



Acknowledgements

The research underpinning these reports was conducted in the Department of Epidemiology and Public Health at University College London (UCL), by Professor Andrew Steptoe, Dr Aparna Shankar, and Dr Snorri Rafnsson. This research work was supported by a grant entitled 'Social connections and wellbeing in older adults' funded by the Economic and Social Research Council's Secondary Data Analysis Initiative (grant number ES/K003178/1).

This report was principally authored by the team at ILC-UK including Jonathan Scrutton, Senior Policy Officer, and Helen Creighton, Policy and Research Assistant.

CONTENTS

Executive Summary	4
ntroduction	5
Context	6
Key Figures	7
A day in the life of an older carer	9
nformal caregiving transitions, subjective wellbeing and depressed mood	. 10
mplications of the research	. 15
Policy recommendations	. 16
Endnotes	. 17

EXECUTIVE SUMMARY

A research team, from the Department of Epidemiology and Public Health at University College London (UCL), has been investigating the mental wellbeing of older people. This research, funded by the Economic and Social Research Council, has addressed a number of different issues including social networks, social isolation and the impact caregiving has on emotional wellbeing.

This report, the second in a two part series summarising the UCL research and exploring the policy implications of the work, focusses on the UCL findings on the subjective wellbeing of older carers. The research finds that:

- Long term caregiving was associated with declines in quality of life and life satisfaction for carers, and an increased risk of depression.
- Giving up caregiving was associated with increased depression amongst both male and female carers.

The report addresses the wider context of these findings, highlighting how our ageing population could potentially lead to large increases in the number of older carers, with the number of carers over 65 already having risen by 35% since 2001. It also highlights the day-to-day realities faced by many older carers, including a high risk of emotional distress; the loss of friends, either because of a lack of time to socialise or because friends were unable to properly understand the constraints and strains of caring; and potential health risks.

The report explores the policy implications of the research, highlighting that while there are already some policies in place to try to support carers, most are aimed at carers in general, rather than those who are older carers specifically. The report highlights how more could be done to protect the emotional wellbeing and mental health of older carers, through appropriate support being provided at all stages of the caregiving cycle.

The report then outlines changes, informed by these findings, which could help to ensure that older carers are better supported to enjoy their later life. Specifically this report recommends that:

- More needs to be done to help older carers maintain their social networks and to provide them with breaks from their caring duties.
- GPs should be made aware of the high potential for depression among older carers, and assessments of their mental health should be made routine.
- Local authorities should promote local groups, activities and volunteering opportunities among ex-carers so that they are aware of what is available.

INTRODUCTION

Three in five people will become carers at some point during their lives¹ and for many this responsibility comes in later life. There are almost 1.3 million carers over the age of 65 in the UK and this number is growing substantially - whilst the total number of carers has risen by 11% since 2001, the number of older carers rose by 35%².

Some find caring a rewarding experience and many cherish the fact that they can help a loved one in their time of need. Moreover, a large number of older people act as carers for their grandchildren, a role which they find very fulfilling. However, in many cases a caring role can also have a negative impact on both the physical and mental wellbeing of an older person. The Princess Royal Trust for Carers reports that 65% of older carers have long term health problems or a disability themselves and 69% say that being a carer has had an adverse effect on their mental health³. Older carers also report that their role makes it hard to find time for a social life and isolates them from friends⁴.

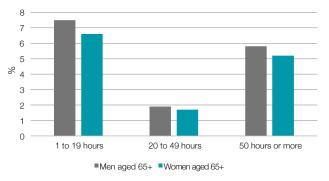
While significant research exists on the effect of caregiving on the wellbeing of older people, there is limited longitudinal research examining how this changes over time, and in particular the impact of ending caregiving responsibilities. Using data from the English Longitudinal Study of Ageing the researchers from UCL have gone some way to filling this gap. In a recent paper, which is explored in this report, Dr Snorri Rafnsson, Dr Aparna Shankar and Professor Andrew Steptoe examine the impact of caring on older people over a two year period.



The UK's population is ageing. There are currently 11 million people aged 65 or over⁵, and this number is projected to rise by nearly 50% in the next 17 years⁶. Moreover there are already 2.97 million persons aged over 80⁷ and close to half a million aged over 90⁸. By 2030 it is expected that this will rise to 5.3 million over 80 and 1.2 million over 90⁹.

Longer lives increase the possibility of caring duties. Older people may have to look after their parents, who will be living to greater ages, as well as their own partners. Longer lives also increase the possibility of grandchildren and the caregiving responsibilities that they bring.

Figure 1: Hours of unpaid care provision each week by the over 65s



Source: 2011 Census

Who are carers?

"A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support."

The Princess Royal Trust for Carers

The responsibilities of the caregiving role can make it difficult to maintain relationships with friends and family. In 2014, 57% of carers said they had lost touch with friends and 75% said they struggled to maintain social networks¹⁰. Caring can also damage physical health, with 7 in 10 older carers reporting that caring had had a negative impact on their physical condition¹¹. Furthermore, caregiving can bring financial difficulties as illness and disability often significantly increase household costs. Financial difficulties can be further exasperated if carers have to give up their work in order to care.

Unsurprisingly, the multitude of strains created by caregiving can lead to psychological strain and declines in mental wellbeing. 42.9% of carers reported a decline in their mental health over the past year¹².

KEY FIGURES



Almost 1.3 million people aged 65 or older are carers¹³.

The number of carers over the age of 65 is increasing more rapidly than the general carer population. Whilst the total number of carers has risen by 11% since 2001, the number of older carers rose by 35%¹⁴.

Among older carers, men are more likely to be providing care than women, with most caring for their partners¹⁵.

75% of carers said it was hard to maintain relationships and social networks because people do not understand the impact that caring has¹⁶.

57% of carers said they had lost touch with friends – almost half attributed this to a lack of practical support to enable them to socialise¹⁷.



69% of older carers say that being a carer has an adverse effect on their mental health¹⁸.



70% of older carers suffer a devastating impact on their health due to their caring role¹⁹.

Two thirds of older carers have long term health problems or a disability themselves. Commonly reported conditions are arthritis and joint problems, back problems, heart disease, cancer and depression²⁰.



One third of older carers reported having cancelled treatment or an operation they needed due to their caring responsibilities²¹.

Half of all older carers reported that their physical health had got worse in the last year and seven in ten said caring had had a negative impact on their physical health²².

More than four in ten older carers said their mental health had deteriorated over the last year²³.

Over three quarters of carers ages 60– 69 said caring had a negative impact on their mental health²⁴.

A DAY IN THE LIFE OF AN OLDER CARER

Caring for a loved one can bring satisfaction and reward. Many carers are proud of the support they are able to offer to their spouse, to a family member or to a close friend, and many would not want to describe their role as a burden. Nevertheless, being a carer can be emotionally, as well as physically, demanding. Older carers, who may have their own health problems, can find it particularly challenging. Indeed, the Alzheimer's Society states that 'caring can be an overwhelming experience, bringing irreversible changes to lives and relationships²⁵'

While everyone's caring experiences are different, this section aims to give an impression of some of the realities of being an older carer:

- Research by the Princess Trust for Carers found that carers aged 60-69 were at particular risk of emotional distress²⁶. They suggested that this may be because this age group were caring while also continuing in paid employment.
- Carers often do not have time to maintain their own social life. Indeed, Carers UK found that many carers lost touch with friends, either because they did not have the time to socialise or because their friends were not able to properly understand the constraints and strains of caring²⁷. A shrinking social circle can isolate carers, leaving them without emotional support.
- Older carers often help their loved one with bathing and going to the toilet. They may also have to deal with incontinence. These are personal, private, and potentially embarrassing activities, which can be hard for both parties to adapt to.
- Carers may have to be awake during the night, perhaps to prevent someone with dementia from wandering, to help with visits to the bathroom or to provide medication.
 Persistently interrupted sleep can lead to exhaustion and can also damage mental health and wellbeing.
- Illness and disability in old age can create a large financial burden. Carers may have to find the money to pay for special care or expensive equipment. Financial difficulties represent an additional source of worry for older carers and may lead to further emotional distress²⁸.

- An older carer may be the one coordinating the care for their loved one. They may have to arrange doctors and hospital appointments, and then help their loved one attend them. They may also have to liaise with community care workers such as district nurses or physiotherapists. This can represent an additional stress. Research published in the British Journal of Medical Practioners highlights that many carers experience 'a great deal of distress and anger' because they 'do not believe that care recipients' basic needs are being met²⁹'.
- Many of the activities involved in caring entail helping the person to move around. This often requires lifting which can be especially difficult for older carers who can easily strain their backs. 'Lifting someone incorrectly can also damage fragile skin, cause shoulder and neck injuries, increase existing breathing difficulties, or cause bruising or cuts³⁰. The Princess Trust for Carers found that less than a half of carers aged over 70 who have to lift the person they care for are able to do so confidently and safely³¹.
- Older carers who are looking after someone with dementia can find it difficult to cope with the changes in the personality of their loved one. People with dementia can become easily frustrated, aggressive, and suspicious of other people. This can be extremely damaging to the carers emotional wellbeing.

Cathy's story

When Cathy Sargent's husband was diagnosed with Alzheimer's she kept a diary of her life as a carer, extracts of which she has made publicly available through the Alzheimer's Society, see http://www.alzheimers.org.uk for more.

Diary extracts (2000)

23 May

When I was in the middle of ironing, Alan removed the plug from the socket and said I was not to continue. When I told him that I had only a few more items to iron, he said that he wouldn't allow it.

When I put the plug back in, he immediately took it out again. I didn't do this again, as I was a bit concerned that he may pick up the hot iron and burn me with it. He said that I knew I was in the wrong and asked why I didn't just admit it. He also mentioned that I had not paid to use the iron.

31 May

Alan became very agitated prior to setting out for our appointment. He thought someone was going to murder him. When we were in the car he said that it was me who was going to murder him. I told him that I loved him and asked him why I should want to murder him. He said he didn't know but that was how he felt.

16 June

Alan got up before me and I went back to sleep. However, I was awakened by a pillow being pressed firmly over my head. I said, 'Stop it Alan, you're smothering me.' He said, 'That's what I'm trying to do. You've stolen my credit cards.' I soon managed to free myself and helped him look for the missing cards.

An hour later he was tearful and apologetic. However, later in the morning he was calling me'scum' because he couldn't find his diary and assumed I had stolen it.

INFORMAL CAREGIVING TRANSITIONS, SUBJECTIVE WELLBEING AND DEPRESSED MOOD

A research team, from the Department of Epidemiology and Public Health at UCL, has been investigating the subjective wellbeing of older people. This research, funded by the Economic and Social Research Council, has addressed a number of different issues including social networks, social isolation and the impact caregiving has on emotional wellbeing. This report focuses on their work on older carers.

In a recent paper titled '*Informal caregiving transitions, subjective wellbeing and depressed mood*'³², Dr Snorri Rafnsson, Dr Aparna Shankar and Professor Andrew Steptoe, examine the effects of being an older carer, as well as the effects of transitioning in and out of caregiving, on older carer's depression and subjective mental wellbeing.

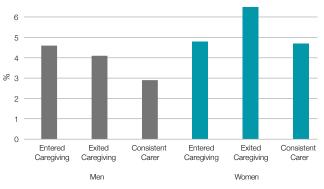
Previous research highlights the impact of caregiving on carers both physically³³ and mentally³⁴. Some academic papers go beyond the direct effects of day to day caregiving and also consider the implications of transitions in or out of caring³⁵. However, much research is hampered by small datasets, a lack of a non-caregiving comparison group and limited measures of wellbeing. The researchers from UCL were able to get round these problems using long term data from the English Longitudinal Study of Ageing (ELSA). ELSA collects data on a wide range of topics from the English population aged 50 and older and was able to provide data on caregiving transitions and emotional wellbeing for over 6000 older people (3007 men and 3564 women).

Moreover this longitudinal data allowed the researchers to investigate the different stages of caregiving, including the points of transition in and out of the caregiving role. The effects of giving up caring in particular are underexplored and rarely recognised and the UCL findings show that more needs to be done to support older carers at this critical time.

Research Design

Using data from the second and third waves of ELSA, Rafnsson et al recorded individuals' caregiving status over a two year period. Individuals were classified as having entered or exited caregiving over the period, as being a consistent caregiver or as never having been a carer, over the two years. Individuals who cared for their grandchildren were excluded from the analysis.

Figure 2: Caregiving status among ELSA participants over a two year period (excluding grandparenting)



Source: Rafnsson et al

As illustrated in figure two, among the ELSA participants 4.6% of men and 4.8% of women entered caregiving over the two year period, while 4.1% of men and 6.5% of women exited care giving. 4.7% of women were consistent care givers across the period while the same was true for 2.9% of men. 84.0% of women and 88.4% of men were

ELSA

The English Longitudinal Study of Ageing (ELSA) collects long term data, covering a range of topics, on the English population aged 50 and older. It collects data relating to health and disability, biological markers of disease, economic circumstance, social participation, networks and well-being. The data used in this research came from waves 2 and 3 of ELSA, and was collected between 2004-2005 and 2006-2007.

non-carers throughout the two year period.

For all of the ELSA participants the researchers also looked at three subjective mental wellbeing measures, and how these changed for individuals over the two years.

- Life satisfaction was first assessed using the Satisfaction with Life Scale (SWLS). An individual's score on this scale is found by giving them five statements and asking for a response based on a seven point scale, ranging from strongly agree to strongly disagree. A typical statement would be: 'In most ways my life is close to my ideal'. Responses for all five statements are aggregated in to a single overall score from 0 to 30.
- 2. Quality of life was assessed using the CASP-19 scale, which takes in to account four main domains: control, autonomy, pleasure and self-realization. The four domains are collated to give a score from 0 to 57.
- 3. Self-reported depression symptoms were assessed using the Centre for Epidemiologic Studies Depression Scale. This is widely used to identify persons at risk of depression and asks questions such as: 'how much of the time during the past week did you feel sad?' This creates a score from 0 to 8.

Using both the data on caring and the responses to the mental wellbeing questions, the UCL researchers then quantified the effect of caregiving, and caregiving transitions, on the mental wellbeing of older people. To ensure the validity of their results, they controlled for a respondent's age, gender, and relationship status, a respondent's education, whether a respondent worked, a respondent's wealth, and their health status.

Baseline Statistics

Before conducting their analysis, the UCL researchers picked out the important statistics characterising the life satisfaction and depression scores of different types of carers.

As seen in table one those older people caring for a child reported the lowest wellbeing. This is perhaps unsurprising as having a sick or disabled child can bring additional emotional and financial strain.

Those caring for a spouse or partner also reported particularly low wellbeing, which again may be due to the additional emotional and financial strain of being the main provider in the household.

Table two (over page) shows that those providing more care (measured by the number of hours each week) as well as those who are live in carers, have consistently lower levels of wellbeing.

Caring status	No. of people in sample	Mean life satisfaction (out of 30)	Mean depression score (out of 8)
Non-carer	7826	21.3	1.5
Grandparent	138	22.5	0.8
Spouse/partner	315	20.2	1.8
Child	72	19.1	2
Parent/parent-in-law	252	21.1	1.4
Other relative/ friend	166	21.6	1.5

Table 1: Carer status, life satisfaction and depression

Source: ELSA and calculations by S. Rafnsson

Hours of care (week)	No. of people in sample	Mean life satisfaction	Mean depression score			
Non-carer	7826	21.3	1.5			
<20 hours	488	21.8	1.3			
20-49 hours	167	20.9	1.4			
50-167 hours	55	20.2	1.7			
168 hours	218	19.1	2.0			
Does the carer live with the person?						
Yes	404	19.8	1.8			
No	539	21.7	1.3			

Table 2: Hours of Caring, Life satisfaction and Depression

Source: ELSA and calculations by S. Rafnsson

The difference between depression and subjective mental wellbeing

Depression is defined as a persistent feeling of sadness that lasts not just a few days, but for weeks or months³⁶. Depression is a medical condition and the NHS states that symptoms range from 'lasting feelings of sadness and hopelessness, to losing interest in the things you used to enjoy and feeling very tearful.' 'There can be physical symptoms too, such as feeling constantly tired, sleeping badly, having no appetite or sex drive, and complaining of various aches and pains³⁷. The researchers looked at depression among ELSA respondents by using the Centre for Epidemiologic Studies Depression Scale.

Subjective Mental wellbeing, as measured by the Satisfaction with Life Scale and the CASP-19 quality of life scale, is not defined in clinical terms. These measures are subjective and allow respondents to choose for themselves how they weight their happiness or satisfaction of different aspects of their life. They allow for a wider picture of an individual's mental state, focussing on positive states rather than solely on negative outcomes such as depression. Indeed, both positive and negative affect can be experienced by people at the same time and considering both is important to gauge individuals' overall wellbeing.

Findings

- Long term caregiving was associated with declines in life satisfaction and quality of life for female carers.
- However, in the short term, entering into caregiving was not associated with increased depression.
- Exiting caregiving was associated with higher levels of reported depression among female carers.
- Women who exited caregiving during the two year period were 54% more likely to report symptoms of depression. There was also evidence that men who exited caregiving may be more likely to report symptoms of depressionⁱ.

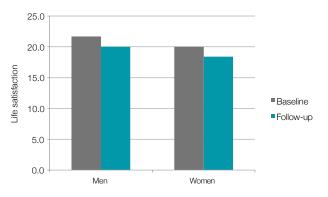
The Evidence on long term carers

Long term carers experienced a steeper decline in both their quality of life and their life satisfaction, compared to non-caregivers. Female long term care givers saw their reported mental wellbeing, as measured by the Satisfaction

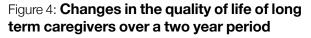
with Life Scale and the CASP-19 quality of life scale, decline during the two year period over which ELSA data was collected. Male long term carers reported similar declines in wellbeing but not consistently enough to reach statistical significance.

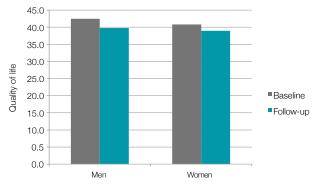
The association found between long term caregiving and a decline in subjective mental wellbeing was independent of socio-demographic factors, health and relationship status. This matches with previous research which has found that wives who provided consistent care are more likely to be socially isolated³⁸, which is then likely to result in a decline in their quality of life.

Figure 3: Changes in the life satisfaction of long term caregivers over a two year period



Source: Rafnsson et al





Source: Rafnsson et al

Both male and female long term carers were found to be at greater risk of depression.

Long term caring was associated with a higher reported level of depression, with both male and female long term carers reporting more symptoms of depression than none carersⁱⁱ.

The decline in quality of life experienced by long term female carers, and the increased levels of depression experienced by long term male and female carers are likely to be the result of the continued stress associated with the caregiving role. Research has shown unpaid carers to have elevated stress levels which negatively impact on their health and wellbeing³⁹. The effect of this stress is likely to be cumulative, meaning long term carers are at particular risk.

The UCL research found that men exiting care giving were up to 61% more likely to report symptoms of depression, however this result was not statistically significant at the 5% significance level.

^{II}However, this result not consistent enough to reach statistical significance.

These effects can be catastrophic for the health of the carer. A recent survey by Carers UK found that 6 out of 10 carers have been pushed to breaking point, and a quarter of those who had reached breaking point required medical treatment as a result⁴⁰. This not only has a devastating impact on the carer, but also on the person they are caring for -1 in 9 carers said that the person they cared for had to be rushed into hospital, provided with emergency care or that social services had to step in to look after them while the carer recovered⁴¹.

The Evidence on entering caregiving

Entering into caregiving didn't significantly affect the life satisfaction, reported quality of life, or depression levels of older people.

This is surprising, as it is normally assumed that the entry into caregiving results in the negative health and wellbeing effects seen in carers⁴². This result, combined with effect of caregiving on long term carers, suggests the negative impacts of caregiving are cumulative - stress, loneliness and social isolation build up over time.

The Evidence on giving up caregiving

Giving up caregiving was associated with increased depression among ex-carers.

Women who exited caregiving were 54% more likely to have depression at follow-up than those who were never care givers. There was also evidence that men who exited caregiving may be more likely to report symptoms of depression but this evidence was less conclusiveⁱⁱⁱ.

Figure 5 compares the prevalence of depression among carers before and after exiting care. For the carers who exited caregiving over the two year period there is a large increase in the prevalence of depressive symptoms.

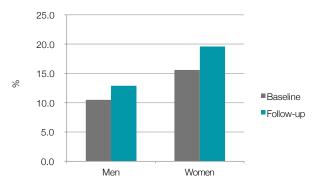


Figure 5: Prevalence of depression among those exiting caregiving

Source: Rafnsson et al

Giving up caregiving is a significant transition point in the life of an older carer. Two major reasons for caregiving to end are the person being looked after moving into a home or passing away. Both of these scenarios are likely to put significant emotional strain on the carer. Research has shown that for carers who have been looking after a partner this can be particularly devastating, with the transition to living alone from being part of a couple increasing the likelihood of social exclusion threefold⁴³.

While the death of the person being cared for is understandably difficult for the carer, the period leading up to the death can also be a particularly stressful time. Not only do the cared for person's physical, emotional, social and spiritual needs often become more demanding; the carer also has to deal with a range of difficult and emotional issues, such as conversations about resuscitation, artificial feeding, organ donation and funeral wishes; as well as dealing with the impending feelings of loss⁴⁴.

[&]quot;The UCL research found that men exiting care giving were up to 61% more likely to report symptoms of depression, however this result was not statistically significant at the 5% significance level.

IMPLICATIONS OF THE RESEARCH

The UCL research highlights the risks to older carer's mental health, with such risks being particularly prominent for long term carers and those exiting care giving. Support for older carers therefore needs to be maintained both throughout their time caring, and when caregiving stops.

Current policy

There are already some policies in place to try to support carers. However most are aimed at carers in general, rather than older carers specifically.

The 1995 Carers (Recognition and Services) Act gave carers the entitlement to request an assessment of their ability to continue in the caring role. The results of such an assessment would then be used when considering the amount of community care services provided to the carer. The Carers and Disabled Children Act, 2000, built on this to allow local authorities to offer support to carers too. The Act enabled local authorities to supply services to help maintain carers' health and wellbeing. The Act also permits authorities to make direct payments to carers if they wish to choose the services themselves.

Carers' assessments also make provision for carers to take time off, with local authorities either providing replacement care, direct payments or vouchers to pay for care. The variety of options available are intended to offer carers flexibility. Carers can take just a few hours break or a few days. Breaks can be arranged overnight, in order to give carers a proper night's sleep. Breaks away, where both carer and the person cared for take a trip, are also possible.

In 2006, the Work and Families Act made provision for carers to request flexible working hours from their employer. This provision was intended to make it easier for carers who work to remain in employment. The Care Act 2014 further built on previous legislation, giving carers and those they care for the same entitlement to assessment and support. It also provided additional funds to local authorities to help ensure they are able to provide for carers needs.

In addition to support from government, a nationwide network of 144 Carers' Centres offer local support to carers. These are independent charities which provide information and advice, as well as emotional support to carers. They help organise breaks, provide training and practical help, and offer advocacy at carer's assessments.

POLICY RECOMMENDATIONS

While current policy does provide some support to carers, more could be done to protect the emotional wellbeing and mental health of older carers. It is important to acknowledge that caregiving is not static, and that people enter into, engage with and exit from caregiving. Appropriate support must therefore be provided at all stages of the caregiving cycle.

Long term Carers

The UCL research found that long term caregiving was associated with a reduction in carers' quality of life and life satisfaction, and an increased risk of depression.

Breaks

- In order to combat stress and anxiety, and to promote mental wellbeing, the NHS highlights the need for social connection, physical activity and the maintenance of lifelong learning⁴⁵. These are often shut off to long term carers, who are unlikely to have the time to take part in such activities. Many cite difficulties in maintaining social networks, as people do not understand the impact of caring, and many are in poor physical health themselves.
- In order to prevent depression among older carers, and to improve their wellbeing, it is clear more needs to be done to provide them with breaks from their caring duties.
- Many older carers worry about leaving their loved ones with someone they, and the person they care for, do not know, especially if the person has dementia. More could be done to encourage people to take breaks if individuals could be guaranteed to get the same stand in carer regularly so that a trusting relationship could be built up.
- Local authorities should develop groups where older carers can chat and exercise together. It may even be appropriate to design some of these groups such that carers can bring the person they care for along with them.

Health

- Many carers find it difficult to attend doctor's appointments because of their caring duties.
 Where appropriate GPs should be able to offer carers home visits.
- Improved GP services for carers would help

improve both their physical, and mental, health.

• GPs should be made more aware of the high potential for depression among older carers, and assessments of their mental health should be made routine.

Caregiving

As previously noted, giving up caregiving is a significant transition point in the life of an older carer. It is likely that the loved one they were caring for has become institutionalised or passed away. Both scenarios will be extremely stressful for older carers. The UCL research found that exiting caregiving was associated with an increased risk of depression for older carers. Services for carers need to be extended to cover this crucial time.

- Left without their loved one, older carers can feel isolated and lonely, especially if their social networks broke down while they were a carer. Local authorities should help older carers integrate back into their communities.
- Local authorities should promote local groups, activities and volunteering opportunities among ex-carers so that they are aware of what is available.
- Local authorities could pay for ex-carers to attend classes or activities of their own choosing.

Bereavement

- Older carers' support systems may be weaker than other peoples. Extra support to help them with the many practical issues surrounding a death, such as the organisation of the funeral, may be particularly appreciated.
- There are a number of bereavement counselling services available, some of which are run specifically for older people. However, older carers could benefit from the development of a dedicated service, designed with their specific needs in mind.

Residential Care

 It needs to be easy to visit people who have been taken into residential care. Older carers may not be able to drive and may have difficulties using public transport. Local authorities should ensure suitable transport is available to take older carers to care homes and hospitals.

ENDNOTES

- 1 *Facts about carers,* Carers UK Policy Briefing, May 2014
- 2 Facts about carers, Carers UK Policy Briefing, May 2014
- 3 Always on call, always concerned: A survey of the experiences of older carers. The Princess Royal Trust for Carers, 2011
- 4 *Facts about carers*, Carers UK Policy Briefing, May 2014
- 5 *Mid 2013 Population* Estimates UK Office for National Statistics, 2014
- 6 *National population projections, 2012* based, Office for National Statistics, 2013
- 7 ONS population estimates, mid-2012
- 8 Mid-2002 to Mid-2013 Population Estimates of the very old (including centenarians), UK Office for National Statistics
- 9 Mid-2002 to Mid-2013 Population Estimates of the very old (including centenarians), UK Office for National Statistics
- 10 Facts about carers, Carers UK Policy Briefing, May 2014
- 11 Always on call, always concerned: A survey of the experiences of older carers. The Princess Royal Trust for Carers, 2011
- 12 Always on call, always concerned: A survey of the experiences of older carers. The Princess Royal Trust for Carers, 2011
- 13 Facts about carers, Carers UK Policy Briefing, May 2014
- 14 Facts about carers, Carers UK Policy Briefing, May 2014
- 15 Facts about carers, Carers UK Policy Briefing, May 2014
- 16 Facts about carers, Carers UK Policy Briefing, May 2014
- 17 Facts about carers, Carers UK Policy Briefing, May 2014
- 18 Always on call, always concerned: A survey of the experiences of older carers. The Princess RoyalTrust for Carers, 2011
- 19 Ibid
- 20 Ibid

- 21 Ibid
- 22 Ibid
- 23 Ibid
- 24 Ibid
- 25 http://www.alzheimers.org.uk/site/scripts/ documents_info.php?documentID=546
- 26 Ibid
- 27 Facts about carers, Carers UK Policy Briefing, May 2014
- 28 Ibid
- 29 Aadil Jan Shah, Ovais Wadoo and Javed Latoo (2010) *Psychological Distress in Carers of People with Mental Disorders*, BJMP 2010;3(3):a327
- 30 NHS Choices, Practical Support, Hands on Caring, Moving and Handling
- 31 Always on call, always concerned: A survey of the experiences of older carers. The Princess Royal Trust for Carers, 2011
- 32 S. Rafnsson, A. Shankar and A. Steptoe (submitted) Informal Caregiving Transitions, Subjective Wellbeing and Depressed Mood: Findings from the English Longitudinal Study of Ageing.
- 33 Vitaliano, P.P., J. Zhang, and J.M. Scanlan,
 (2003) Is caregiving hazardous to one's physical health? A meta-analysis. Psychol Bull.
 129(6): p. 946-72
- 34 Pinquart, M. and S. Sorensen (2003)
 Differences between caregivers and noncaregivers in psychological health and physical health:
 a meta-analysis. Psychol Aging. 18(2): p. 250-67.
- 35 Pearlin, L.I. (1992) *The Careers of Caregivers. The Gerontologist.* 32(5): p. 647.
- 36 NHS choices, Clinical Depression
- 37 Ibid
- 38 Hirst, M., *Carer distress: A prospective, population base study.* Social Science and Medicine, 2005. 61(3): p. 697-708
- 39 Adelman, R.D., et al., *Caregiver burden: A clinical review.* JAMA, 1024. 311(10): p. 1052-

1060

- 40 Carers UK (2014). Carers at breaking point
- 41 Ibid
- 42 Kramer, B.J. and Lambert, J.D. Caregiving as a *Life Course Transition Among Older Husbands: A Prospective Study*. The Gerontologist, 1999. 39(6): p. 658-667
- 43 ILC-UK (2012). Is Social Exclusion still important for Older People?
- 44 The National Council for Palliative Care (2013). Who cares? Support for carers of people approaching the end of life
- 45 NHS choices, Five steps to mental wellbeing.



ILC–UK 11 Tufton Street London SW1P 3QB Tel : +44 (0) 20 7340 0440

Published in February 2015 Registered Charity Number: 1080496.

University College London Gower Street London WC1E 6BT Tel: +44 (0)20 7679 2000

© UCL 1999-2015

