, travel for carers”
- “Activities for PMLD children.”
- “Suitable leisure activities for my child with autism”

Support (Emotion)

The type of support required was varied and examples are emotional, companionship, meeting other people in the same situation, helping with looking after children and knowing who to speak to find out information and more information to be sent by post or email.

- “someone to help with basic day to day things like cleaning so i can concentrate on my 2 children (both have SEN)”
- “Companionship, opportunity for social interaction”
- “More support from the medical profession to assist my father to stay at home with his complex conditions, rather than keep being admitted to hospital”

- “More opportunities to meet other carers, learn about initiatives and systems affecting caring, and to practise staying well.”
- “Support for children/parents who slip through the system as they are not disabled enough for special school, but also aren't actually mainstream. There's nothing for us. We're isolated”
- “The carers newsletter is good from CCC. More information by post or email.”

Practical help/support

- “more practical support”
- “Having a downstairs bathroom”
- “carers transport to appointments with patient”
- Being highly dependent on equipment (wheelchair, hoist, hi-lo bath, hospital bed, slings, toilet/shower chair etc.) to assist on my caring role, any delay obtaining repairs, spare parts, replacement, assessments can be highly and usually unnecessarily stressful.

All information in one place

Having one place to go to or one person to contact who can list all services and support and how to access it.

- “all relevant and up to date information readily accessible”
- “One place/person to go to for advice, information, guidance before patient leaves hospital to return home, and afterwards.”
- “having a named social worker, with a direct line”

The future

Carer's have a fear of the future and what the future holds for the person they care for. They would like to put a plan in place in case anything happens to them which would mean that they are unable to care. Planning for transition was raised. There was also some concern regarding work opportunities.

- “Being clearer about what might happen in the future - both for daughter and for us as carers. What will happen when we aren't here and what about the plans we had for our future?”
- “High quality work opportunities for my daughter. If she is gainfully employed then I am happy. I would like her to have work experience opportunities with a person to shadow her.”
- “Knowing that when my child turns 19, it will be an easy process to get them into independent living.”
- “Peace of mind from having more formal emergency back up in place.”
- “More security for the future, my child is only 6 now but the thought of the future terrifies me”

Education/school

Carers would like better help/support with the education of a child with disabilities and better understanding of their condition and their specific needs. Transport to and from special schools is needed.

- “Regular volunteers similar to Homestart for the under 5s “
- “School providing equipment for YP to use at school as identified in assessment”

- “Being able to trust school etc to support daughter to develop rather than just 'looking after' and feeling that daughter is developing in independence jeans own self for the future”
- “Cambridgeshire council has only made my life more difficult by refusing my son school transport--forcing my to take even more time off work.”

For the carer

Carer’s would like more flexible employer, a need to improve their own health and a GP who conducts an annual check-up and is aware of how caring impacts on their health.

- “Getting my health better.”
- “More sympathetic employer. Have been refused time off to care.”
- “GP surgery to be more aware of how my caring role impacts on my health”

Availability/Flexibility of services

Comments included: funding for new services, more flexible or timely services and ensuring carers needs are considered by services for the cared-for person.

- “More appropriate support from Social Services to enable my parents to be more independent”
- “Not having to fight to access every service, not being told that there is no help out there and whilst it is appreciated by the various professionals that we have been at breaking point, due to budget cuts there is nothing they can offer us.”
- “To be included not excluded In decision making by services about my young adult son rather than being treated as though I don't understand the pressure on the service to respond”
- “More hospice sessions with more flexible hours”.
- “More flexibility with appointments at a time to suit me”
- “Shorter lead times for services needed ie physio/occupational therapy”

Integrated care

Carers felt the need for all services to work together, to communicate together and to listen to each other to ensure that they all understood the views and concern of the patient. Carer and patient should be involved in meetings and professionals to be open and honest.

- “More coherent view of care/treatment as mother under so many different doctors who don't speak to each other “
- “Regular follow-up home visits from linked professionals such as physios, GPs, stroke clinic with notes copied to main family carer. Involve that person in meetings whenever possible.”
- Not having to be an expert in every service - there needs to be training in how to think outside the box so I can think less.

Other

- Stop making everything contingent on DLA. That process infringes on my son's human rights to receive care.
- Training associated with caring that could add to a qualification.

7.2 Young carers – focus group report

When the Cambridgeshire Carers JSNA survey questions (see section 7.1) were tested with young carers, they were found not to be relevant or well-tailored to this group of carers. Focus groups were therefore held across Cambridgeshire with young carers aged 8-18. The focus groups were carried out as part of regular young carers groups activity and asked: How does caring affect:

- School and learning?
- Friendships?
- Hobbies and free time?

Key findings:

School and learning:

Young carers in the 8-11 year old group said that they worry about being made fun of at school and also that they worry about the person they care for whilst at school.

- “At school everyone makes fun of me because my dad is very ill.”
- “I worry while I am at school because of my parents could of got hurt or something.”

For carers aged 11-15, there were various impacts of caring, including worry about the person they care for whilst at school, tiredness, arriving late and trouble with concentrating. Having enough time for homework and being bullied were other issues.

For 15-18 year olds, the impact of caring on learning focused around the pressure of exams and the stress felt as a result of not having time to revise.

- “Constant worry, not being able to concentrate on learning - no time to revise.”
- “Less time to revise for exams - late night revision.”

Friendships:

8-11 year olds talked about sometimes not being able to see friends out of school:

- “Don't let people go to sleepovers but do come round sometimes.”
- “Well it effects me cos some people think my mum has died.”
- “I can not invite people cos of Dad.”

The 11-15 year olds talked about a lack of understanding from their peers and feeling different.

- “Friends are harder to make and keep.”
- “Can't keep up with latest trend.”
- “Friends don't understand my role as a carer.”

Some of the 15-18 year olds said their friends are ‘fine’ with them being a young carer, others saying that their friends do not understand their situation.

Hobbies and free time:

Some of the 8-11 year olds reported an impact of caring on their free time:

- “I can't go out as much as my friends because mum's ill and she can't watch us.”
- “I do a lot of things.”
- “I have to look after my family”

11-15 year olds said that they don't have much free time and comments about hobbies included not being able to see things through, not fitting in or it not being fun (because of worry about home).

- "Can't hang out with mates and go down town "

Similarly, 15-18 year olds reported not having enough free time to relax and being worried about home.

Young carers valued going to young carer groups and making friendships there.

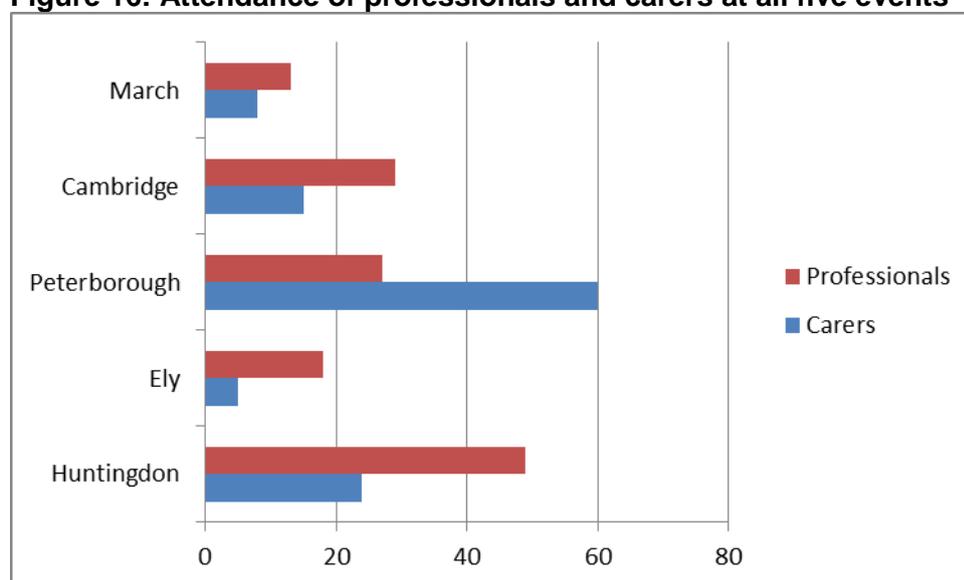
7.3 Carers Connect

Carers Connect is a new lottery funded support network which has been set up by Carers Trust Cambridgeshire for carers in Cambridgeshire and Peterborough. Carers Connect aims to provide help and information as well as giving carers a voice to help shape the services they need, directly and through linking with other organisations. Carers Connect will run groups as a joint carer and cared for forum at which the cared for would be looked after, giving the carer the opportunity to socialise separately with other carers. The network will also identify volunteer carer ambassadors.

Carers Connect has so far held five events throughout the county. These events were held in Huntingdon, Cambridge, March, Ely and Peterborough. Professional speakers were facilitated from a variety of statutory and voluntary sector organisations and discussion groups consisting of carers and professionals. The carer and professional sessions were used to gather information on what carers would like to achieve within Carers Connect.

112 carers, 22 organisations and 10 speakers took part in five Carers Connect events held across Cambridgeshire in 2013. Figure 16 shows the number of carers and professionals attending each event.

Figure 16: Attendance of professionals and carers at all five events



Source: Family carer network

At the forums, carers were asked the question: What helps carers to stay healthy and well? And 'How can we support carers to stay healthy and well?' In response, carers cited that the current system was not holistic. They found that the pathway into support and services was not clear. Carers also stated that they valued impartial information and that the lack of continuity added to their stress levels. Carers said that they wanted to be able to meet their own health needs through

exercise, socialising and working. Carers also placed a high value on Health and Wellbeing days, Carer groups and respite care as well as wanting more support from GP's.

Reducing carers stress can be done by:

- Listening to carers
- Respecting their needs
- Allowing access to basic services.
- Offering one point of contact and a co-ordinated service.

GP surgeries can also play a key role by keeping an eye on the carer, carrying out regular health checks and follow up checks. Finally, carers asked for more involvement in training for health professionals to make them more aware of carer issues.

The forums also explored what Carers Connect could and should look like. The feedback from the events particularly highlighted the following points:

- How do you get opinions through to someone who can make a difference?
- Carers have no voice at all!
- No one listens and takes your issues forward
- No voice for your cared for due to services not listening
- No feedback – No questions answered from those who seek carer opinions
- An integrated assessment procedure that addresses all of the needs of the carer and the cared for to avoid repeated duplication
- Lack of replacement care and transport to enable carers to participate in the Carers Connect
- The current assessment process is not carer or cared for friendly – needs replacing with an MDT equivalent that reflects the needs of all involved

Young carers and young adult carers need to be at the heart of Carers Connect. At the forums, young carers and young adult carers spoke about the following themes that are important for us to recognise:

- Young carers and young adult carers need to be able to speak about their own personal caring situation if they wish and know that they will not be discriminated by teachers and their peers.
- Once identified, we don't want to be treated differently, just give us help if and when we need it.
- Teachers and employers need to understand that young people have real caring commitments and need to enjoy the flexibility given to adult carers.
- 26% of young carers become persistent truants when looking after family.
- We are the experts in our own lives!
- Acknowledge the positive and not so positive of caring.

8 What services are available for carers in Cambridgeshire? Services and assets.

8.1 Cambridgeshire County Council

The adult social care team at Cambridgeshire County Council both commission and provide services for carers in Cambridgeshire. This section describes both functions of that team. Further information on commissioned services is given in Section 8.2.

8.1.1 Service description

8.1.1.1 Carer Assessments

Currently, anyone providing 'regular and substantial care' to support someone else who meets or is likely to meet critical or substantial needs under the Fair Access to Care Services eligibility criteria has the right to receive a carers assessment. This assessment may offer services in their own right to promote the carers ability to continue to care.

As a result of the new Care Act 2014²⁴ from April 2015 the threshold to trigger a carer's assessment will be reduced to encompass a greater range of informal carers in order for earlier identification and to enable appropriate information, advice, and linking to appropriate support to be available before the health, employment, and social opportunities of the informal carer deteriorate.

Carers Assessments help to identify individual need and determine the support that will be beneficial to the carer in their caring role. Ideally the assessment gives the individual time to reflect on themselves, their life, their health and wellbeing, work education and leisure needs, other relationships and responsibilities, what is important to them and what might assist them to continue caring.

Following an assessment, carers may:

- Receive a one-off direct payment.
- Receive support from social care services at Cambridgeshire County Council.
- Be signposted to another organization who provide the support needed.
- Have an Individual Carers Emergency Respite (ICER) plan developed.

8.1.1.2 Carers one-off direct payment

This scheme enables carers to apply for a one off payment to assist them in their caring role. For example, they can purchase specified services or resources where it was identified in the Carers Assessment that this would enable/support them to continue in their caring role. For example, to purchase a tumble dryer to assist with additional laundry loads if the cared for was incontinent, or money for a massage if that would enable the carer to feel less stressed/have some much needed 'me time'.

8.1.1.3 Respite and Day Care for the cared-for person

Whilst these services are aimed at the cared for person, they have benefits for the carer in providing a break from care. The various adult social care Service Teams – Older Peoples, Learning Disability Partnership (LDP), Physical Disability and Mental Health etc arrange for services such as Day Opportunities (Day Care) and Respite for the cared for which give a break to

²⁴ <https://www.gov.uk/government/publications/the-care-bill-factsheets>

the carer. These services are delivered through either a provision arranged by the field team or through a direct payment whereby the individual and their family make the arrangements themselves. With the exception of LDP, the majority of Respite and Day care is delivered through either private companies on a spot purchase basis or through contracts with local voluntary organisations such as Age UK, St Raphael Club, Headway, Alzheimer's Society, Carers Trust etc.

Through the use of direct payments, individuals can access other services and activities provided that it is in the cared for persons support plan and meets their identified eligible needs. These services can also assist the Carer; for example, an older person with physical disabilities who has had a lifelong interest in fishing or bird watching using their direct payment flexibly to enable them to access support to continue these activities that interest them, but which also provides some break for the carer.

8.1.1.4 Adult Placement Scheme

Cambridgeshire Learning Disability Partnership run the Adult Placement Scheme which matches volunteers with individuals with a learning disability to enhance their life and to also provide a break for carers. For example, matching someone with Down's syndrome, who loves football but has no family member interested in sport, with a (paid) member of the community who regularly attends the local football matches.

8.1.1.5 Equipment

Equipment, assistive technology and even some adaptations can be provided to support the cared for and to assist the carer where the appropriate qualifying conditions are met. Some of this support is provided directly by CCC teams for example Sensory Services can provide vibrating pagers to enable people with hearing loss to be alerted to smoke alarm, telephone etc which can relieve some of the concerns of a carer.

Other equipment is provided by jointly funded services and partnership working. For example, the Assistive Technology Service supplies a range of equipment which can assist both the carer and the cared for. One example would be pressure sensors that alert the carer if someone with dementia leaves their bed or room in the night.

8.1.1.6 Carers Breaks

Carers breaks are commissioned by Cambridgeshire County Council and provided by Carers Trust Cambridgeshire. This service provides community care support to the person who is being cared for so that the carer can have time off.

The scheme is intended to support those Carers who are currently not receiving ongoing support from Adult Social care through the provision of services to the person who needs care.

8.1.1.7 ICERS – Individual Carers Emergency Respite Service

This service enables a carer to plan for how their cared for person would be able to cope or be looked after in the event of an emergency affecting the carer. Carers can come up with their own emergency plan, for example a planned arrangement with neighbours and relatives. Usually though the service consists of short term emergency stand-in care commissioned via Carers Trust Cambridgeshire to cover assistance for c48 hours.

8.1.1.8 Joint drop-in sessions for the carer/cared for/person with a frailty, long term condition or disability

These joint sessions started in January 2014 in areas identified as having a high population density and a high number of carers in the last census. The sessions were initially based in

Cambridge, Huntingdon and March and by summer 2014 will be in place in a total of nine areas. They are run by the locality Carers Support Managers in tandem with a worker 'seconded' from the Physical Disability Team to offer information, advice, guidance and signposting as necessary. (In addition the Carer Support Managers continue to hold separate carer sessions – satellite sessions - in smaller localities around the county).

The sessions are held in set locations on the same day each month eg the third Wednesday, last Thursday etc. Each session has a visiting expert who leads the talk or activity on things like Welfare Benefits, Healthy Eating, and Chair Based Exercise etc. In addition there are opportunities for chatting, refreshments, to follow up on individual queries or concerns, or to complete a carers assessment.

Individuals do not have to meet eligibility criteria to attend the sessions or receive information and guidance. The idea is to offer a service that is more preventative, that enables individuals/carers to get the advice, information and knowledge early on, and make links with any potential support before ever hitting crisis point.

8.1.1.9 Carers Support Team

The Carers Support Team support carers who care for someone who is not a social care user. The services provided include:

- **Carers Directory:** The Directory is produced biennially and is a valued reference book for Carers and professionals. It provides a wide range of information, details about support and resources as well as invaluable and numerous contact details. The Directory is circulated to approximately 5500 individual carers and 2300 organisations and professionals to distribute.
- **Carers Magazine:** The magazines are produced quarterly and in addition to listing important contact details they give details of various events and sessions for Carers provided by both professional and community organisations. The magazine features articles on topical issues such as welfare reform and changes to the benefit system and articles about local sources of support within the community.
- **Annual Away Day:** The Carers Support Team organise an annual Carer Away day in different locations in the county. Expert speakers host informal discussion groups to enable carers to access information on relevant subjects like access to employment and flexible working or Lasting Power of Attorney. The team invite partners from other broad ranging community organizations to set up information stalls and answer questions. It is also a chance for carers to meet peers and relax with activities such as hand massages and art therapy etc.
- **Awareness Raising Sessions:** The Carers Support Managers organise various sessions during the year either separately or with partner organisations to try to identify 'hidden carers' and to raise awareness of the potential support available. For example last year sessions were put on during Carers Week to raise awareness plus on Carers Rights Day around Carers and employment.
- **Information, Advice, Guidance and Signposting:** The Carers Team run various information, advice and guidance sessions around the county. Carers can also book an appointment to complete an assessment with one of the Carers Support Managers. These sessions are mainly delivered in partnership with the Physical Disability Service and are aimed at providing preventative advice to carers, the person with care needs and anyone with an illness or disability. Smaller population areas continue to have separate Carer drop in sessions. (See 8.1.1.7)
- **Specific Sessions and Training:** The County Council also organises, delivers or commissions various specific sessions on pertinent topics such as Back Awareness or the CRISP programme – Dementia training provided by Alzheimers Society to support Carers to understand and manage to better care for and support someone with dementia.

Cambridgeshire Care Training Network (CCTN) is an information, advice and guidance service for the development needs of the social care workforce run by Cambridgeshire County Council. They signpost to learning information and highlight any resources that may be of use to those in Adult Social Care. As part of this offer they now have a dedicated web page for carers. Please visit www.cctn.org.uk and click on 'Carers' Development' in the left-hand navigation bar. Links to other organisations and agencies will be hosted on the new Carers' page in order to signpost to the support or development opportunities available to family carers. This includes the Carers' Support Directory produced by the Carers' Support Team that has a wealth of information. There are also other pages of the CCTN website that may be of use to carers. These include a resources page which signposts to free e-learning. http://www.cctn.org.uk/ctn_eLearning24.html and the workbooks available via SCILS http://www.cctn.org.uk/ctn_SCILS24.html that cover a wide range of topics. CCTN keep in close contact with local training providers and highlight on this page any training specifically designed for carers.

- Peer Support Scheme: This scheme has some funding available to provide small grants to carers who wish to set up their own small informal support groups. The Carers Support Team can advise on the process

“My thanks to all the team involved in Carers Away Day. It was the first one I had attended and found it very helpful. Lots of information, but also time to talk to staff who answered queries and chat to some other carers.” Attendee, Carers Away Day 2013

Case Study

Mrs A. was having some issues with looking after her mother Mrs B. who is 89 years old. Mrs B. has a heart condition which she had been managing well with medication. Mrs A is working part time and lives in the next street to her mother and visits morning and evening each day.

Mrs B. copes well but has recently been having a few memory issues which the G.P. says are age related and not severe enough to warrant a referral to The Older Peoples Mental Health Team at the moment.

Mrs A. has noticed that her mother has not been taking her medication at times and also that she has stopped cooking for herself as often as she once did. Mrs A. receives the Carers Magazine and is aware there is support available to her through the Carers Support Team although she had not had any direct contact with her local Carers Support Manager at this time.

Mrs A. telephoned the local Carers Support Manager and had a talk on the telephone about her increasing concerns for her mother. She said she felt she would like to talk to someone in more depth about her concerns. The Carers Support Manager suggested that she might like to attend the next Adult Support Drop In and have a face to face talk. The Carers Support manager also informed Mrs A. that the speaker at the next Drop In was The Medicines Management Team and they may be able to support her mother with her medication issues.

Mrs A. attended the Drop In and was able to secure some equipment to help her mother remember to take her medication on loan from The Medicines Management Team. She was also able to talk to the CSM about her mother not preparing meals and the CSM was able to give her the details of a local Hot Meals provider as well as details about organisation that provide pre-cooked meals that her moth could just Re-heat.

Being in contact with the local Carers Support Manager has ensured that Mrs B. can remain independent for a little longer and that Mrs A. Can continue with her job and also knows that she can get further information and support that is relevant and local from The Carers Support Team.

8.1.1.10 Emergency care scheme for Parents/Carers of Disabled Children

The Emergency Care Scheme is for parents and carers of disabled children. It helps parents and carers put together a plan so should unexpected emergencies occur there is some short term care available for their child which fully meets their needs.

The scheme is designed to help parents and carers think about who could be called upon in an emergency such as illness, accident or admission to hospital and to clarify what help they can look for from family, friends and neighbours.

As well as family, friends or neighbours, parents and carers can nominate other care providers such as Link carers, Residential Short Break care or the Community Support Service for the provision of emergency care for their child, as long as they are currently receiving a service from them.

Once the plan is in place there is a 24 hour telephone response service so that nominated emergency carers can be contacted and care co-ordinated for up to 48 hours.

8.1.2 Activity data

8.1.2.1 Carers' assessments

It is not currently possible in the social care data to split information on the number of carers who received an assessment from those who received a review. In 2012/13 the number of carers who received an assessment or review from the Council was 3,128. Following assessment, 3,006 of these carers received a service including information and advice.

8.1.2.2 Adult Social Services care provisions

Identifying the number of carers receiving a service from social care data is challenging. This is because many of the services which provide the carer with a break from caring are recorded in the information relating to the person they care for. For example, if an older person receives day care, this may provide their carer with a break. However, it is difficult to take information about the number of people receiving services and link this to the number of carers to whom this provides a break to. Short breaks and respite care cover a range of services and situations and there is evidence that people need breaks in difference ways at different times (The Scottish Government, 2005). Given this breadth of definition, identifying from the data what constitutes a break for a carer can also be challenging.

In 2013/14, Cambridgeshire County Council commissioned around 19,600 bed nights of short-term building based care for the purpose of carer respite, for carers of adults. (Source: Monthly Placements Commitment, FINAL extract for 2013-14). These bed nights were used by 509 adults. This figure does not include those cared for people who accessed day services or who purchased replacement care to give the carer a break.

It is not currently possible to identify people who care for friends or relatives in longer term residential care placements, because of the way this information is recorded. It is also not possible to find out information about carers whose relative has recently died.

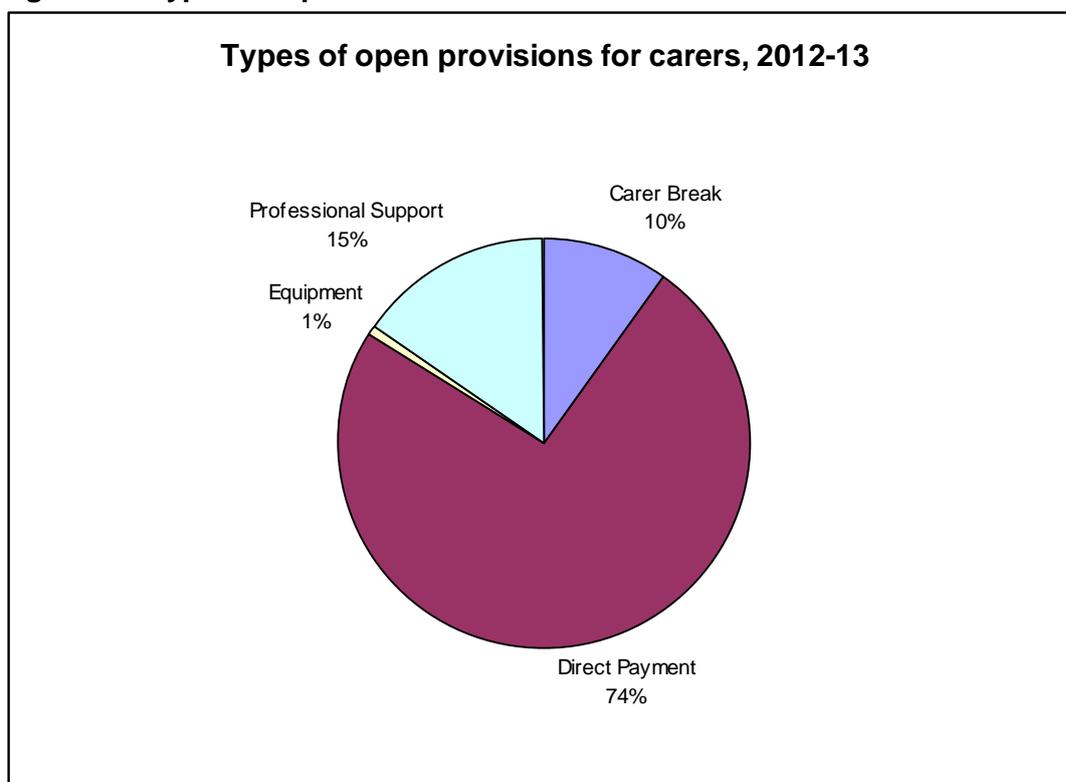
If a carer has received an assessment and been identified as eligible for a service, either because they meet certain eligibility criteria, or sometimes if the person they care for is not receiving services themselves, it is more straightforward to identify and count the number of services received.

- In 2012/13 the number of carers who received a service from Adult Social Care was 3,237. .

Figure 17 shows a breakdown of the types of service provided. The total number of distinct services provided during the year was 4,004. This is higher than the number of carers receiving a service because some people received more than one service during the year. Most commonly (74%) of carers were supported with a direct payment, of which 86% were Carer's Grant payments of £175. Further data on what these payments are spent on is not available. Other services provided were:

- Professional support: support provided by the Care Manager over and above the work going into completing an assessment or review or setting up a care package. This may take the form of on-going therapy, support or counselling.
- Equipment See 8.1.1.4.
- Carer break (commissioned from Carers Trust Cambridgeshire).

Figure 17: Types of Open Provisions for Carers 2012-13

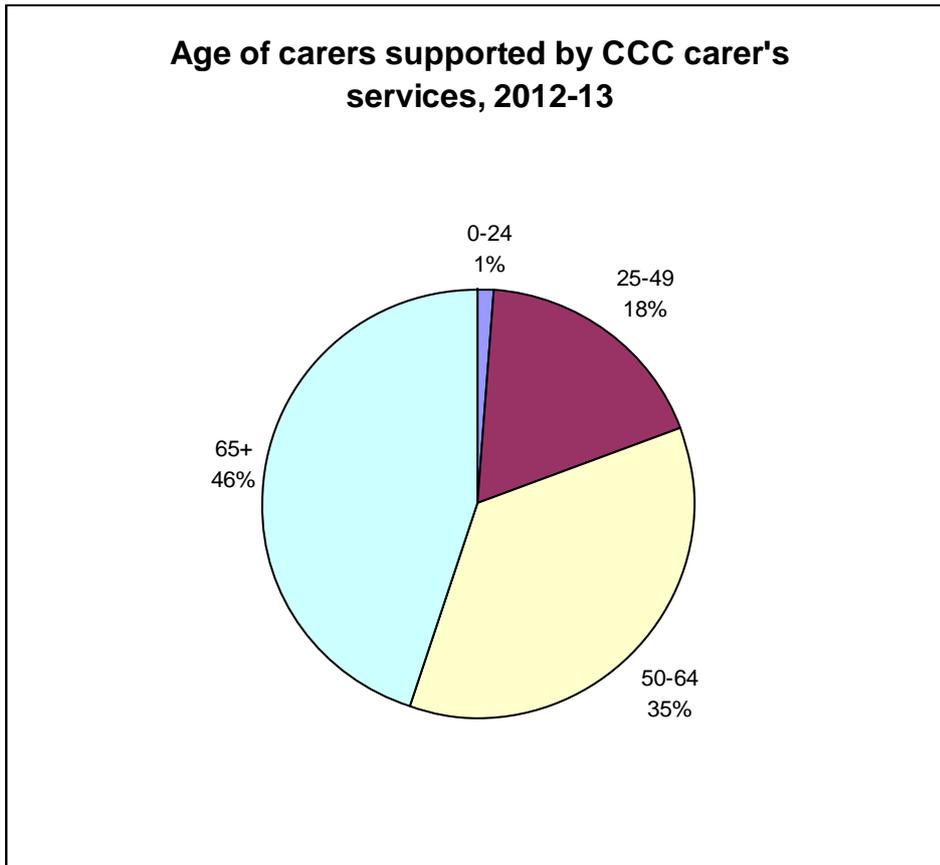


Source: SWIFT database, Cambridgeshire County Council

Comparison of the number of carers who were assessed or reviewed and received a service in 2012/13, with the number who received a service in the 2012/13 suggests that there were approximately 230 carers who received a service but were not reviewed during 2012-13. It is good practice that all carers are reviewed annually.

Figure 18 shows a breakdown of carer age for carers who received services in 2012/13. A majority (81%) of the carers supported by the Council were 50 or over at the time of the delivery of the service. Carers receiving support from Cambridgeshire County Council were most commonly over 65 (46%). This age profile is different to the Census profile, with a higher proportion of older carers than in the population in general.

Figure 18: Age of carers supported by CCC Carer's Services, 2012-13

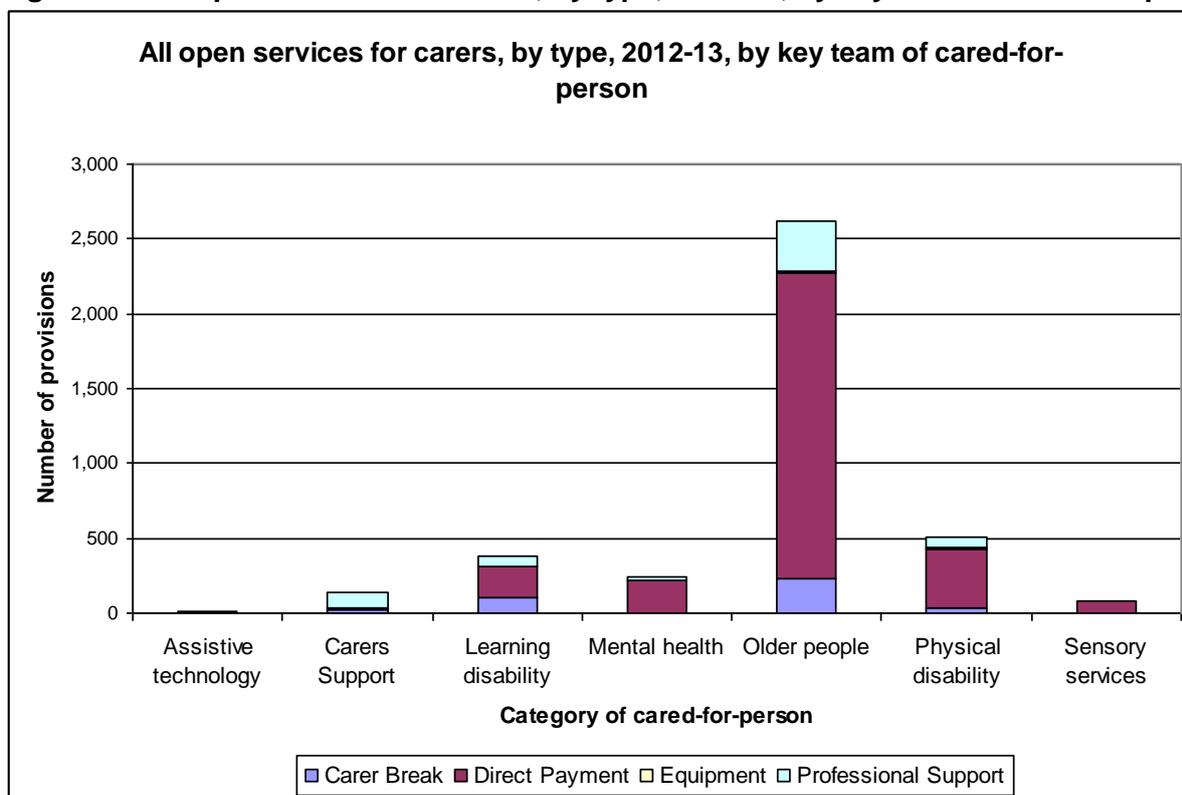


Source: SWIFT database, Cambridgeshire County Council

If the age of the carer is compared with the age of the person they are caring for (where both are receiving social care support), in the majority of cases the age of the cared for person and the age of the carer are similar. However, there is a significant number (919, 28% of all carers who receive support) of people who are under 65 and care for someone older than 65. The number of people who are over 65 supporting people under 65 is likely to be much lower – 245 at a maximum.

Figure 19 shows the number of carers by the social care team which is providing a service to the person they care for. This is used as a proxy for the need of the person that they are caring for. It shows that most carers receiving services from Cambridgeshire County Council are caring for an older person.

Figure 19: All open services for carers, by type, 2012-13, by key team of cared for person



Source: SWIFT database, Cambridgeshire County Council

Figure 19 identifies ‘assistive technology’ as a category. This is because a small number of people receiving adult social care only receive assistive technology, so do not fall under a particular team heading. Much more assistive technology and equipment is provided by adult social care which assists carers in their role, but this is mostly recorded under the record of the cared for person so is not shown.

8.1.2.3 ICER – Individual Carers Emergency Respite plans and Emergency plans for Parents/Carers of Disabled Children

2000 Carers were supported to plan emergency care on the ICER in 2012/13. The ICER is provided by Carers Trust Cambridgeshire - commissioned by the County Council. Carers Trust Cambridgeshire surveys reveal that it is one of the most valued services, alongside flexible breaks for carers.

The 2000 figure probably underestimates the number of carers who have a plan in place, since informal emergency plans with family and friends may not be recorded. There is some evidence nationally that carers may not inform the person who they have nominated in their plan that they have been nominated.

Currently (June 2014) there are 250 emergency plans for parents/carers of disabled children in Cambridgeshire.

8.1.2.4 Carers Support Team

Between April 2013 to April 2014:

- The Carers Support Team distributed the Carers Directory and quarterly Carers magazine to approximately 5,500 carers and 2,300 different professional organisations.
- The team received approximately 950 contacts relating to family carers.
- 385 new referrals progressed to Carers Assessments.
- 584 carers received information and advice which included 509 referrals for the Carer's magazine and Directory, 175 information packs and 145 referrals to other organisations.
- 309 new referrals progressed to ICER Applications.
- 259 new referrals progressed for Direct Payment Applications.
- 338 referrals were made to partner organisations for support.

Your Life, Your Choice website (From Feb 2013 – Feb 2014):

- Over a year Your Life, Your Choice website received 35,240 visits in total.
- 1,929 page views received for the carers area on YLYC.
- On average there are 160 views a month.

8.1.3 Service feedback: 2012 Adult Social Care carers survey results

The Carers Survey was designed by the Department of Health to understand at a national level how well services are meeting user and carer needs. At a local level it is intended to be used to inform service delivery and to monitor and develop standards.

The 2012 Adult Social Care Carers Survey was sent to a randomly selected sample of 991 carers who look after someone aged 18 or over who had been assessed or reviewed by the Council between 1 September 2011 and 31 August 2012. 650 questionnaires were returned (65.6%).

The survey gives the carers' perception of the services provided to the cared for person, those supported by the Council, ie people who support someone who is eligible or could reasonably be considered eligible for support from the Council, above the FACS threshold 'substantial' or 'critical'. The results may not be representative of all carers who live in the county.

About the carers ...

- 58.2% of respondents are aged 65 and over (54.1% 2010).
- 76.1% of respondents care for someone aged 65+.
- 73.5% of respondents live with the person they care for (74.9% 2010).
- 63.0% of respondents retired (64.6% 2010).
- 37.0% of respondents care for or help the cared for person for 100 or more hours per week (31.9% 2010).
- 58.4% of respondents have been looking after or helping the cared for person for over five years.

What carers are telling us ...

- 75.4% are either 'extremely, very or quite satisfied' with the support or services the carer and cared for person has. (85.5% 2010)
- 10.2% are either 'extremely, very or quite dissatisfied' with the support or services the carer and cared for person has. (6.3% 2010)

What the carers are telling us ...

- 10.9% of respondents feel they are neglecting themselves. (10.8% 2010)
- 12.1% of respondents feel they have little social contact with people and are socially isolated. (8.4% 2010)
- 15.3% of respondents feel they have no encouragement and support. (8.3% 2010)

Key Themes from written comments/experiences

The key themes from written feedback reflect some of the national findings on needs of carers these included:

Financial hardship
Availability of information and advice
Emotional support – including isolation and low mood

1. NHS services

8.1.4 GP surgeries

The GP surgery is often the first point of contact for carers. Because of this and because of the nature of the role of GPs in providing continuing relationship-based care to families; GPs and the wider primary care team are in an ideal position to identify, help and support carers (The Princess Royal Trust for Carers and Royal College of General Practitioners, 2011) have identified five key ways in which GPs can support carers:

1. Just listen!
2. Think of depression
3. Ask about finances
4. Signpost to services
5. Plan for emergencies

The Quality Outcomes Framework includes an indicator (Management 9) which relates to identification of carers: 'The practice has a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment'.

In Cambridgeshire data are not collected from practices by Cambridgeshire and Peterborough Clinical Commissioning Group on number of carers registered at each GP practice.

In order to identify and support carers, GP surgeries can (The Princess Royal Trust for Carers and Royal College of General Practitioners, 2011):

- Identify a carers' lead within the practice.
- Identify carers and keep an up to date practice carers register.
- Ask carers to self-identify and ask patients to identify their carers.
- Opportunistically identify carers in the surgery, on hospital admission or discharge, on letters from specialists and through the annual flu vaccination programme.
- Seek permission to share patient information with carers and involve carers in care planning.
- Provide or signpost carers to training to help them to perform their caring roles.
- Consider screening carers at least annually for depression.

- Provide flexible appointments for carers.
- Invite carers for annual flu vaccinations.
- Consider providing other services for carers eg annual health checks or in-practice specialist carer support worker sessions.
- Develop links with local carers' organisations.
- Encourage carers to apply for benefits that they are eligible for.
- Signpost carers to other sources of information and support.
- Refer carers for social services carers' assessment.
- Ensure carers have an emergency plan in place.
- Include young carers in all of the above. And in addition, question why the young person is taking on a caring role. Does the person cared for need referral for a review of care needs? Provide age-specific information and support, Develop links with local young carers leads. Consider referring the young carer to local children's services for an assessment.
- Audit support for carers.

8.1.4.1 Influenza vaccination

The 2014/15 national flu immunisation programme identifies informal carers as an eligible group for receiving annual influenza vaccination. More specifically the following group is identified as being eligible: 'Those who are in receipt of a carer's allowance, or those who are the main carer of an elderly or disabled person whose welfare may be at risk if the carer falls ill.' GP practices are key in identifying those eligible for a vaccination and giving the vaccine. It is also important that those in contact with carers who may be eligible encourage carers to seek vaccination from their GP.

8.1.4.2 Cambridgeshire in-practice specialist carer support worker sessions pilot

A project is being piloted in two GP surgeries in Cambridgeshire (Milton Surgery and Nuffield Road Medical Centre) where patients with dementia and their carers are able to drop in to monthly sessions based at the practices to receive advice and support on issues relating to their caring role. This includes signposting to groups and support with applying for benefits. The patient and their carer can also be seen in their own home if they prefer. The project has been well received by patients and carers and this information is being used to evaluate the pilot.

8.1.4.3 Carers Services Prescription Service

The Cambridgeshire Carers Services Prescription is supported by Carers Trust Cambridgeshire and allows GPs and primary care staff to provide a formal signposting to a carer support service giving access to:

- Health and care information to carers.
- Support to access ongoing services.
- Flexible breaks at short notice to improve health and wellbeing.
- Integrated health and social care through offering carers assessments and emergency support and in future, to facilitate better wrap around services involving MDTs and the voluntary sector. Care is organised around the family.

Additionally, it supports primary care by:

- Supporting and training health professionals to improve recognition of carers and provide more carer aware health services.
- Working with patient groups to improve carer support.

The GP Prescription Early Adopter Service was introduced in 16 - 22 practices in 2010 and was expanded throughout Cambridgeshire from January 2012. In December 2013, the service was extended to Borderline and Peterborough LCGs.

The service is an exemplar for carer support across the country. It is one of the 10 best practice examples identified by the Standing Commission on Carers and as best practice by the Centre for Civil Justice, the National Carers Hub and the Royal College of GPs, featuring in their Supporting Carers Action Guide (2nd edition) distributed to GPs. Carers Trust Cambridgeshire won the Charity Awards 2012 for Effectiveness for co-production and delivery of this service.

Since inception, 1,574 prescriptions have been issued (data to April 2014), with a year on year increase shown. In 2012/13 466 prescriptions were issued and 662 in 2013-14 in Cambridgeshire. In 2013, 78% of prescriptions were issued to carers who were not in receipt of support, suggesting that the service is meeting its aim of identifying 'hidden' carers'. Only 2% of carers were from an ethnic minority group.

The main reasons for prescribing were stabilising or improving carer emotional (60%) or physical (55%) health, with avoidance of admission to hospital or uptake of permanent residential care accounting for 19%. Being tired/overwhelmed was the main reason for referring carers (68%), with 75% having no social support in place. The proportion caring for more than 50 hours per week has remained consistently high (83%), with 38% regularly or often having interrupted sleep; and 78% feeling they could never (37%), or only for 1-2 hours (43%), leave the person the cared for alone.

Of the 81% of carers who received a break and accessed other support, 80% were referred to Cambridgeshire County Council for a Carers Assessment and ICER plan (support at home during a carer emergency). 51% of the carers given a prescription took up the whole offer of information, an assessment and a break. A further 24% of carers, on having the information and an assessment, felt they didn't need a break at that time and an additional 131 carers (10%) were referred directly to Cambridgeshire County Council's Carer Support Team. Carers felt the biggest impacts of the prescription were to help them feel less stressed (71%), to relax (63%), maintain their wellbeing (57%), maintain their health (44%), to become more informed (32%) and to be recognised as a carer (22%).

"It was a godsend." *Carer quote*

Financial savings as a result of the service have not been estimated but could be achieved as a result of reductions in hospital admission and delays in emergency care. In addition, use of the service to enable keeping hospital appointments, reduced footfall to surgeries and improving wellbeing could have an impact.

8.1.4.4 User feedback (GP practices)

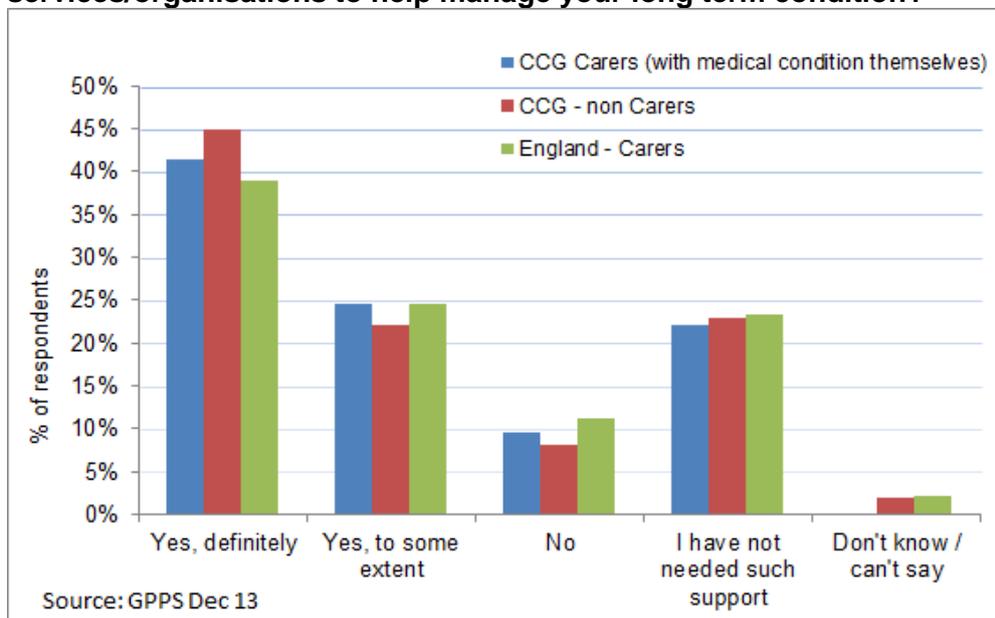
In the General Practice Patient Survey (GPPS) responses from carers to questions about services in primary care were generally positive. The only suggestion (reflected nationally) was that Saturday openings and opening hours after 6.30 pm would be helpful.

- Carers are more likely to have a 'preferred GP'. In England, 63% of carers responded to the General Practice Patient Survey (GPPS) that they had a preferred GP, compared with 57% of non-carers. Locally, in Cambridgeshire and Peterborough CCG (data not available for Cambridgeshire alone) 66% of carers said they had a preferred GP compared to 56% of non-carers. Of those who have a 'preferred GP' the majority see them all of the time or most of the time.

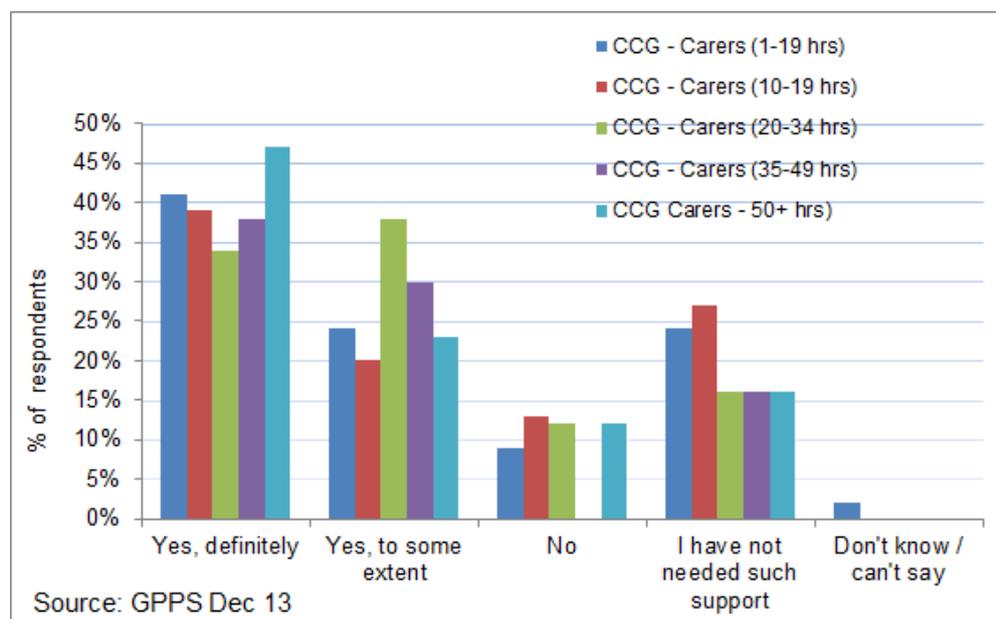
- In all people surveyed, the overall experience of making an appointment was rated as 'very good' by 40% (compared with 41% of non-carers) in England and 39% of both carers and non-carers 'fairly good'. Similarly in the CCG, 42% of carers rated 'very good' (compared with 44% of non-carers) and 39% of both 'fairly good'.
- In all people surveyed, the overall experience of their GP practice was rated as 'very good' or 'fairly good' by 90% (compared with 88%) in England. Same for carers and non-carers

Figure 20 shows the responses to the question as to whether, in the last six months, people had had enough support from local services or organisations to help manage. This response is only from carers who reported a medical condition themselves. Carers report slightly lower or similar views to non-carers with the majority reporting a positive view of the support they had received.

Figure 20: GPPS: In the last six months, have you had enough support from local services/organisations to help manage your long term condition?



**Figure 21: GPPS: In the last six months, have you had enough support from local services/organisations to help manage your long term condition?
Respondents by hours of care provided**



8.1.5 Involving carers in hospital and community-based care

NICE guidance and good practice documents recommend that carers involved in patient care are identified as soon as possible and supported appropriately. This includes having information sharing and confidentiality protocols in place. In addition, national carer policy points to the need to take a holistic approach to assessing the needs of the carer and cared-for person together.

Older people and adults who are identified as vulnerable to admission to hospital may have a Multidisciplinary team plan which identifies their health and care needs and is available to all professionals involved in their care at any time of day. Carer status should be recorded in the plan at the point it is set up, either in primary or community care. It may be possible in future to identify the proportion of MDT plans which have a carer record in primary/community care.

It is important that carers' needs are identified at hospital discharge. It is currently not possible to measure how well carers' needs are assessed at discharge across Cambridgeshire; in future use of the MDT record in the secondary care setting may provide this for carers of older people.

The Draft Outcomes Framework for Older People and Adult Community Services to improve health, wellbeing and maintain independence has a clear theme of ensuring that carers have an overall excellent experience of care and support, are involved in care planning and have their needs and wishes considered.

<http://www.cambridgeshireandpeterboroughccg.nhs.uk/downloads/CCG/Priority%20Older%20Peoples%20Programme/Older%20Peoples%20Programme%20-%20Outcomes%20Framework%20Mark%201%20-%20Jan%202014.pdf>

- Indicators to measure whether these outcomes are being met around specific pathways include:
- "All patients with a long term condition (under the care of community services) feel supported to manage their condition and maintain their independence."
- "Proportion of patients and carers who are assessed as having achieved the long-term health outcome or functional goals they desired/planned for jointly with staff (eg activities of daily living".

A pilot project to support family carers of chronically ill patients admitted to hospital began in Addenbrookes Hospital in Cambridge in May 2012. One year on, it has helped well over 400 'high risk' family carers who may not have otherwise coped after their family members (mostly Alzheimer's, cancer, heart and stroke patients or frail and elderly people) were discharged. The pilot provided family carers with prompt expert support and advice - helping them to manage better and prevent their loved ones from returning to hospital. Only a fifth of carers had received a Carers Assessment before coming in contact with a support worker and less than one in 12 had an emergency plan in place. A follow up survey after eight weeks showed that 98% of carers felt their health and wellbeing had been supported and 42% had accessed some additional support as a result of the service.

Nurses and Discharge teams are supported to refer family carers. Carers Trust Cambridgeshire estimates that it has saved Addenbrooke's Hospital £177,000 in readmission costs.

<http://www.carerstrustcambridgeshire.org/wp-content/uploads/2013/09/CRCC-Annual-Report-2012-13-06.09.13-v1.0.pdf>

8.1.5.1 School nursing

A school nurse in Cambridgeshire acts as a champion for young carers. The aim of this role is to disseminate information about the needs of young carers and encourage identification of carers whenever children and young people are in contact with the school nursing service. School nurses have a role in assessing the health needs of young carers and tailoring support to individual needs. This may require a multidisciplinary assessment of whether the caring role is appropriate or whether there are issues relating to safeguarding

8.2 Voluntary organisations

8.2.1 Alzheimer's Society

Cambridgeshire Alzheimer's Society provides the following support to carers:

8.2.1.1 Peer Support Groups

This facilitated group offers social support to people with dementia and their carers. It allows carers of people with dementia to discuss the diagnosis of dementia and its consequences in an informal environment in the presence of, and supported by their peers. There is discussion of experiential learning from peers and information sharing around key areas of concern, experienced symptoms and coping mechanisms. The service aims to reduce social isolation by providing social networking opportunities and a confidential and safe environment.

Carer feedback about the group is positive. Carers report that the most useful aspects of the group include:

- Friendship.
- A supportive environment to talk about problems where others understand.
- Sharing experiences and finding ways to cope.

8.2.1.2 Dementia café

This service is directed primarily at people in the early stages of dementia and their carers. The café is a facilitated social event providing structured activity, information giving, open discussion

and social engagement. Dementia Support Workers and health professionals are there to answer questions and offer support.

8.2.1.3 Cognitive stimulation group

Gender specific support groups run on a weekly basis over eight weeks, by invitation only. This service is for people with mild dementia and is designed to stimulate memory recall. The cognitive stimulation group does not include carers, although carers benefit from the positive reaction and the respite they receive while the group takes place.

8.2.1.4 Service data

In 2012/13 979 carers in Cambridge and Ely, 638 carers in Huntingdon and 266 carers in Fenland and Marshland were supported.

8.2.2 Care Network

8.2.2.1 Service description

Care Network Cambridgeshire is a charity serving older residents of Cambridgeshire and adjoining areas. The Care Network Community Navigator Project points the way to local community activities and to statutory and voluntary organisations, so that all older people can find something which suits them. Community Navigators are local volunteers who help older people find their way to activities or services which they would enjoy or find useful.

Examples could include:

- A community car scheme for a lift to activities and appointments.
- A local friendship club, lunch club or activity group.
- Modifications to home or mobility aids.
- Financial health-check to maximise income.
- Help at home to support through an illness or with a one off task.

The community navigator service is also able to signpost carers to services provided by other groups to meet the carers' needs. 30 carers were signposted to Carers Trust Cambridgeshire for the period 01/01/13 – 30/09/13. Additionally there were a further seven signposted to carer services or assessments.

Care network have since contacted the people to whom the information was provided to ascertain whether they have contacted Carers Trust Cambridgeshire and have found that whilst some have, a large number have not made contact for a variety of reasons.

8.2.3 Carers Trust Cambridgeshire

8.2.3.1 Service description

Carers Trust Cambridgeshire is a network partner of Carers Trust, providing services and help for family carers and their families across the county and Peterborough. Carers Trust Cambridgeshire supports family carers of all ages and offers flexible, professional care services to adults and children with a range of disabilities and health conditions. The main activities can be summarised as:

1. Providing high quality care for people with care needs, whilst offering double value through giving a break to unpaid, informal, family carers. These include:
 - Short breaks at agreed times (short respite breaks) for carers of all ages, including Adult Flexible short breaks, more regular breaks and short breaks via GP Prescription.
 - Personal care and medication.
 - Palliative care.
 - Overnight and bathing services.
 - Day clubs for those adults with care needs.
 - Individual Carer Emergency Respite service, providing free support for carers' emergencies on behalf of Cambridgeshire County Council, if they have had a Carers Assessment.
 - After and before school help for families and children with disabilities.
 - Children's clubs for children with autistic spectrum conditions and disabilities.
2. Providing a range support directly for carers themselves, in order to help maintain their health and wellbeing, through information, advocacy, peer support groups, training and short breaks at an early stage, before their situation becomes critical. This includes the Carers Prescription Service (see section 8.2.1) which assists GPs to identify and support carers, provide information and emotional support and, where agreed, a short break via a prescription referral. This service was available through all Cambridgeshire GP practices in 2012-2013.
3. Young Carers and Young Adult Carers Services.

Carers Trust services supported about 200 young carers through groups, activities and one to one support in Huntingdonshire and Fenland, principally at weekends and during school holidays. These enabled children and young people to have a break and have opportunities to enjoy childhood away from their caring responsibilities, as well as offering peer support. A new project supporting young adult carers in Huntingdonshire and Fenland will support up to 50 young adult carers aged 16-21 to complete a year-long project that will target issues such as Education, Employment and Training, Confidence and Aspiration, Health and Wellbeing and Economic Wellbeing. The project will work with up to 10 families of young adult carers to identify needs of families and signpost them to further support.

4. Children's groups

Overall, Carers Trust supported over 100 children with disabilities and provided about 7,000 hours of care and support, through and two fortnightly groups for 11-18 year olds and two fortnightly groups for 5-11 year olds with autistic spectrum disorders in Cambridge and a Saturday community group in St Neots, in addition to one to one care in the home. What do we aim to provide? "... a chance to be like everyone else for a couple of hours."

8.2.3.2 Service data

In 2012/13, 2,317 carers were referred to Carers Trust and main referrer was social services (1,068) with other key referrers being local GP (485), Primary Care Trust (263) and self-referral as a result of an information stand at an event (241). In the same year, 1883 new carers received a service from Carers Trust.

Table 19 shows the number of carers receiving each type of service (including carers already known to the service).

Table 19: Number of adult carers receiving services from Carers Trust Cambridgeshire, by type of service

Type of service	Number of adult carers receiving a service
One-to-one care services	818
Group care services	673
Information and emotional services	1,416
Other services provided by CTC employees and volunteers	2,334
Services provided by third parties on behalf of CTC - Advocacy	28

Source: Carers Trust Cambridgeshire

See section 8.2.5.2 for data on services provided by Carers Trust Cambridgeshire to young carers.

Table 20 shows the reasons given by carers for using breaks from care, the most frequent reason given was to plan for emergencies.

Table 20: How carers use breaks provided by Carers Trust 2012/13. (Note not all carers provided a response)

Carer declared reason for use of breaks from care	Number of carers
to remain in return to employment	31
to remain in/return to education/training	0
to attend training to assist in caring responsibilities	29
to attend appointments	2
to attend a social event or carry out a hobby	101
to do chores	15
to get some rest and relaxation	345
Emergency cover 80% avoidance of hospital or residential care	90
Plan for emergencies so feel reassured and valued	2,334

Source: Carers Trust Cambridgeshire

8.2.3.3 Service feedback

In 2012/13, 790 users of Cambridgeshire Carers Trust (excluding users of carer groups who had previously been surveyed) were sent a user questionnaire. 158 (20%) carers responded. Overall:

- 100% of respondents said that services maintained and respected their privacy.
- 97% said Carers Trust treated them with dignity and respect.
- 96% said they would recommend Carers Trust services to others.
- 93% agreed that care provision was tailored to each person's personal preferences.
- 87% said services met individual personal preferences about the way care is provided.
- 84% of those replying said Carers Trust services ensured the person cared for had interesting things to do and fostered independence.

The ICER emergency service – where support is provided if a sudden and unexpected emergency stops carers from carrying out their role – scored highest in importance with carers. Having regular breaks in the home was ranked second, with the carer prescription service (through GP surgeries), information from Carers Trust Cambridgeshire and short notice breaks also scoring highly.

69% of carers felt services had improved as a result of their input. Overall, users gave their individual care plan a score of nearly 87%, with well over half saying it had met intentions; and two thirds happy that it had met their needs.

8.2.4 Pinpoint

8.2.4.1 Service description

Pinpoint is an independent information, support and parental involvement network run for parents by parents in Cambridgeshire. Pinpoint believe that all parents should be given a voice and help in accessing support and services for their families, in particular parent carers of children and young people with additional needs and/or disabilities. The services provided to parent carers include:

Information:

- how to get the support they need
- who they can speak to if they need help and advice
- issues that may interest them

Support groups help local parent groups to develop and grow so that every parent who needs it can get support from someone like them.

Pinpoint can:

- give advice on getting started
- provide free publicity
- help with managing groups as they grow
- sometimes provide small bursaries to parent-led groups

Parent carer involvement - Pinpoint works with parent carers and local service providers and commissioners to design and develop services that meet the needs of families. This includes:

- Running workshops with parent carers, service providers and commissioners to discuss views on services and how they can be improved.
- Facilitating action groups around specific topic areas which involve parent carers, service providers and commissioners working together to bring about service improvement eg Addenbrooke's Hospital passport, continence service, wheelchair service.
- Enabling parent carers to participate in the interview process when commissioning new service providers.

8.2.4.2 Service data

In 2012/13:

- There were 600 parent carers on the Pinpoint mailing list.
- 37 events were ran for parent carers.
- About 450 parent carers attended the events. Events included support groups, parent participation meetings, a conference, workshops, etc

- There were 13,807 visits to the website.

There are many other support groups run for parent carers by parents themselves, schools, local voluntary sector organisations, children's centres, etc.

8.2.4.3 Service feedback

An impact report produced by pinpoint in February 2013 surveyed 58 parent carers about pinpoint's services. The results said:

- 67% said they are more informed about services and activities for families that they would otherwise not have known about.
- 30% said they are more informed about their legal situation and their rights.
- 78% said their knowledge about their rights and entitlement had improved (by being involved with pinpoint).
- 66% said that being part of the pinpoint network and/or receiving pinpoint services had improved their self-confidence.
- 24% said that pinpoint has helped them to make contact with other parents and made them feel less isolated.

8.2.5 Centre 33

8.2.5.1 Service description

Centre 33 is a well-established registered charity and private limited company operating from Cambridge, and working with young people aged eight to 25 in Cambridgeshire. Centre 33 provides children and young people with open and easy access to a confidential, safe place where they can get the support they need to fulfil their potential. Centre 33 works alongside young people to overcome the effects of poor health, isolation, disadvantage and inequality. Centre 33's Young carers Support Service provides a range of services for eight to 18 year old Young carers who live in Cambridge City, South Cambridgeshire and East Cambridgeshire (note that Carers' Trust Cambridgeshire provide these services for children and young people in Huntingdonshire and Fenland). These include:

- Home visits: contact with the Young carers Project usually begins with a home visit after receiving a referral. A discussion will take place about the project and the support that is appropriate for the young person.
- Nine fortnightly groups which provide a supportive environment for young carers to come together, have some time out from their caring responsibilities, try new activities, feel supported and meet new people. Transport can be provided to ensure the most isolated young carers are able to access groups. Some groups are run in partnership with staff from children and young people's services locality teams.
- One to one support and activities: These sessions provide additional support, for example supporting a young person through a particularly difficult time such as a terminal illness. Support may involve advocacy or supporting to access another service. The Centre 33 team may work closely with Locality teams in a 'team around the child' and also liaise closely with child protection services and other statutory services.
- Participation: Young carers from across the nine groups meet monthly to raise awareness of young carers issues and develop training and information packages to

professionals, young people and the community. In 2012/13 this included a project with the Drug and Alcohol Team (DAAT) to produce awareness raising information for professionals working with substance misusing parents to help identify young carers. Using Cambridgeshire Young carers Strategy Group Action Plan, the participation group work closely with Carers Trust Cambridgeshire Young carers to have a county wide approach to identifying issues to explore and challenge.

- Advocacy: Liaison with schools, home, friends and professionals. Multi-agency Common Assessment Framework (CAF) assessments, Team Around The Child (TAC) meetings and providing support with Child in Need (CiN) or child protection (CP) cases.
- Quarterly newsletter: The 'Juicy News' is produced quarterly by young carers in Cambridgeshire and offers support to young carers who may not want to get involved in a project but may like information and contact with us through other means.
- Activities, Trips and Holidays

Since 2011, Centre 33 has been the county-wide lead for the strategic planning of young carers Services, funded by Cambridgeshire County Council, thus supporting young carers to directly influence the planning of services to their families across agencies.

8.2.5.2 Young carers Service data (includes information from both Centre 33 and Carers' Trust Cambridgeshire)

During 2012/13:

- 562 young carers were registered with young carers projects across Cambridgeshire.
- 335 young carers attended fortnightly support, activity and respite.
- 137 young carers went to one-to-one support sessions.
- 175 attended activities trips and holidays.

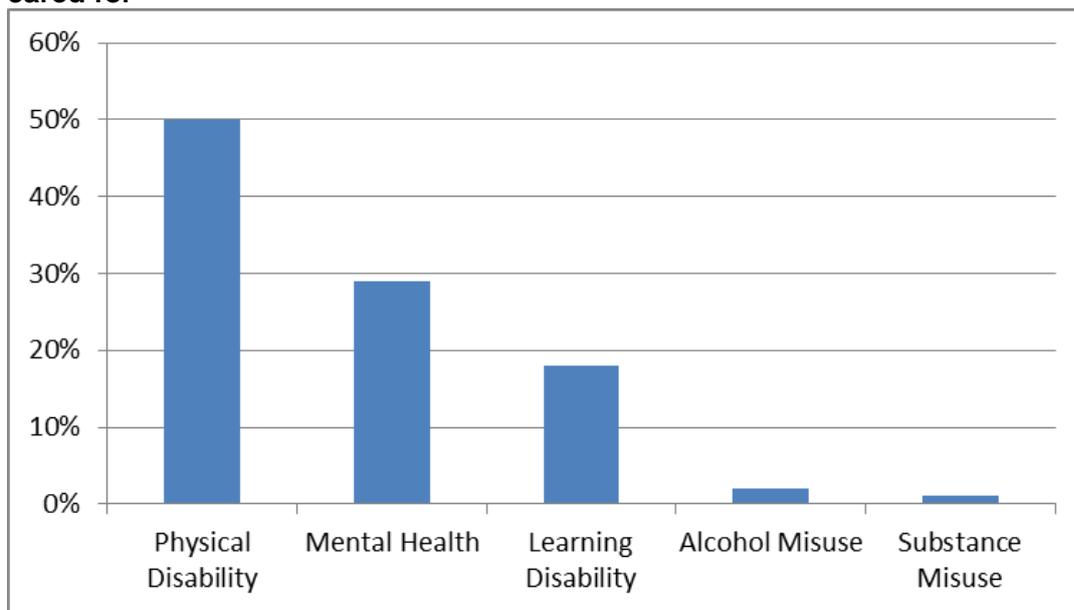
In addition 40 young carers were involved with specific and focused participation activities, through Centre 33's strategic planning role.

Data from Centre 33 from 2012/13 shows that of the 135 carers they actively worked with in 2012/13:

- 61% (of) were girls and 39% boys.
- 92% white UK and 8% BME communities.
- 20% primary school age and 80% secondary school age.
- 65% care for their mother.
- 25% for a sibling.
- 6% for their father.
- 2% grandparent 1% step mother.
- 1% step father.
- 58% are in a lone parent family.
- 26% have more than one person at home that they care for.

Figure 22 shows that in 2012/13 Cambridgeshire Young Carers Projects worked with a higher number of young people who care for a family member with physical health issues, followed by mental health and learning disability. Only 4% of young carers reported caring for a parent alcohol or drugs misuse. This suggests that young carers of adults with drug and alcohol issues are not being identified often enough and referred for support.

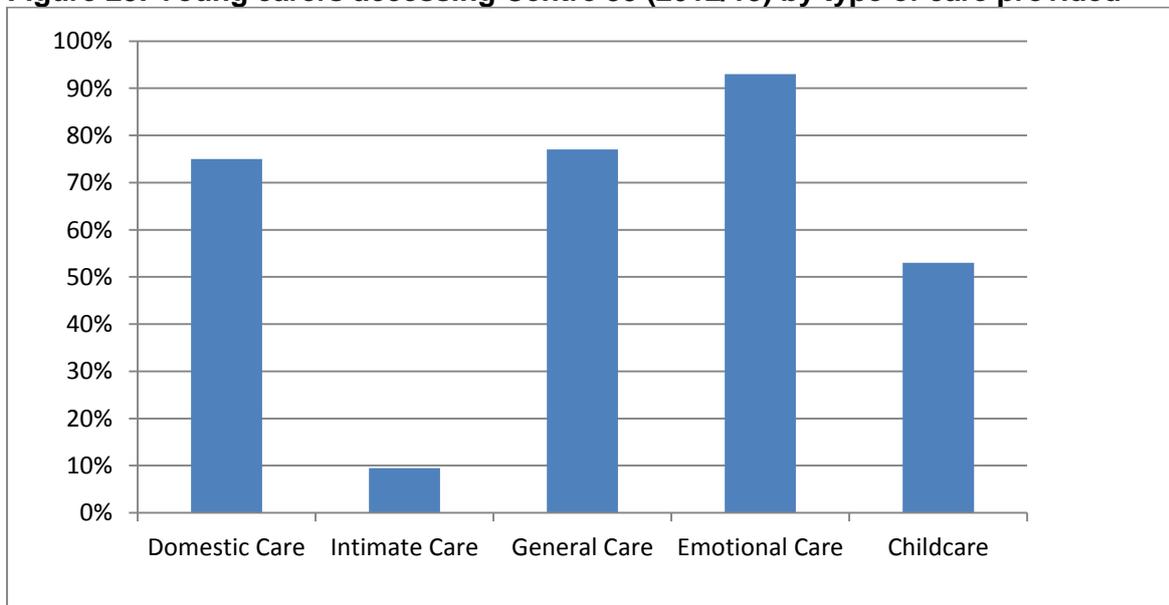
Figure 22: Young carers accessing Young carers' Projects (2012/13) by condition of person cared for



Source: Centre 33 and Carers Trust Cambridgeshire

Figure 23 show the caring responsibilities of young carers known to Centre 33. It shows that around 10% of young carers Centre 33 are providing intimate care, 75% domestic care and 93% provide emotional care. Emotional care could include listening to their parent's worries and having knowledge beyond their years. These roles and responsibilities all impact on the young person as they tend to take this worry with them, impacting on their school work, ability to concentrate and concerned about what is happening at home when they are not there, has an impact on their sleep and feeling they need to stay at home more to provide support.

Figure 23: Young carers accessing Centre 33 (2012/13) by type of care provided



Source: Centre 33

In 2012/13 the majority of referrals to Young Carers Projects were from Children's Services. Despite 75% of young carers that Centre 33 are actively working with caring for an adult; only 4% coming from Adult Services and none through the drug and alcohol services and Adult Mental Health. This suggests that young carers are being referred by children's services as a result of concerns being raised, rather than preventative referrals when an adult is diagnosed. It is recognised that it is a causal link between young carers mental health issues and the emotional burden of supporting people with complex needs but support for Young carers from specialist services is negligible.

8.2.5.3 Service feedback

"It helps me feel better about having a disabled mum – I don't have to worry about her"

In 2012/13 Centre 33 evaluated outcomes by asking young carers to select the outcomes they want from the project using a specific tool. These outcomes are then revisited annually or when a young person moves between groups. In addition parents/guardians are invited to complete a questionnaire on how well they feel the project is supporting their young person.

Evaluations demonstrated good outcomes for four key areas identified most frequently by young carers:

- 85% had time to chill out because of the project.
- 89% made new friendships through accessing the project.
- 86% tried new activities through the project.
- 68% felt that they were being heard and had time to chat on the project.

8.2.6 Making Space

The Making Space Cambridgeshire Carers Service supports adult carers (relatives and friends) of people with mental illness throughout Cambridgeshire. A high percentage of the carers supported by Making Space are not receiving support from statutory services except for their GP. The service aims to offer an easily accessible service to carers when it is needed. Support is tailored to individual needs and includes one to one appointments and group meetings for those who like to meet other carers. 319 carers received a service between 1 October 2012 and 1 October 2013.

Examples of support provided:

- Information provision: This includes information on services, diagnosis, pathways of care, side effects of medication. The aim is to enable carers to feel more confident when speaking to Mental Health Professionals.
- Signposting to voluntary organisations who can provide additional support both to carer and cared- for person. Examples include Richmond Fellowship, Mind, Cambridge Reuse, CAB, Rethink, AA and Addaction, Wildlife Trust.
- Support and assistance in applying for benefits.
- Maintaining mental wellbeing and emotional support. This includes general support and coping strategies.
- Liaison with other services on behalf of the carer, including support with obtaining a carers assessment, improving communication, making complaints.

8.2.7 Dementia Carers Support Service

The Dementia Carers' Support Service was piloted in East Cambridgeshire in January 2011 and has since expanded to cover Cambridge City and South Cambridgeshire. It was set up in response to the National Dementia Strategy (Department of Health, 2009) objective 4, which is

about enabling easy access to care, support and advice following diagnosis. For many family carers and other supporters, the task of supporting a loved one with dementia requires time, patience, commitment and dedication. The service uses the knowledge and skills of Dementia Carers' Support Volunteers, who are experienced carers with a desire to help others. Volunteers are linked to current carers of persons with dementia as a professional befriender or buddy. The majority of the volunteers are former carers of people with dementia, some are former carers of people with related illnesses such as stroke, head injury etc and others are professionals with experience in caring for people with dementia. The volunteers provide emotional and practical support, give information and signpost to other services when needed. The frequency of support is agreed with the carer at the initial meeting and the form of contact varies according to need, from personal contact to contact via telephone or email. The volunteer's support is consistent and will last throughout the journey of the caring role, unless the carer chooses otherwise.

The team also has one full time equivalent coordinator and a part time team administrator. Volunteers receive training and regular supervision. A number of regular support groups are facilitated where possible.

Referrals to the team are received from Community Mental Health Trusts, Outpatient Clinics, Primary Care, Liaison Psychiatry and On-Call Services, Third Sector and from carers themselves.

One carer said "The more we see of each other the more I am amazed at what a good match we are! It's just so good to be able to talk and find that you are not condemned for some of the thoughts that you have, in fact they are normal!"

Between January 2011 and January 2013, the service received a total of 146 referrals, of which 116 were assessed, 22 have not been assessed (either because carer did not think they were ready for the service or did not respond) and two referrals were inappropriate. In January 2013, of the 116 carers that had been assessed, 74 were matched, 20 were waiting to be matched and were being supported by staff, 19 refused the service at that moment and three did not want befrienders but chose to attend the carers group instead.

8.3 Citizens Advice Bureau

The Citizen's Advice Bureau (CAB) offers a holistic advice service. Frequently, clients come to CAB about one matter when in fact they have other issues. The CAB covers a wide range of topics with the exception of Nationality and immigration information. The CAB is regulated by the Advice Quality Standard and the Financial Conduct Authority.

Citizen's advice in Cambridgeshire is split into two areas: Cambridge and District (covering Cambridge City and South Cambs) and Rural Cambridgeshire (covering East Cambridgeshire, Fenland and Huntingdonshire). Data just from the Cambridge CAB shows that in 2013, 400 enquiries related to people who had caring responsibilities. This equated to approximately two queries per day and was mostly enquiries relating to benefits and debt but also covered questions about homelessness, relationship breakdown, employment issues and domestic violence amongst other things.

8.4 Schools

As part of local authority visits to schools, each Adviser or Associate for every Primary school will ask the head teacher- "do you have any young carers at the school?" They will ask the school to comment on their attainment and progress and any special provision being made. This is new data collection and may provide useful information on Young carer needs in Cambridgeshire. However, it is not currently possible to identify young carers in the schools data across Cambridgeshire, which means that it is not possible to look at educational outcomes specifically for this group and compare then with Cambridgeshire as a whole.

8.5 Cambridgeshire Carers Assets map

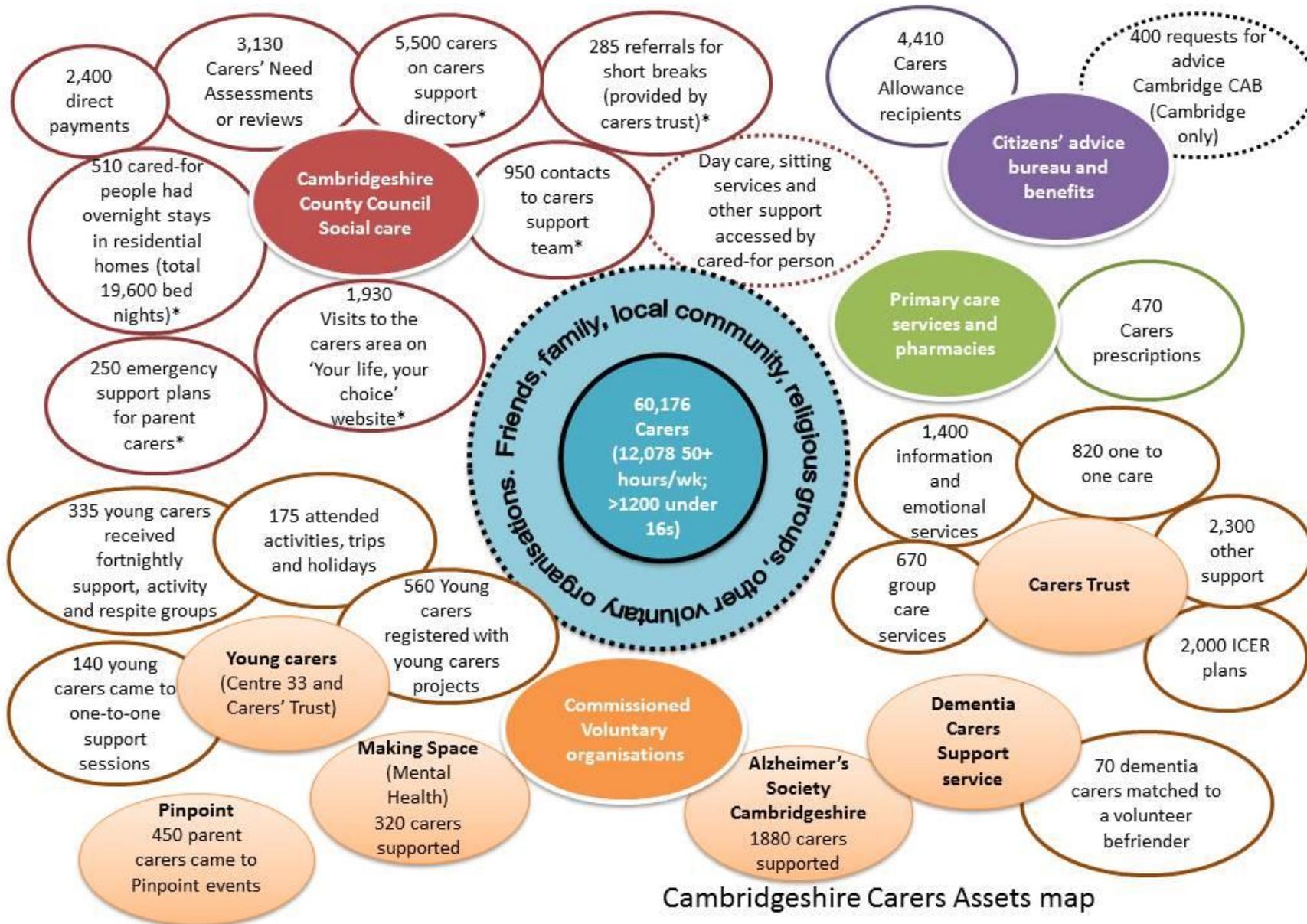
The carers JSNA has taken an assets mapping approach to services in Cambridgeshire. Services identified how many carers were in contact with them or received a service in the financial year 2012/13. The results are shown in the diagram below. The diagram is intended to be indicative of Cambridgeshire assets for carers and has several limitations:

- Many assets for carers cannot be counted, for example the support provided by friends, family, local community networks and religious groups. Other assets are more challenging to count, for example the services provided by many voluntary and community services in Cambridgeshire.
- Where we have numbers, these may underestimate the number of contacts because of the way data are recorded; for example for social care, information may be recorded against the record of the carer or the cared-for person.
- The categories are not mutually exclusive, so carers are likely to be in contact with several of the assets shown.
- Some services are commissioned by one organisation and provided by another.

Key to the diagram:

- The diagram shows assets provided in one financial year (2012/13; unless marked with an asterisk, in which case the data are from 2013/14). Of the 60,000 informal carers in Cambridgeshire, not all will need to access services in a given year. The challenge is knowing how far we are meeting need with existing assets – this requires a range of information sources, most importantly feedback from carers themselves.
- The diagram is colour coded. Services provided by Cambridgeshire County Council Social care are coloured red, benefits and citizen's advice services in yellow, commissioned voluntary organisations in orange and primary care in green. Other community assets are shown as a blue ring around the central bubble, which shows some information about the number of carers in Cambridgeshire.
- Where the numbers presented are unknown, uncertain or likely to underestimate assets, a dotted line has been used in the diagram.
- Numbers of service provisions have been rounded to the nearest 5.

See sections above for more detail on individual services.



Cambridgeshire Carers Assets map

9 What keeps carers healthy and well? Evidence and best practice

The key questions asked in the literature review were:

1. What do we know about which interventions are effective in supporting carers to stay healthy and well?
2. Is there evidence that these interventions improve outcomes for the cared for person in terms of service use?

Given the breadth of scope of the JSNA, the literature review focused on systematic reviews of the literature where the intervention was focused on improving the health or wellbeing of the carer. Whilst systematic reviews provide a relatively high level of evidence, the breadth of the literature review undertaken for this JSNA means that it is likely to provide an overview of the subject area only. The search strategy may have missed more recent individual studies not included in the larger reviews.

A review of other previous reviews of interventions to improve carer wellbeing was identified (*Parker et al 2010*) which summarised evidence published until 2009. The search for evidence therefore focused on reviews published after this. In addition a wider search for relevant reports, guidance and documents was carried out.

A glossary of some of the terms used in this section is available at Appendix 3.

9.1 What works? Evidence of effectiveness of interventions to keep carers healthy and well from systematic reviews of the literature

9.1.1 Overall summary

The key findings are summarised below

- No consistent evidence was found that interventions for carers improve carers' wellbeing or quality of life. The reason for this is likely to be that many of the individual studies on which the reviews were based are small and variable in quality. The outcomes being measured in studies were often not standard across studies eg ways of measuring emotional wellbeing. There were very few (particularly UK based) studies which measured cost effectiveness of interventions. This is not the same as saying that there is evidence that interventions for carers do not have benefits or are not cost effective.
- There was contradictory evidence for the impact of any type of intervention on carers' burden. However, many interventions resulted in carer satisfaction. The best evidence was that education, training and information for carers (particularly when targeted at a particular parent group) improved knowledge and caring 'abilities'
- The relationship between breaks from care and carers' emotional wellbeing is not straight forward. Many of the studies in reviews are small and of variable quality. There was some evidence of respite having a negative effect in some groups (because of feelings of guilt). There was suggestion that it is important that interventions are tailored to the individual family situation.
- Cognitive reframing (aims to reduce carers' stress by changing certain of their beliefs, such as beliefs about their responsibilities to the person with dementia, their responsibilities to the person with dementia, their own need for support, and why their relatives behave as they do) may be useful when used alongside other interventions for carers of people with dementia (reduced carer depression, anxiety and stress, but did not impact on coping or burden)

- The best evidence was that education, training and information for carers (particularly when targeted at a particular parent group) improved knowledge and caring 'abilities' (Parker et al 2010)
'The size and complexity of the issue of providing carers with the best possible support to enable them to continue helping those they love deserves better primary research than our meta-review has uncovered'(Parker et al 2010)
- There is weak UK-based evidence for carers assessment improving emotional wellbeing and access to services
 - But subsequent uptake of services poor and carers not necessarily satisfied with services.
 - Evidence that how assessment delivered is important.
- There was contradictory evidence for the impact of any type of intervention on carers' burden.
- However, many interventions resulted in carer satisfaction.

9.1.1.1 More detailed summary of findings (Carers in general)

The starting point of the literature review was a 'meta-review' of English language systematic reviews published from 2000 onwards on interventions aimed at carers of all ages supporting adults (Parker, et al., 2010). The meta-review excluded parent carers and carers of people with mental health problems. Most of the studies included focused on interventions aimed at adult carers of people with dementia and/or carers of older people with some form of cognitive or physical frailty. A small number of reviews incorporated interventions for carers of just one condition group. The remaining reviews focused on carers in general.

Parker et al (2010) found that the strongest evidence of effectiveness of any intervention focused at supporting carers was for those involving education, training and information for carers. Particularly when active and targeted at a particular carer group, these interventions increased carer knowledge and abilities as carers. However, whilst there was some suggestion that this might improve carer mental health or coping, further research which is specifically designed to ask this question is needed.

Parker et al (2010) found no evidence for the impact of respite care on the physical health of those caring for frail older people or as a result of support interventions for carers of dementia sufferers. There was only weak evidence of impact in relation to carers of people with diverse conditions. The authors note that:

'This is an obvious gap in the research evidence, given that we know that carers' physical health can be affected by caring'

The meta-review found inconclusive evidence for the benefits of respite care for mental health of those caring for frail older people. No consistent evidence was found that interventions for carers improve carers' wellbeing or quality of life. There was a suggestion that respite care for those looking after frail older people may have a negative impact on carers wellbeing or quality of life. One review identified that the relationship between breaks and carers' emotional wellbeing is not straight forward; having both potentially positive (offering carers a rest) and negative (guilt and anxiety) effects. There was only tentative evidence from reviews with methodological problems that psychosocial support for carers of people with dementia may have a positive impact on depression. There was no, or contradictory, evidence for the impact of any type of intervention on carers' burden and no, or contradictory evidence that interventions for dementia carers improved carer coping. Whilst there was evidence among people caring for those with diverse conditions of satisfaction with a range of different interventions; the meta-review authors comment that, as with other service evaluation, it is difficult to know whether this represents being grateful for receiving 'something' rather than 'nothing.'

In summarising, Parker et al (2010) found that beyond the evidence for education, training and information, there is little 'secure evidence' about any of the other interventions from the higher quality evidence reviews which made up the meta-review. This is not the same as saying that there is evidence that these interventions do not have any benefits, rather that better quality research is needed to demonstrate their worth.

Parker et al. (2010) found very little available evidence of cost-effectiveness of interventions for carers and the available evidence was not reported in sufficient detail to enable an assessment of how generalisable it is to the UK setting.

One of the reviews included in Parker et al (2010) focused on UK systematic reviews of the literature published in the last five years (Victor, 2009). It is useful to consider some of the results of this review as it attempts to answer a question about how interventions support carers and the contextual factors which influence outcomes. This review did not include young carers and the search strategy may have resulted in relatively poor identification of studies concerning parents caring for disabled children. It is important that in presenting the results of this review that they are not seen as 'adding weight' to the results presented in Parker et al (2010) as the review is included within the meta review results; Parker et al (2010) provides a stronger level of evidence as it synthesises the results of multiple reviews.

Statutory carer assessment

Victor (2009) found that the studies looking at outcomes for carers after receiving a carers assessment were weak (as they looked at small numbers of carers and did not make comparisons with carers not receiving an assessment) and inconsistent. However there was evidence of potential benefits relating to improved emotional wellbeing and the uptake of support services. There was also some limited evidence of increased knowledge, better physical health and support to work. Whilst studies showed potential benefit in uptake of services, the proportion of carers who received additional services after assessment was relatively low and carers were not necessarily satisfied with the services they received. How the assessment was conducted was important to its outcome:

- Ensuring carers felt recognised, valued and supported.
- Practitioner skills and approach: particularly good interpersonal skills, provision of active assistance, skilled and knowledgeable in carer support, follow up assessments appropriately.
- Assessment process and scope: appropriate information provided prior to the assessment, sufficient time, comprehensive outcomes-based focus which considers the carers expertise, the use of appropriate tools.

Information services

Victor (2009) found weak evidence that information-based services improved carers knowledge and uptake of services. Very tentative evidence (based on single studies of small numbers of carers) suggested that the manner of information giving is important (relevance and layout of information, staff manner, query resolution, ease of access to the service and helpfulness of services to which carers are referred). The review also found weak evidence from one study that information services did not make carers feel empowered in their contact with service providers.

Direct payment schemes

Victor (2009) found weak evidence from one study that direct payment schemes can alleviate financial pressures, relieve stress and facilitate the provision of appropriate, effective support services for parent carers of disabled children.

Support workers

Victor (2009) found some evidence of carer support worker interventions leading to improvements in a number of outcomes for carers. These included improved emotional wellbeing (weak evidence from studies on GP-based mental health specialist, dementia carer, lung cancer carer

and South Asian advocacy workers). However this finding is not definite as the better quality studies which related to stroke specialist support workers did not show good evidence of improvements in emotional wellbeing. Emotional support appeared to be achieved in a number of ways including enabling more confidence and a better outlook, being given permission to (and an opportunity to) discuss their own needs and the ability to contact someone if needed. The review also found some evidence that stroke specialist support workers and lung cancer carers support may have helped to improve carers' knowledge base. The studies of the dementia care workers and lung cancer carer worker also showed the number of carer needs (information, access to practical support and emotional support) could be reduced through these interventions. There was weak or qualitative evidence that a GP-based support worker, advocacy workers for Pakistani and Bangladeshi parent carers and stroke specialist workers increased and improved service support for carers. Despite the finding that stroke support workers did not improve emotional wellbeing, there was some evidence that they improved carer satisfaction.

In terms of factors which might influence improved outcomes for carers of support services, Victor (2009) found that success might depend upon the nature of the problem or the needs of the carer; flexibility and individualisation of services seemed to be helpful.

Carer support groups

Victor (2009) found that the majority of carers were satisfied with carer support groups and that these resulted in carers gaining information (particularly for some Asian carers who find it difficult to access information in a language they can understand elsewhere); having improved emotional wellbeing (through mutual support) and obtaining social support (through building friendships and participating in social activities). Evidence from small studies suggested the type of group (focusing on carers for people with a particular condition) may be important. The review concludes that further research on benefits of professional-led versus peer-led groups would be useful.

Stress management, coping and counselling programmes

Victor (2009) found reasonable quality evidence of carer satisfaction for these types of interventions. There was evidence from one study that benefits for carers may not be maintained in the longer term. Better knowledge of conditions was found in studies of carers for people with schizophrenia, dementia, Parkinson's Disease and palliative care needs (but with mixed evidence of whether better knowledge resulted in behaviour change). There was mixed evidence on the benefits of these programmes in improving emotional wellbeing and evidence from two randomised controlled trials of no difference in coping.

Befriending schemes

Victor (2009) found evidence from one good quality study which showed no evidence of benefit in terms of emotional wellbeing or general health as a result of access to befriending support; although the low proportion of people who took up the support did show benefit in terms of depression compared with those who did not.

Complimentary therapies

Victor (2009) found weak evidence from only two studies of benefits of chair massage and aromatherapy to carer wellbeing.

Carer education and training

Victor (2009) found that studies looking at this outcome included randomised controlled trials or longitudinal trials (those without controls but following up over time). These studies provided some good evidence of carer satisfaction for a written booklet format but no or small improvements between groups receiving or not receiving education on stroke. Only one of the stroke studies showed improvement in knowledge. Findings suggest that 'usual care' following stroke may provide sufficient information for carers. There was quite strong evidence of improvements to knowledge from education programmes for carers of people with dementia and schizophrenia (although mixed evidence on whether these resulted in behaviour change such as use of

services). Relatively weak evidence explaining the benefits of carer education suggested that providing this sort of intervention at an early stage of caring may be most beneficial as well as providing information face to face. Studies around carer training programmes were diverse and often weak in quality with some evidence that programmes could validate carer expertise, provide new knowledge, lead to development of new skills (but with some evidence that new skills not maintained over time), provide social support and improve emotional wellbeing.

Employment related interventions

Victor (2009) found some weak evidence suggesting benefits of this type of intervention in helping carers gain employment, suggesting further exploration would be useful. The limited evidence available suggested that availability of flexible work and provision of support services for the person receiving care influenced employment related outcomes.

Carer breaks

Victor (2009) identified studies which were of a relatively weak design for demonstrating outcomes for carers. Overall studies reported carer satisfaction with breaks, facilitating accomplishment of every day jobs, social activities and, to a lesser extent, employment. There was little robust evidence of improvements to emotional wellbeing (although studies of dementia carers failed to take account of carers' worsening emotional wellbeing over time) and evidence from qualitative studies that breaks could result in both positive and negative effects to emotional wellbeing (negative emotions including anxiety about person receiving care and feelings of guilt). A key factor in the success of services was confidence about the nature and quality of the alternative care received as a result of the break. There was some limited evidence of improvement to physical health and social inclusion through carer breaks, as well as some qualitative evidence that breaks enabled carers to continue in their caring role. Potentially important organisational factors in the success of carer breaks were the extent and timing of provision, as well as flexibility.

Gaps in the evidence

Victor (2009) identifies the need for further research into personalised approaches to support (eg individualised budgets); interventions to support carer employment; and interventions focused on carers physical health.

Implications of UK evidence (taken from Victor, 2009)

“The current focus of local authorities on meeting performance targets for the number of carer assessments achieved needs to be matched by concern with the quality of these assessments.

- *Attention to staff training and approaches in helping carers to access services is particularly important.*
- *Further research is needed to consider the relative value of different models of helping carers to access support including carer assessment (conducted by social services or the voluntary sector) and carer support workers.*
- *The evidence suggests it is worth supporting and researching carer support groups further. Given the potential influence of support group characteristics upon their outcomes, those organising and running groups should consider the aims, activities, membership and leadership of individual groups carefully.*
- *Within local areas, it might be helpful to review the number and range of different groups available and to consider whether there are gaps in provision or whether some provision might benefit from changes.*
- *Stress management, coping and counselling programmes are worth exploring further. It may be particularly useful to carry out some qualitative research into how these interventions work and the contextual factors which may influence this.*

- *Education and training should continue to be provided to fulfil specific carer needs for knowledge and skills development. Those developing and running these types of intervention should consider structural aspects of the intervention likely to influence its success, particularly the timing and the format of delivery.*
- *Carer breaks should continue to be a priority in carer service development. Those planning breaks services across a local area should consider whether they are offering an adequate supply and range of types of carer breaks.*
- *Those planning and running specific breaks services should consider, in particular, the flexibility of their provision and the nature and quality of the alternative care provided.*
- *It would also be useful for service providers to consider how they can help carers experiencing difficult emotions such as guilt when using breaks services. Future research and service planning must continue to consider any outcomes of carer interventions for the person receiving care and also how this may influence the use of and benefits gained by carers from services.*
- *A number of common factors relating to intervention delivery which came through particularly consistently as potentially significant need to be considered in the planning and delivery of carer services. These included: the approach and qualities of the staff delivering interventions; the flexibility, tailoring and personalisation of services; recognition by service providers of a carer's role, knowledge and expertise; and structural aspects of interventions including the timing of delivery (generally earlier in the caring experience was better), content, the characteristics of the target group and the format of delivery.*
- *In some cases, it will be beneficial to develop services for specific groups of carers (according to either their own characteristics or those of the person they care for).*
- *Service providers should consider the needs of less assertive carers and consider proactive approaches to supporting these carers.*
- *Policy makers, commissioners and service providers should continue to consider carer specific needs as well as those of the person receiving care and their shared needs and preferences.*
- *Service providers should not be complacent about high levels of carer satisfaction but should continue to consider how services can better meet the needs of carers."*

9.1.2 Summary of evidence for particular carer groups

The evidence search to identify systematic reviews of the evidence published after Parker (2010) found that reviews examined the evidence for specific groups of carers. The results are therefore presented by specific carer group.

9.1.2.1 Summary of findings for dementia:

- Cognitive reframing (aims to reduce carers' stress by changing certain of their beliefs, such as beliefs about their responsibilities to the person with dementia, their responsibilities to the person with dementia, their own need for support, and why their relatives behave as they do) may be useful when used alongside other interventions for carers of people with dementia (reduced carer depression, anxiety and stress, but did not impact on coping or burden)
- Only tentative evidence that: psychosocial support and professionally led support groups for carers of people with dementia may have a positive impact on depression.

- No evidence of benefits of respite for carers of people with dementia to carers quality of life, stress or burden. Evidence of increase in burden in one review.
- No good evidence found of cost-effectiveness of interventions for carers of dementia
- Inconclusive evidence for the benefits of respite care for mental health of those caring for frail older people (some evidence of benefit but potential negative effect)
- Some evidence of a positive effect of group psychosocial support for carers of frail elderly on coping ability, knowledge of resources and social support, but inconsistent evidence on carer burden
- Suggestion that there is a need to tailor interventions with the needs and wishes of family care-givers and integrated approaches useful

9.1.2.2 More detailed summary of findings for dementia carers and carers of frail elderly

A systematic review and meta-analysis (Vernooij-Dassen, et al., 2011) which focused on cognitive reframing interventions for family carers of people with dementia found that there was evidence that this intervention reduced carer depression, anxiety and stress, but did not impact on coping or burden. Cognitive reframing is intended to reduce carers' stress by changing certain of their beliefs, such as beliefs about their responsibilities to the person they are caring for, their own need for support, and why the person they're caring for behaves as they do. The review authors noted some problems with the way some of the individual trials were carried out but concluded that cognitive reframing may be useful when used alongside other interventions for carers of people with dementia.

A systematic review of four trials which compared respite care for carers of people with dementia with no respite care (Maayan, et al., 2014) found no evidence of benefits to carers quality of life, stress or burden. Respite was defined as 'any intervention designed to give rest or relief to caregivers'. The authors conclude that further good quality studies are needed.

A systematic review looking at the benefits of dementia adviser services (Corbett, et al., 2010) reported some evidence of benefit on quality of life. However, the reported benefit found on pooling the results of the individual studies on neuropsychiatric symptoms was not in fact significant and no benefit was found for carer burden. The studies reviewed were diverse and often included other interventions (making it potentially difficult to isolate the effect of the dementia advisor). In addition none of the included studies were based in Western Europe, making the findings potentially difficult to apply to the UK.

A meta-analysis of true controlled trials and lower quality experimental trials into professionally led support groups for caregivers of people with dementia (Chien, et al., 2011) found moderate benefit on psychological wellbeing and depression and a small but significant effect on carer burden. Caution is needed because, whilst the quality of the trials within the review was assessed, this information is not presented in the review. However the authors report that the effect size was greater in the better quality studies. The authors do not give any information about the setting of the trials, so it is difficult to know how generalizable the findings are to the UK. The analysis looked at factors which were associated with greater benefit; these included: length and intensity of group sessions and use of theoretical models for psychological wellbeing and depression.

A meta-analysis of trials looking at support to family carers of elderly people with dementia (Schoenmakers, et al., 2010) found a very small and not statistically significant reduction in carer depression and a non-significant reduction in carer burden from psychosocial support. 'Psychosocial support' meant a range of different interventions which teach the caregiver cognitive, behavioural or social strategies to handle problems and to improve the carers wellbeing. The meta-analysis found that respite care resulted in increased reported carer burden (based on two studies where the person with dementia went to either a day or night care centre). Recipients of case management had a reduction in depression, but this was not significant. The authors

discussion points out that many studies include participants from a wide range of ages, with a variety of relationships to the person with dementia and from a range of settings and points to problems with the quality of many of the included studies. The authors recommend that future research should focus on tailoring interventions to the needs and wishes of family caregivers.

A systematic review of the evidence for psychological interventions for carers of people with dementia (Elfish, et al., 2013) considered evidence from quantitative and qualitative studies published between 2005 and 2011. Three studies were from the UK, with the majority of the remainder being from the USA. Seven of eight included studies of psycho-educational skill building found a positive impact on measures relating to depression, anxiety, emotional wellbeing, quality of life, attitudes towards caregiving and anxiety (some studies found no change in the group receiving the intervention, but a decline in the control group). The authors reported that one UK-based qualitative study of Eastern European and South Asian carers found a need for more culturally sensitive and aware services at the point of diagnosis. The review found a positive impact for multi-component interventions on depression and social support. Finally, studies on technology-based delivery of multicomponent or psychosocial interventions found a positive benefit in terms of reduced depression, burden and social support. The review used a scale to assess quality of the studies, but did not provide detail of this or detail of the quality of the individual studies. Information on the size of the effect is also not available. The reviewers report various methodological problems with many of the included studies. As a result it is difficult to judge the reliability of the findings. The reviewers suggest the need for further better quality research, including into cost effectiveness of interventions.

Jones, et al (Jones et al 2012) found insufficient evidence of cost-effectiveness of interventions to support informal caregivers of people with dementia residing in the community. Their review concluded that further research is required to establish this.

Lopez-Hartmann, et al. (2012) carried out a systematic review of the evidence for a range of interventions (respite, psychosocial and ICT) for carers of frail elderly, looking at a range of outcomes (mental health outcomes, quality of life, coping, knowledge, strain, economic burden, social support). The review included both existing reviews of the evidence (some of which were also included in the meta-review by Parker, et al. (2010)) and primary research not covered by these reviews. Overall the review found that the effect of caregiver support interventions is small and inconsistent between studies. The review found that there is some evidence that respite care can reduce depression, burden and anger in carers of frail elderly but may have a negative effect on quality of life and anxiety. The evidence for psychosocial support at the individual caregiver level was conflicting or non-significant across the outcomes considered. For group psychosocial support there was some evidence of a positive effect on coping ability, knowledge of resources and social support, but with inconsistent effects on burden. The reviews which included technology based interventions found a positive (but not statistically significant) effect on some of the outcomes. Whilst the review was not set up to specifically look at integrated care, the authors conclude that integrated and tailored support packages should be preferred when developing support packages for carers of frail elderly.

9.1.2.3 Summary of findings for carers of people with cancer or terminal illness:

(See also section 6.2)

- Few of the studies in included reviews were UK based.
- Evidence of a small effect of interventions including cognitive behaviour therapy (CBT), education, interpersonal counselling, behavioural marital therapy and emotion-focused therapy on carer quality of life, but not enough evidence to recommend which.
- Low quality evidence that interventions to support carers to cope emotionally, reduces distress in the short term. Limited or conflicting evidence for psychological/psychosocial support interventions on measures of carer wellbeing.

- Only low quality evidence for emotional support for carers of person with terminal illness on carer distress

9.1.2.4 More detailed summary of findings for carers of people with cancer or terminal illness

A review by Hopkinson, et al. (2012) looked at psychosocial interventions focused on adult patients and family carers across the whole cancer journey as opposed to solely at the end of life. The review included 27 studies predominantly published in the US between 1999 and 2009, 13 of which included outcomes for carers. The complex interventions all comprised information or education and/ or teaching problem-solving skills or coping skills and/or training in cognitive and behavioural skills. The review found that the outcome areas where a positive change was found were mostly in the domain of emotional health and wellbeing and there was some evidence for the benefits of interventions which support the patient-carer relationship. However, the significance of the study findings were not clearly reported, the studies had small numbers of participants and were sometimes of poorer quality. The review concluded that further studies with a greater number of participants are needed and in addition the theoretical basis behind working with patient and carer as a couple needs further exploration.

Badr and Krebs (2013) pooled and re-analysed the results of 20 previous studies (a meta-analysis) of interventions conducted with both cancer patients and their partners that aimed at improving quality of life. The included studies mostly focused on breast or prostate cancer in couples coping with early-stage disease. Interventions included cognitive behaviour therapy (CBT), education, interpersonal counselling, behavioural marital therapy and emotion-focused therapy. There was variation in number of sessions, session length, number and length of follow-ups and mode of delivery. The meta-analysis found a small (but nevertheless statistically significant) beneficial effect on carer psychological and relationship outcomes. No evidence was found on cost-effectiveness. There was insufficient evidence to recommend one intervention over another and often study authors did not explain a theoretical model behind the chosen intervention. The review did not give information about the setting of the studies, making it difficult to judge whether the results are relevant to the UK setting.

Caress, et al., (2009) reviewed the evidence for interventions which support family carers to provide physical/ practical care to a family member with cancer. The review found that few interventions focused on assisting carers to learn to provide physical care for their family member with cancer. Interventions using problem-solving processes showed promise of benefit to patients and/or carers, although the contribution to physical care was not always clear because of the way the intervention was reported. The reviewers reported that most of the studies were based in the USA and that there were methodological issues which make the results less reliable.

Waldron, et al. (2013) conducted a systematic review of randomised controlled studies of psychosocial interventions in which quality of life was measured as an outcome for adult caregivers. All the studies were classified as skills-training interventions with a cognitive-behavioural approach that included psycho-education. The review found nil to small effects in the four included studies where the impact on quality of life can be calculated with two studies reporting (statistically) significant changes in quality of life.

A review of 11 studies involving 1836 adult caregivers who were caring informally for a friend or relative with a disease in the terminal phase (Candy, et al., 2011) included trials evaluating interventions providing emotional support and advice on coping. In addition two of the studies aimed to support the family and friends indirectly by addressing the needs of the patient. Apart from one of the studies providing patient care, none provided practical support. The studies compared those who had received the intervention with those who had not. The review found low quality evidence that directly supporting the caregiver reduces psychological distress in the short term (statistically significant) and may possibly improve coping skills and quality of life (not statistically significant). One study found no improvement in sleep. Most of the studies did not look

for potential harms of the intervention although one study identified higher levels of family conflict in some of the participants receiving the intervention in one of the trials. The findings of some of the studies reported in the review may be less reliable because they under-report key-design features and may have been conducted poorly.

A review of psychosocial interventions for family carers of palliative care patients (Hudson, et al., 2010) published between 2000 and 2009 found limited evidence of benefits in terms of a variety of outcomes related to carer wellbeing. There was conflicting evidence of benefits of psychosocial support across three of the highest quality included studies which included carer wellbeing as an outcome. Two included qualitative studies reported carer satisfaction with psychosocial support interventions.

Harding, et al. (2011 (Harding, et al., 2011)) reviewed studies published between 2001-2010 which evaluated interventions falling into the categories of: one-to-one psychological methods, psychological interventions for patient/carer dyads, palliative care/ hospice interventions, information and training interventions, respite interventions, group interventions and physical interventions. The most commonly evaluated model of intervention which looked at outcomes for carers was 'group interventions.' Of the highest quality studies in this category, one found significant improvements for caregiver quality of life and task burden; however another found no effect for caregivers of group training intervention. The next highest category in terms of number of studies published was for one-to-one psychological models; only one of the higher quality included studies showed benefit in respect to positive rewards of caring. The review identified the need for further studies which have tightly focused aims and outcomes across a range of populations and settings and in particular on the needs of carers of children with terminal illnesses.

Many reviews of interventions to support carers of a terminally ill friend or relative have identified that retaining participants in trials can be challenging given the potential burden of being involved in a trial when seriously ill or looking after a seriously ill friend or relative.

9.1.2.5 Summary of findings parent carers of young children:

- Evidence that short breaks from care can improve carer wellbeing as perceived by carers themselves and allow carers time to rest and relax.
- Studies that have tried to quantify the impact on health and wellbeing are of poor quality and have found less consistent results in demonstrating a sustained effect on carer wellbeing.
- Lack of evidence on impact of short breaks on other areas of wellbeing such employment.
- Further evidence exploring short breaks within context of other family support services needed.

The summary points above come from a single systematic review of the evidence (Robertson, et al., 2011) of the impact of short breaks provision on families with a disabled child. The review included both qualitative and quantitative evidence including 33 UK studies.

9.1.2.6 Summary of findings carers of people with mental illness:

- Not enough evidence to show which type of family intervention works for carers of people with schizophrenia or psychosis.
- Evidence that carer education improves knowledge but limited evidence of wider benefit.

9.1.2.7 More detailed summary of findings for carers of people with mental illness

(Lobban, et al., 2013) reviewed 50 studies which evaluated family interventions to support carers/ relatives of people with schizophrenia or psychosis. The authors contacted the original trial

authors to obtain additional information about what interventions were delivered. The review found a wide range of interventions, which were categorised into one of the following categories: (1) passive education only; (2) psychoeducation only; (3) psychoeducation plus mutual support; (4) psychoeducation plus skills training; (5) psychoeducation plus skills training plus mutual support. Whilst across the 50 studies, 60% found a positive outcome for carers across a range of outcome measures, the study was not able to find a significant association between positive outcomes and a particular type of intervention – making it difficult to identify what works. The studies included were often of poor methodological quality and a range of outcome measures were considered, making it inappropriate to combine studies in a meta analysis. The need for further research was highlighted, particularly with regard to thinking about how to evaluate integrated systems which embed the needs of carers throughout services.

(Macleod, Elliott, & Brown, 2011) carried out a review of 68 studies for evidence on interventions for family carers of people with schizophrenia. The search strategy aimed to limit the review to interventions which could be carried out by community mental health nurses. The review found that educational interventions (either individual or in groups) improved carer knowledge but had limited impact on carer burden. Interventions which support carers to develop coping strategies and support mechanisms were found in most studies which measured burden as an outcome to reduce carer burden, but conflicting evidence for other measures of wellbeing. However, there was a wide range of intervention components across the studies and a lack of any standard measure of burden, making it difficult to determine the most successful components from the studies. Behaviour family therapy was found to reduce either carer burden or knowledge in most of the 12 studies which studied this included in the review. Relatively few studies looked at the benefits of mutual support groups; the studies included found positive outcomes, but different outcome measures were used across the studies. There was no evidence that day care significantly impacted on burden or health. Limited information was given in the review on the quality of the included studies, making it difficult to interpret the results. In addition the limited search strategy may have resulted in some studies being overlooked.

Chien & Norman (2009) reviewed the evidence for mutual support groups for family caregivers of people with schizophrenia and other psychotic disorders. Whilst the review found some short term benefits for carers, most of the included studies were found to be of poor quality. The only UK study included in the review was a randomised controlled trial of a family support programme compared with usual care. This study was reported as having shown benefits for the carers in the family support group immediately after the intervention and at six months, but no significant differences between the support group and the usual care group.

9.1.2.8 Summary of findings carers of stroke and long term illness

- Information provision for stroke patient and their caregivers found a small but beneficial effect on caregiver knowledge, but no significant impact on carer stress. Some evidence that 'active' information provision ie followed up and reinforced was more effective than passive.
- Further research is needed on what works best to support carers with long term illness.

9.1.2.9 More detailed summary of findings for carers of adults with chronic diseases

Smith, et al (2009) performed a systematic review and meta analysis of 11 randomised controlled trials of information provision for stroke patients and their caregivers. They found a statistically significant but small improvement in carer knowledge but no effect on caregiver stress or satisfaction. They concluded that the best way to give information after stroke to improve outcomes for patients and their carers requires further research.

Glasdam, et al. (2010) carried out a systematic review of interventions for carers of adults with stroke, diabetes, cardiovascular disease and cancer. The review found no studies of interventions

to support carers of adults with diabetes which met their inclusion criteria. Whilst 22 of the 32 included studies included positive outcomes, there was insufficient description of the interventions to make them replicable elsewhere and a range of outcome measures were used with little discussion of whether the outcome measure chosen was a valid measure for benefit for the given intervention. It was therefore difficult to recommend any particular intervention to improve wellbeing of carers of adults with chronic diseases.

9.1.3 Other evidence

The evaluation of the National Carers' Strategy demonstrator sites programme (CIRCLE, 2011) reports on a programme in which the Department of Health supported 25 local partnerships to develop innovative services for carers. The programme focused on three areas of support:

- New approaches in offering breaks to carers (short-term respite for carers of people with dementia/mental ill health; alternative care in the home; personalised breaks).
- Delivering annual health and health and wellbeing checks for carers (including using non-clinical staff).
- Providing support in hospital and primary care settings.

A mixed methods evaluation was carried out which included case-studies, surveys, staff interviews and local evaluation data. Key findings of the evaluation included:

- Sites which succeeded in identifying and engaging large numbers of carers used a combination of techniques such as adopting tailored initiatives for target groups of carers.
- Partnerships and networks played an important role in engaging with carers eg reaching young carers through partnerships with school, colleges, youth centres and universities.
- Most carers became aware of the carers' breaks and health checks services from their GP surgery or carers centre.
- Carers were positive about the support they had received.
- Most sites reported evidence of improvements in health and wellbeing, however, the methods for evaluating this varied across sites and the evaluation report does not allow the strength of the evidence to be assessed. A measure of wellbeing (which measured mood, vitality and general interests) used across all health check and breaks sites showed an increase in 'poor wellbeing'; however the authors point out that this was based on a small sample (the statistical significance was not reported), without a comparison to carers not receiving a service and may have reflected increased strain in the caring situation.

Whilst the project had aimed to gain a better understanding of which models of delivery and types of carer support are cost effective in terms of direct provision and the wider potential cost savings in the health and social care system, this was not possible from the data collected by the pilot sites. Total overall sites costs and cost per carer supported varied across the sites. Some sites presented evidence from case studies, professional opinion or small surveys that all three models have the potential to deliver cost savings. However, robust evidence which used comparisons with carers not receiving an intervention was not provided. Providing this sort of evidence in the future was identified to be a key challenge.

The report makes the following recommendations:

1. In all localities, efforts to bring local authorities, NHS organisations and voluntary sector organisations together to develop and deliver effective support for carers, in partnership, should be strengthened.

2. Local carer support partnerships should involve a diverse range of carers in service development.
3. In delivering support to a wide range of carers and reaching carers not already in touch with services, local partnerships should work flexibly, and sometimes on an ad hoc basis, to engage carers in specific target groups.
4. Effective carer support at the local level should always include a varied portfolio of carer support services, which can be adapted to meet individual needs.
5. Portfolios of carer support need to be agreed locally between local authorities, NHS organisations, voluntary sector organisations and other organisations where appropriate.
6. Hospitals should routinely provide mechanisms to identify and support new carers, centring their efforts on wards where patients have received a new diagnosis or are due to be discharged and on out-patient clinics where patients are likely to be accompanied by those who care for them.
7. Every GP practice should be encouraged to identify a lead worker for carer support, who can assist in carer identification, help in referring carers to suitable local services, and ensure carers' access to health appointments and treatments is not impeded by their caring circumstances.
8. All staff who interact with carers, in hospitals, GP practices, local authorities and in the voluntary sector should be trained to consider how caring responsibilities can impact on a carer's health and wellbeing and equipped to advise on how a carer can access a health and / or wellbeing check.
9. All relevant organisations should regularly offer carer awareness training to their staff.

9.2 What improves carers' health and reduces service use?

A rapid review of the literature was carried out to look for evidence that these interventions improve outcomes for the cared for person in terms of service use, again concentrated on reviews of the literature and published national reports.

9.2.1 Overall summary:

- There are gaps in the limited UK-based evidence that supporting carers reduces service use in those they are caring for.
- This is not the same as saying there is evidence that interventions are not effective.
- There is a need for well controlled trials for specific groups, informed by pilot studies.
- Further evidence is needed for cost effectiveness of respite care.
- There was mixed evidence on impact of respite care on delaying institutionalisation with a focused review of UK literature finding delays in admission to residential care associated with home help care, day care and (for some groups) institutional day care.
- However, one well conducted systematic review found no reliable evidence that respite delays entry to residential care.
- This is not the same as saying there is evidence that services are not cost effective.

9.2.2 More detailed summary

A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers (Mason A. , et al., 2007) found some evidence of a small positive effect upon carers in terms of burden and mental or physical health.

Many studies reported high levels of carer satisfaction. The review found no reliable evidence that respite delays entry to residential care. Some of the included studies had methodological problems. The best quality studies were from outside of the UK and it may be difficult to generalise the findings. Cost effectiveness evidence was only available for day care. Economic evidence suggests that day care is at least as costly as, and may be more expensive than, usual care (only one economic evaluation was UK based). The authors concluded that the current evidence base is insufficient to inform policy and that better quality research is needed.

A systematic review and meta-analysis of cognitive re-framing for carers of people with dementia (Vernooij-Dansen, Draskovic, McCleery, & Downs, 2011) showed beneficial effects over usual care for carer mental health. Only one study included institutionalisation and did not demonstrate any delay in this outcome. No benefit was found in terms of carer burden.

A systematic review of respite for people with dementia and their carers (Lee & Cameron, 2004) found a lack of high quality research in this area. The three randomised controlled trials included in the study varied widely in the intervention, duration and outcomes studied. There was insufficient evidence on rate of institutionalisation.

A focused review of the UK literature by the Audit commission (Pickard, 2004) looked at the effectiveness and cost effectiveness of respite care of older adults (60+ or 65+) and included cost effectiveness studies from the US literature. For findings on cost effectiveness, the review drew largely on one UK study from 1994/05 which was concerned with the effects of the community care reforms on outcomes for the general population of frail elderly people using community services. Daycare, home help/care, institutional respite care and social work/counselling were found to be effective and/or cost-effective for carers in terms of one or more of the outcomes - in improving carer welfare and delaying admission to institutional care.

A report for the Princess Royal Trust for Carers and Crossroads Care (2011) states that investing in respite care results in savings resulting from reduced costs to health and social care: spending more on breaks, training, information, advice and emotional support for carers reduces overall spending on care by more than £1bn per annum, as a result of reductions in unwanted (re)admissions, delayed discharges and residential care stays". In making this statement, the document cites a randomised controlled trial of family support to families of stroke patient, reporting that this trial found a shorter length of hospital stays (and resulting costs) in the treatment arm. A case study of case coordinators for carers of people with end-stage heart failure in Tower Hamlets (which is reported as reducing hospital admission) is also presented. Similarly support pre-discharge at a hospital trust in Bristol is reported as reducing bed days. With regard to reducing admission to residential care, three non-UK studies are cited, but there is no discussion of whether the findings of these studies are generalizable to the UK. The document is not presented as a systematic review (eg does not state inclusion criteria, does not discuss methodological rigour of included studies). Savings for individual councils are given in an appendix; these are modelled based on assumptions in reductions in residential care.

A pilot project in Scotland (Kelly, Watson, West, & Plunkett, 2010) aimed to prevent crises for carers through early identification and support to carers (including carers assessment) when in contact with services and the promotion of integrated joint working between sectors. The project promoted certain core outputs (eg supporting carers and improving access to carers' assessments using dedicated project workers) which were then applied slightly differently across four pilot sites. The evaluation reported benefits eg an increase in the number of carers identified as such during a hospital admission, but did not result in a reduction in readmissions during the course of the project.

A social return on investment study (The Princess Royal Trust for Carers, 2011) modelled potential economic savings resulting from carer support at carers' centres and estimated that there are wide societal benefits which exceed the cost of this support. This evidence was based on applying financial values to benefits based on the evaluation of five case studies. A set of assumptions were used relating to the impact of support on factors such as ability to work, prevention of ill

health and prevention of admission to residential care. A range of data was used to model the impact of caring on a range of factors. The data sources and assumptions were clearly presented. The impact of support on carer outcomes, such as reduced risk of illness and a delay to admission to residential care, was based on consensus opinion relating to the five case studies plus unpublished data. In addition a randomised controlled trial from the US on the impact of family intervention to delay nursing home placement of patients with Alzheimers disease was cited, but with minimal discussion of the generalizability of this study to the UK population or reference to the wider literature. As a model based on consensus, it provides a lower level of evidence than the systematic reviews presented above and does not provide direct evidence of cost effectiveness.

9.3 Good practice guidance:

The Triangle of Care - Carers Included: A Best Practice Guide in Acute Mental Health Care available at <http://static.carers.org/files/caretriangle-web-5250.pdf>

Commissioning for carers. Royal Colleague of General Practice 2013. Available at http://www.rcgp.org.uk/clinical/clinical-resources/~/_media/Files/CIRC/Carers/RCGP-Commissioning-for-Carers-2013.ashx

10 What is this telling us?

10.1 What are the key inequalities?

National survey data tells us that carers report that caring has an impact on their physical, emotional and economic wellbeing. Carers may also not prioritise their own health for and may miss routine health appointments, like influenza vaccinations or check-ups, with doctors or dentist.

Carers may give up work as a result of their caring responsibilities. This is significant given the importance of 'meaningful activity' (such as employment) to maintaining an individual's positive mental health. Such activity also reduces social isolation.

Cambridgeshire asset mapping has identified the importance of local community networks and services in supporting the health and wellbeing of carers. Carers in new communities may, therefore, be at risk of having fewer opportunities for support.

In addition, young carers are more likely to grow up in poverty, have poorer school attendance and attainment, to be not in education, employment or training (NEET) and to be bullied and see physical aggression at home. All of these issues may impact on future life chances into adulthood.

Carers from BME groups are likely to be under-identified in Cambridgeshire. Services for carers are not necessarily culturally sensitive in relation to the Gypsy and Traveller community. This community is at particular risk of missing out on Carers Allowance because of the impact of travelling and may be forced to move away from established community networks to be able to access equipment and adaptations.

10.2 What are the key trends?

The number of carers in Cambridgeshire increased between 2001 and 2011, the proportionate increase was greater than for the general population. There will be further population growth in Cambridgeshire, including new developments, which means the number of carers are expected to increase. The population in Cambridgeshire is ageing, which will result in a larger number of adults with care needs.

10.3 What are the gaps in knowledge/services?

10.3.1 All carers

The Care Act 2014 requires services to prevent and reduce future needs through the early identification and support of carers. Considering the large number of carers identified in the census work, is needed to understand how best to support carers who do a small amount of caring, especially those who are likely to go on to care more intensively for someone whose needs are increasing over time, with staying healthy and well. Given the low level of evidence available on what works best to keep carers healthy and well, building in evaluation of interventions will be crucial.

The survey carried out as part of the JSNA process yielded some useful information, but further work is needed to systematically capture the views of carers. This could include use of reference groups or known distributions groups (for example receiving carers' magazine) or better use of information collected at contact points with carers (eg carers' assessment, carers' prescription). The best response was achieved with parent carers, suggesting that there are good networks within this particular group of carers. This further suggests that there may be learning from models like Pinpoint for other carer groups.

NICE guidance and good practice documents recommend that carers involved in patient care are identified as soon as possible and supported appropriately. This includes having information

sharing and confidentiality protocols in place. In addition, national carer policy points to the need to take a holistic approach to assessing the needs of the carer and cared-for person together. It is important that carers are recognised and supported within acute hospitals and that their needs are identified at hospital discharge. Work in Addenbrooke's Hospital has shown the capacity to recognise and support carers and link to community based support, emergency planning and referral to GP carer registers where they exist. It is currently not possible to measure whether carer status is being recorded in the multidisciplinary team record at discharge across Cambridgeshire.

Asset mapping of services in Cambridgeshire suggests that not all carers providing high intensity care (as identified in the 2011 census) have a plan in place to deal with an unexpected emergency that stops them being able to carry out their caring role. However, this information does not include carers who have nominated a friend or family member in this role. It is also important to ensure services and the wider community are able to support carers with lower level, 'urgent' issues, including supporting carers out of hours. Planning is also important for transitions in care eg child to adult, death of carer.

Accurate data are not available on the number of carers registered in primary care in Cambridgeshire. The GP surgery is often the first point of call for carers and most want to use surgeries as a source of support or referral. The Cambridgeshire carers' prescription service has resulted in the identification and referral for support of carers not in receipt of any other support and linked many to emergency support and ICER plans. National surveys suggest that GPs could do more to support carers. A survey carried out as part of this JSNA suggests that some carers in Cambridgeshire are not registered as carers with their GP and where they are, do not receive practice services tailored to their needs eg flexible appointments. The prescription service shows that some surgeries are providing very good support for carers but this is variable. Further work is needed to understand the provision of services to carers in Primary care in Cambridgeshire and include in a Cambridgeshire carers assets map.

Most carers who are recently bereaved do not require specific 'bereavement counselling'. However, education is needed for GPs and other primary care professionals in identifying when a referral is needed. Whilst support services for the bereaved have been mapped by Cambridgeshire and Peterborough Clinical Commissioning Group, the availability and quality of services for bereaved carers in Cambridgeshire is not known. Support for carers both during a terminal illness and following death is variable and there are inequalities in provision on the basis of the diagnosis, place of death and socio-economic status.

In addition to the key findings above, a carers JSNA stakeholder event identified a general need for joint working and joint training across organisations.

10.3.2 Young carers

Joint working between services specifically working with young carers and mainstream preventive services for children and young people is needed to ensure that young carers are seen as a vulnerable group, their needs identified early and seen in the context of the whole family (for example through ensuring good parenting support)

National data tells us that young carers have poorer educational outcomes than their peers. Information from local focus groups tells us that children are worried about meeting deadlines and managing homework at school. However, at a population level it is not possible to identify numbers of young carers in Cambridgeshire schools or to look at local educational outcomes for this potentially vulnerable group. Support at transition to adulthood (from age 14) is needed to ensure young carers continue in education or training and to ensure good health outcomes. A multidisciplinary approach is needed to ensure each child or young person is able to access education and fulfil their educational potential.

Data on the referrals of young carers to organisations like Centre 33 and Carers Trust Cambridgeshire suggest that adult services need to do more to identify young carers and take action to support their needs, particularly mental health, drug and alcohol services. There is poor take up of young carers services by black and ethnic minority communities.

There are few dedicated services for young adult carers in Cambridgeshire although The Carers Trust Cambridgeshire has funding for a new project this year in Huntingdon and Fenland. This suggests that this group of carers may be missing out on advocacy, information and advice on issues such as finance and employment as well as emotional support and opportunities to socialise. However, currently the way data on service use by young adults, is recorded makes it difficult to identify the support this group is receiving from adult services. With a lack of engagement, young adult carers have no voice. They need mechanisms to be heard and involved in the planning, review and evaluation of Carers Services.

Cambridgeshire young adult carers have identified the following gaps:

- Poor access to Information and Advice for young adult carers.
- Poor access to Carers Assessments for young adult carers.
- Poor access to support to access social and leisure activities for young adult carers.
- Poor access to participation opportunities and chances to be heard for young adult carers.

11 References

- Badr, H., & Krebs, P. (2013). A systematic review and meta-analysis of psychosocial interventions for couples coping with cancer. *Psycho-oncology*, 22, 1688-1704.
- Beautrais, A. (2004). *Suicide Postvention: - Support for families, whanau and significant others after a suicide. A literature review and synthesis of evidence*. Wellington, New Zealand: Beautrais AL (2004) Suicide Postvention: - Support for families, whanau and significant others after a suicide. A literature Ministry of youth Affairs.
- 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*. The Cochrane Collaboration.
- Carers Trust. (2013). *A Road Less Rocky - Supporting Carers of People with Dementia*.
- Carers UK. (2012). *"In Sickness and in Health". A survey of 3,400 UK carers about their health and well-being*.
- Carers UK. (2013). *The State of caring*.
- Carers UK. (2014). *Caring and Family Finances Inquiry: UK report*.
- Caress, A.-I., Chalmers, K., & Luker, K. (2009). A narrative review of interventions to support family carers who provide physical care to family members with cancer. *International Journal of Nursing Studies*, 46, 1516-1527.
- Centre for Reviews and Dissemination. (2006). *Systematic review of the clinical effectiveness of self care support networks in health and social care*. University of York.
- Chien, L., Chu, H., Guo, K., Liao, Y., Chang, L., Chen, C., et al. (2011). Caregiver support groups in patients with dementia: a meta-analysis. *International Journal of Geriatric Psychiatry*, 26, 1089-1098.
- Chien, W., & Norman, I. (2009). The effectiveness and active ingredients of mutual support groups for family caregivers of people with psychotic disorders: a literature review. *International Journal of Nursing Studies*.
- CIRCLE. (2011). *New Approaches to Supporting Carer' Health and Wellbeing: evidence from the National Carers' Strategy Demonstrator Sites programme*.
- Corbett, A., Stevens, J., Aarsland, D., Day, S., Moniz-Cook, E., Woods, R., et al. (2010). Systematic review of services providing information and/or advice to people with dementia and/or their caregivers. *International Journal of Geriatric Psychiatry*, 27, 628-636.
- Department of Health. (2008). *End of Life Care Strategy*.
- Department of Health. (2012). *Preventing suicide in England: A cross-government outcomes strategy to save lives*.
- Elfish, R., Lever, S., Johnstone, J., Cawley, R., & Keady, J. (2013). Psychological interventions for carers of people with dementia: A systematic review of quantitative and qualitative evidence. *Counselling and Psychotherapy Research*, 13(2), 106-125.
- Glasdam, S., Timm, H., & Vittrup, R. (2010). Support Efforts for Caregivers of Chronically Ill Persons. *Clinical Nursing Research*, 19(3), 233-265.
- Harding, R., List, S., Epiphaniou, E., & Jones, H. (2011). How can informal caregivers in cancer and palliative care be supported? An updated systematic literature review of interventions and their effectiveness. *Palliative Medicine*, 26(1), 7-22.
- Hirst, M. (2004). *Hearts & Minds: The health effects of caring*. Glasgow: Carers Scotland.

- HM Government, Carers UK and Employers for Carers. (2013). *Supporting Working Carers: The Benefits to Families, Business and the Economy*.
- Hopkinson, J. B., Brown, J. C., Okamoto, I., & Addington-Hall, J. (2012). The Effectiveness of Patient-Family Carer (Couple) Intervention for the Management of Symptoms and Other Health-Related Problems in People Affected by Cancer: A Systematic Literature Search and Narrative Review. *Journal of Pain and Symptom Management*, 43(1), 111-142.
- Hudson, P., Remedios, C., & Thomas, K. (2010). A systematic review of psychosocial interventions for family carers of palliative care patients. *BMC Palliative care*, 9(17), 1-7.
- Jones, C., Tudor Edwards, R., & Hounsborne, B. (2012). A systematic review of the cost-effectiveness of interventions for supporting informal caregivers of people with dementia residing in the community. *International Psychogeriatrics*, 24(1), 6-18.
- Kelly, T. B., Watson, D., West, J., & Plunkett, S. (2010). *The Moffat Project: Preventing Crisis for Carers. Final Evaluation Report*. The Princess Royal Trust.
- Lee, H., & Cameron, M. (2004). Respite care for people with dementia and their carers. *Cochrane Collaboration*(1).
- Lobban, F. P., Glentworth, D., Pinfold, V., Wainwright, L., Dunn, G., Clancy, A., et al. (2013). A systematic review of randomised controlled trials of interventions reporting outcomes for relatives of people with psychosis. *Clinical Psychology review*, 33, 372-382.
- Lopez-Hartmann, M., Wens, J., Verhoeven, V., & Remmen, R. (2012). The effect of caregiver support interventions for informal caregivers of community-dwelling frail elderly: a systematic review. *International Journal of Integrated Care*, 12, 1-16.
- Maayan, N., Soares-Weiser, K., & Lee, H. (2014). *Respite care for people with dementia and their carers*. The Cochrane Collaboration.
- Macleod, S., Elliott, L., & Brown, R. (2011). What support can community mental health nurses deliver to carers of people diagnosed with schizophrenia? Findings from a review of the literature. *International Journal of Nursing Studies*, 48, 100-120.
- Mason, A., Weatherly, H., Spilsbury, K., Arksey, H., Golder, S., Adamson, J., et al. (2007). A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers. *Health Technology Assessment*, 11(15).
- Moriarty, J. (2005). *Update for SCIE best practice guide on assessing the mental health needs of older people*. London: Social Care Workforce Research Unit.
- Office for National Statistics. (n.d.). *VOICES survey*.
- Parker, G., Arksey, H., & Harden, M. (2010). *Meta-review of international evidence on interventions to support carers*. York: Social Policy Research Unit, University of York.
- Phillips, L. (2000). Abuse of Female Caregivers by Care Recipients: Another Form of Elder Abuse. *Journal of Elder Abuse & Neglect*, 12, 123-143.
- Pickard, L. (2004). *The effectiveness and cost-effectiveness of support and services to informal carers of older people. A review of the literature prepared for the audit commission*. Audit Commission .
- Qin, P., Agerbo, E., & Mortenson, P. (2002). Suicide risk in relation to family history of completed suicide and psychiatric disorders: a nested case-control study based on longitudinal registers. *Lancet*, 360, 1126-1130.
- Robertson, J., Hatton, C., Wells, E., Collins, M., Langer, S., Welch, V., et al. (2011). The Impacts of short break provision on families with a disabled child: an international literature review. *Health and Social care in the Community*, 19(4), 337-371.

- Royal College of General Practitioners. (2013). *Commissioning for carers*.
- Schoenmakers, B., Buntinx, F., & DeLepeleire, J. (2010). Supporting the dementia family caregiver: The effect of home care intervention on general well-being. *Aging and Mental Health, 14*(1), 44-56.
- Smith, J., Forster, A., Young, J., & stroke, o. b. (2009). Cochrane review: information provision for stroke patients and their caregivers. *Clinical Rehabilitation, 23*, 195.
- Stroebe, M., Schut, H., & Stroebe, W. (2007). Health outcomes of bereavement. *Lancet Dec 8; 1960-73, 370 (9603); 370(9603), 1960-73*.
- The Princess Royal Trust for Carers. (2011). *Social Impact Evaluation of five Carers' Centres using social Return on Investment*.
- The Princess Royal Trust for Carers and Royal College of General Practitioners. (2011). *Supporting Carers: An action guide for General practitioners and their teams*.
- The Princess Royal Trust for Carers and Crossroads Care. (2011). *Supporting Carers: The case for change*.
- The Scottish Government. (2005). *National Care Standards: short breaks and respite care services for adults*.
- Vernooij-Dansen, M., Draskovic, I., McCleery, J., & Downs, M. (2011). Cognitive reframing for carers of people with dementia. *The Cochrane Collaboration*(11).
- Victor, E. (2009). *A Systematic Review of Interventions for Carers in the UK: Outcomes and Explanatory Evidence*. London: The Princess Royal Trust for Carers.
- Waldron, E. A., Janke, E. A., Bechtel, C. F., Ramirez, M., & Cohen, A. (2013). A systematic review of psychosocial interventions to improve cancer caregiver quality of life. *Psycho-Oncology, 22*, 1200-1207.
- Whittingham, K., Barnes, S., & Gardiner, C. (2013). Tools to measure quality of life and carer burden in informal carers of heart failure patients: A narrative review. *Palliative Medicine, 27*(7), 596-607.

12 Appendices

12.1 APPENDIX 1: Census question and definitions

The 2001 and 2011 Census forms asked whether you provided unpaid care to family members, friends, neighbours or others because of long-term physical or mental ill-health or disability, or problems related to old age and for how many hours per week.

Carer

Provision of unpaid care

- A person is a provider of unpaid care if they look after or give help or support to family members, friends,
- neighbours or others because of long-term physical or mental ill-health or disability, or *problems related to old
- age. This does not include any activities as part of paid employment. No distinction is made about whether any
- care that a person provides is within their own household or outside of the household, so no explicit link can be
- made about whether the care provided is for a person within the household who has poor general health or a longterm
- health problem or disability.

The following Carer categories are available:

- All categories: Provision of unpaid care
- Provides no unpaid care
- Provides unpaid care: Total
- Provides 1 to 19 hours unpaid care a week
- Provides 20 to 49 hours unpaid care a week
- Provides 50 or more hours unpaid care a week

General Health

- General health is a self-assessment of a person's general state of health. People were asked to assess whether
- their health was very good, good, fair, bad or very bad. This assessment is not based on a person's health over
- any specified period of time.

The following categories of General Health are available:

- All categories: General health
- Very good or good health
- Fair health
- Bad or very bad health

12.2 APPENDIX 2: Consultation

Consultation: people providing care in Cambridgeshire – February 2014

Consultation: People Providing Care in Cambridgeshire

Feb 2014

Background

Joint Strategic Needs Assessments (JSNAs) describe the future health, care and wellbeing needs of local populations, the strategic direction of service delivery and the commissioning requirements to meet those needs. The reason for doing a JSNA is to develop the evidence base for the health and social care response so that it more closely meets the prioritised needs of local people and to inform the Joint Health and Wellbeing Strategy.

The Cambridgeshire JSNA has adopted a client based model that has a phased approach. Consequently each phase focuses upon the development or updating of a JSNA for a specific client group. One topic selected for the JSNA programme of work for 2013-2014 is 'carers'. The Carer's JSNA will summarise the key areas of need for carers in Cambridgeshire, including carers of all ages, including young carers and parent carers.

As part of this work, a public consultation was held focusing on those who care and seeking views on the question "How do we support carers to stay healthy and well in Cambridgeshire?"

Introduction

Between 13 January and 14 February a consultation was run to support the development of the carers JSNA. Questions examined the types of people who were carers or were cared for. It then looked into respondents' involvement with health and other services, their general wellbeing, their current level of support and longer-term planning.

In total, 85 people responded, and this document summarises the consultation responses. Separate consultation exercises were also held with younger carers for whom an online survey was not the best method of communication.

Section 1: The Respondents and Those they Care For

85% of those who responded were female, and the majority were aged between 35 and 54 (73%). The following chart summarises the age breakdowns.

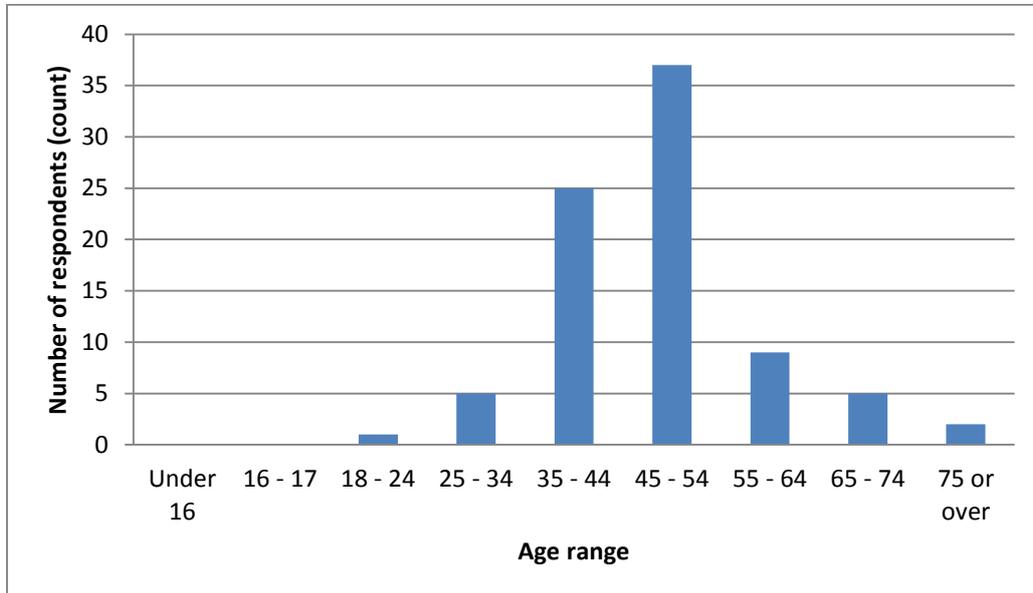
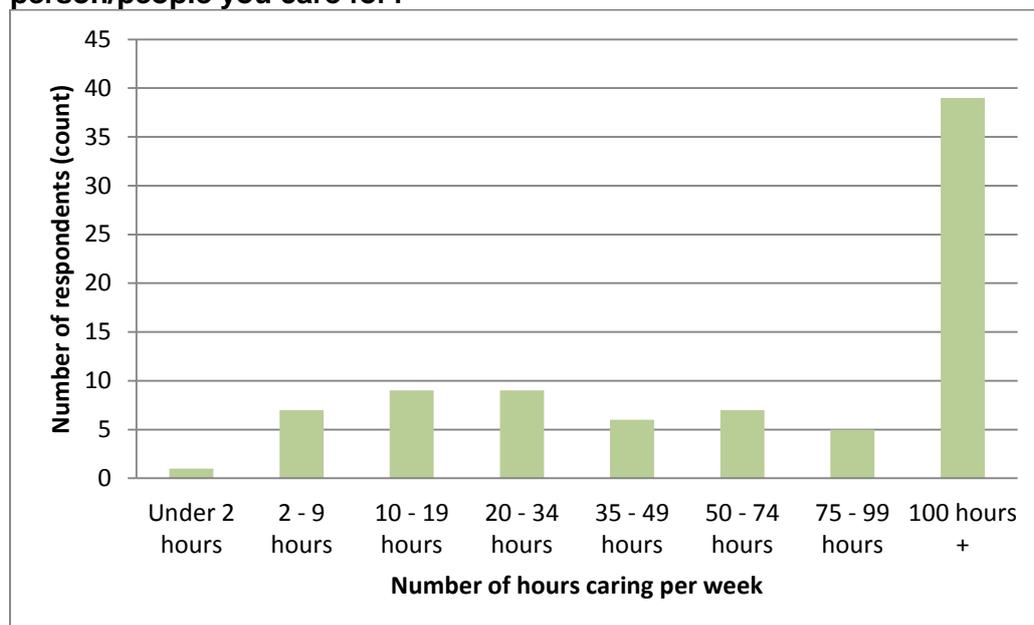


Fig 1: Age of respondents

For the most part, respondents personally did not have any long-standing conditions/disabilities (58%). Respondents were invited to list their connection to the person/people they cared for. Children were more commonly cared for (71%), with 21% caring for a parent. The following chart outlines the length of time carers spent each week looking after or helping the person/people they care for. As you can see, the majority stated they spent 100 hours or more as a carer. Examining this by age showed the same trend for all groups.

Fig 2: Length of time each week respondent spends looking after or helping the person/people you care for?

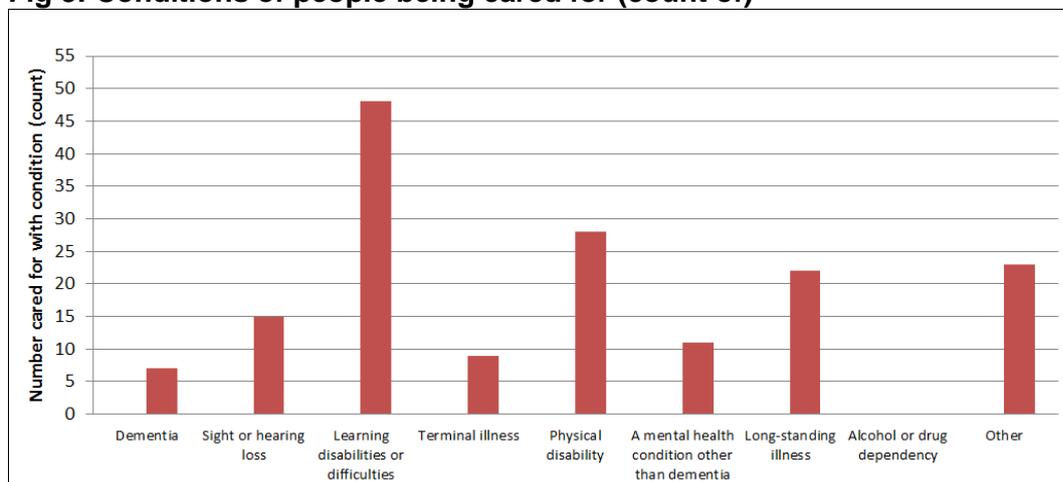


Looking at those who were cared for, respondents were asked to consider a number of questions focused on the person they spend most time caring for. It should be noted that a number of respondents did indicate that they cared for more than one person.

The highest proportion were aged under 16 (45%), and 17% were aged over 74. The significant majority of those cared for for 100 hours or more were aged under 25 (82%) – a higher percentage than for all respondents(69%). 74% of respondents indicated that the person they care for lived with them. Of those that indicated they lived elsewhere, 77% were aged over 64 years (59% over 74).

Respondents were asked about the conditions the person they cared for suffered from. Learning disabilities/difficulties were identified by 57%, and the following chart breaks down answers to this question. Note that respondents were invited to select more than one answer.

Fig 3: Conditions of people being cared for (count of)



Other conditions mentioned included ADHD, Autism, chronic fatigue syndrome, hypermobility, sleep apnoea and genetic disorders linked to the SETBP1 gene.

A higher proportion of respondents (46%) indicated that no further equipment (such as grab rails, ramps or free-standing hoists) or special adaptations (EG widening of doorways) was required to support their caring role. 8% indicated a need for equipment/adaptations that that not been made so far. This accounted for seven respondents, three of which indicated they spent over 100 hours per week caring.

Respondents were then asked to consider their experience of accessing assistive technology or sensory equipment (alarms/sensors/remote health monitoring) to support their caring. 34% of respondents indicated they were not aware of what technology was available – and 55% of these were people who cared for someone for 100 hours or more per week. Overall, 9% of respondents indicated they did get support and were happy with it.

Issues around service provision for set groups of people requiring care were comment on in this section. One respondent indicated difficulties accessing care, one example being around mental health support where episodes requiring support are typically unpredictable.

Section 2: Respondents' involvement with health & other services

64% of respondents indicated that their GP was aware of their caring responsibilities. This was unsurprisingly higher with those who spend more hours as a carer (71% of those caring for 100 hours or more). Letting a GP practice know of a carer's status means they can better support carers to stay healthy and well as well as giving advice on other services which can support people

in their caring roles. Respondents who indicated that their GP was aware were asked about extra support they might receive. The following table outlines their responses – as you can see the most common response is that nothing is done differently.

Fig 4: Response counts to question “If your GP does know that you have caring responsibilities, do they give you extra support or treat you differently as a result?” (Tick as many as apply)

Respondents (count)	Does your GP provide you with extra support?
32	They know I'm a carer but don't do anything different as a result
14	They can do telephone appointments if I can't get to the surgery
9	They ask about my caring responsibilities
7	Other - please specify:
4	They have referred me to social services for a carers' assessment to look at my needs & possible support available
3	They do home visits if I can't get to the surgery
3	They give me information on local sources of support
2	They give me a regular health check to ensure I'm coping
0	They give me advice and information on financial and practical support for caring

Other comments showed that some carers have indicated they are looking after someone, but that it has not been made explicit and therefore no support has been offered. Responses are either neutral or positive where support has been offered. For this cohort, 37% indicated they had gone on to have a carers assessment – and of those the most common outcome was for them to be added to a mailing list (50%), registered with an ICER plan (35%) and signposted to other sources of information (30%)

For those 14 people that stated their GP was not aware of their caring responsibilities, 5 indicated a lack of awareness that they could register with their GP, and 4 stated they did not feel it was necessary as it did not affect their health. All four of these people indicated that they had varying lines of support including from family members, and not having needed any out-of-hours support.

For all respondents to the survey, only 27% indicated they had received a carer's assessment as part of their caring role. This assessment is a discussion that helps services to understand the impact that caring is having on a carer's life, and ensuring their welfare is considered and supported. The majority of these were carers who also indicated their GP surgery was aware of their situation. The following table outlines the actions resulting from those who had caring assessments carried out:

Fig5: Response counts to question: “If you have had a carer’s assessment, please tell us the outcome” Please tick as many as apply.

Respondent (count)	Results following carer’s assessment
12	Added to Carer's Mailing List for Newsletter and Directory
9	Registered an Individual Carers Emergency Respite (ICER) Plan
8	Access to a local Carer's Drop In or group
8	Other
7	Information and advice, including signposting to other sources of information
4	Replacement care to take a break from your caring role
2	Adjustment to the support and services for the person you care for
2	Referral for Carer's Advocacy Service

Assessment done when caring as well for my husband, now deceased.
I don't think I have had one, but we receive services, so I might have!
I spend my time telling people what's available
I've been looking after my daughter for 16 years and had to put her into emergency respite last week
mental health said they did not do carers breaks it was blanked out on the form
Nil from carer's assessment.We have been supported in many ways since the birth of our disabled son.
Personal budget can be used for respite care
Shared care for child. No care yet for parent but still in early stages of medical investigations
This was many years ago and nothing positive came out of the assessment
Yes but not as a result of my caring - it's via my daughters assessment

Section 3: Respondent wellbeing

Respondents were then asked to consider the effect that caring has had on their life, and on their general wellbeing. Respondents were asked about people they could contact, at any time if they needed support. Family members (66%) and friends (49%) were highlighted by more respondents, with 13% indicating they had no one to contact. Specific comments linked to organisations & groups including the County Council, Carer’s Trust, the Disability Partnership and Macmillan amongst. It was noted by one that “*Friends and family are good to talk to but don't really offer much practical help*”. The ability to talk freely and openly with those they could contact was raised – the following table outlines how far people felt they could and couldn’t do so with:

Fig 6: Response to question “Of those people you contact for support, can you talk openly and share your feelings with them?” – % respondents.

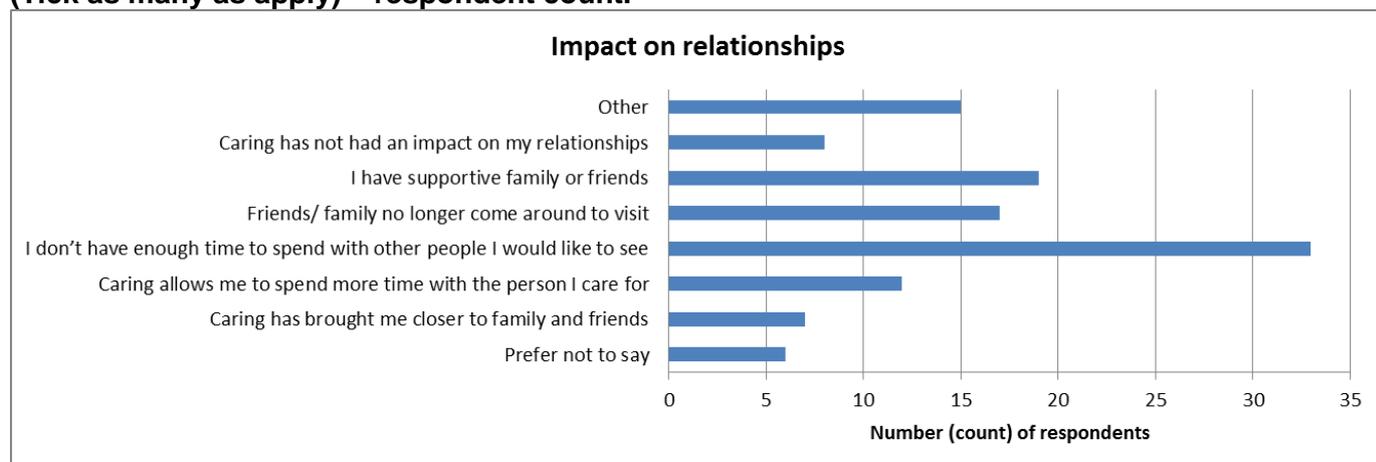
Contact group	% Yes	% No
A family member	59	12
A friend	46	12
A support group	16	13
A professional	19	10

Further details were given by some respondents on their experience of communicating their situation with others. Many indicated a sense of isolation, and that the sometime chaotic life of being a carer was not always understood by others – be it family, friends, or professionals: “*Unless it is someone who lives with what you do then they often don't understand the feelings that you have, I am often told by well meaning people that there are people out there who are worse off than us which is true but not helpful.*” Emotional and mental health issues were noted, with a number stating that they only sought help when in real need.

Respondents were asked to consider the impact that caring has had on their capacity to work. 35% indicated they had given up work to care, 34% that they reduced their working hours to care, and 26% that they took a less qualified job or turned down promotions to fit around their caring responsibilities. With regards to the impact on schoolwork, training or education, 18% felt they were unable to take up further education or training as a result of their caring responsibilities. Again a common reflection was that the unpredictable hours of caring caused issues due to the typically inflexible nature of work or education/training. 80% of respondents indicated that their school/workplace was aware that they cared for someone.

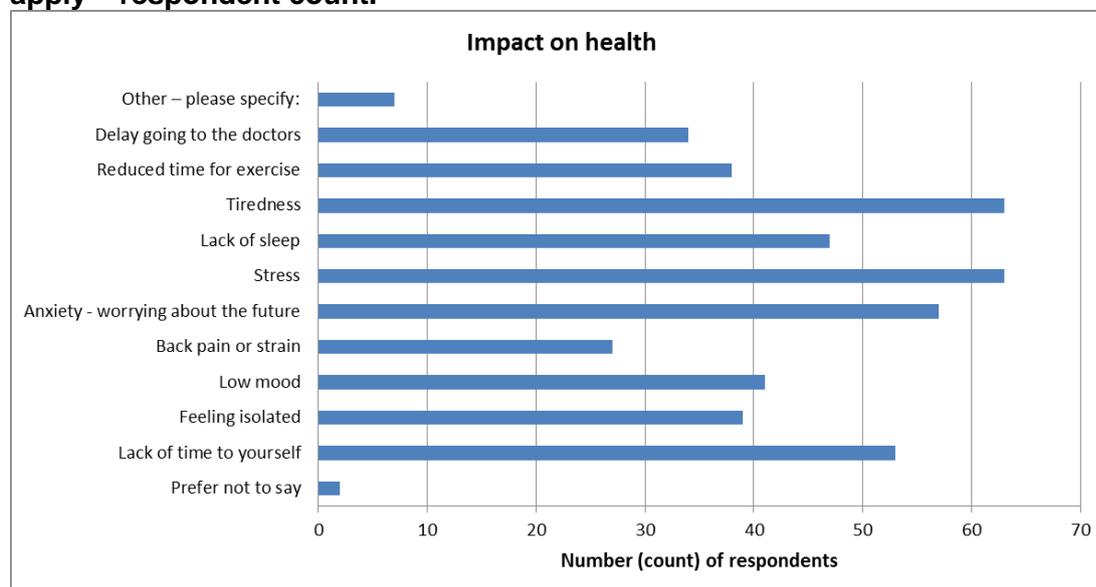
Many respondents stated that caring responsibilities meant they did not have enough time to spend with other people they would like to see. The following bar chart summarises the varying impacts on personal relationships that caring has had. In further comments many indicated the strain that caring for a person has on family relationships. Some indicated a complete family breakdown, leading to separations and divorce. Others highlight the strain and restrictions having time to maintain relationships – “*Negative impact on other children in the family, have to look after A, no time for B and C.*”

Fig 7: Response to question “Has caring had an impact on your personal relationships?” (Tick as many as apply) – respondent count.



Respondents were asked to consider the impact of being a carer on their health. The following bar chart summarises responses to that question. Further comments reflected on the impact on their mental health, and considerations of whether other longer-term conditions were exacerbated by the stresses of having caring responsibilities.

Fig 8: Response to question “Has being a carer impacted on your health?” Tick as many as apply – respondent count.



Unsurprisingly, no respondents indicated that their health had improved as a result of caring. 61% stated that it was worse. Respondents highlighted having prioritised the health of the person they care for and their family above their own – and a concern around the type of support seeking professional advice might result in = “I put off going to the drs as I know they will offer anti depressants, I don't want tablets I need help and support in my caring responsibilities”. One noted

the worst strain as being having to deal with “*unhelpful 'professionals' [...] can't you send them on communication skills courses?*”

The survey then moved on to examine how far respondents felt they were able to get advice and support and whether they are able to plan for the future.

Section 5: Current support and planning for the future

In this section we'd like to get to know more about how far you are able to get advice and support and whether you are able to plan for the future. 37% indicated they had made no preparations – a further 31% indicated that they had relatives or friends who would take over their caring for a short time. Only 12% indicated they could use an individual carers emergency respite (ICER) plan, and 7% that they could use the disabled children's emergency care scheme. With regards to finances, only a very small percentage had had a review of their finances or know where to get one – either because they did not know (45%) or did not want one (24%). 67% commented that they worried about finances and being able to cover all costs associated with caring either sometimes or all the time. The internet was cited as a common source to find information and advice about support services and benefits (42%), with others highlighting social care services or friends, relatives or fellow carers. Schools and specialist hospital staff were noted as being information sourced, alongside support groups and organisations such as Macmillan, PinPoint and the National Autistic Society. 75% indicated they had not tried to access information and services outside of normal working hours, but for those that did, 87% found it difficult or very difficult to do so. E-mails and the internet in general were highlighted as being excellent 24/7 sources. Mental health support was noted as being difficult to access outside of working hours.

12.3 APPENDIX 3: Glossary of terms used in the literature review

Meta-analysis²⁵ – A statistical synthesis of data from separate but similar, i.e., comparable, studies, leading to a quantitative summary of the pooled results.

Randomised-controlled trial²⁵ – An experiment in which subjects in a population are randomly allocated into groups, usually called study and control groups, to receive or not to receive an experimental preventive or therapeutic procedure, manoeuvre, or intervention.

Respite –Carers trust define respite as ‘taking a break’. See <http://www.carers.org/help-directory/respice-care> for types of respite

Systematic review²⁵ – Systematic reviews focus on peer-reviewed publications about a specific health problem and use rigorous, standardized methods for selecting and assessing articles.

²⁵ Last,J.M. A dictionary of Epidemiology. 4th Edition. Oxford University Press 2001.