



Prepared to Care?

Exploring the impact of caring on people's lives



Executive summary

The Carers Week partnership wanted to find out from the UK's carers how prepared as a society we are and what could make a difference to carers' lives and the people they care for. **Prepared to Care?** explored the impact that caring has on people's lives. In particular it focused on carers' relationships, career, finances and health and well-being.

The following are the findings of the survey of over 2,100 carers and their experiences. It concludes with recommendations from carers.

Key findings

- Seven out of ten (75 per cent) carers were not prepared for all aspects of caring.
- Eight out of ten (81 per cent) carers were not prepared for the emotional impact of caring.
- Eight out of ten (78 per cent) carers were not prepared for changes to their lifestyle because of a caring role.
- Seven out of ten (71 per cent) carers were not prepared for the change in relationship with the person they care for.
- Just under two-thirds (63 per cent) of carers were not prepared for the impact caring had on their career.
- Seven out of ten (72 per cent) carers were not prepared for the financial impact of their caring role.

Relationships

- Two out of five (42 per cent) carers had had a breakdown in a relationship with a family member.
- Two out of five (43 per cent) carers have seen their relationship improve with the person they care for.
- Six in ten (61 per cent) carers have found it difficult to maintain friendships.

Career

- Nearly half (45 per cent) of carers that responded to our survey have given up work because of their caring role.
- Two out of five (42 per cent) carers have reduced working hours because of their caring role.
- A third (34 per cent) of carers have missed out on the chance of a promotion.

Finances

- Six out of ten (60 per cent) carers have had a reduction in income because of their caring role.
- A quarter (26 per cent) of carers have taken out a loan or fallen into debt because of their caring role.
- Half (49 per cent) of carers have used savings to buy essentials such as heating and food.

Health and well-being

- Seven out of ten (72 per cent) carers have had to reduce the amount of exercise that they take.
- Six out of ten (61 per cent) carers have suffered from depression because of their caring role.
- Nine out of ten (92 per cent) carers feel more stressed because of their caring role.

Support, advice and information

- Eight out of ten (81 per cent) carers were not aware of the support available because of the time it took them to identify themselves as carers.
- A third (35 per cent) of carers were given the wrong advice about support available because of the time it took them to identify themselves as carers.
- Half (46 per cent) of carers that responded to our survey had been offered a Carer's Assessment.

Prepared to Care? recommendations

As part of this survey carers stated what would make a difference to their role as carers. Their list of recommendations includes:

- 1. Better public understanding and recognition of carers.**
- 2. Access to information and the right support from the beginning.**
- 3. Professionals understanding the role of carers, sharing information, decision making and planning with them.**
- 4. Access to good quality practical and emotional support and information as well as breaks from caring.**
- 5. Flexible working practices and understanding from employers.**
- 6. Financial support – fair and easy to navigate welfare system.**

1. Introduction

Every day in the UK 6,000 people take on new caring responsibilities¹. This often comes at a price as carers find their lives change in so many ways. Caring has an impact on relationships, careers, finances and a person's health and well-being both positively and negatively. When someone becomes a carer it can happen suddenly or build gradually over time and many people do not recognise the changes it is having on their life. Added to this, carers also talk about how they struggle to readjust when their caring role ends or changes, especially if they have put their career on hold, lost touch with friends or seen their personal finances reduced.

The impact that caring has on people's lives is a serious concern. The number of people now looking after a family member or friend who is ill, frail or disabled has risen by 11 per cent in the last 10 years. There are now 6.5 million² carers in the UK - predicted to reach nine million by 2037³.

In preparation for this year's Carers Week, a group of charities⁴ set out to explore how much, as society, we are Prepared to Care? Through an online survey, the UK's carers were asked to share the impact that caring had had on their lives and their experiences of gaining support from professionals and services. The following report, *Prepared to Care? Exploring the impact of caring on people's lives*, shares the personal accounts of carers as they discuss the realities of caring for a family member or friend.

The Carers Week partnership would like to thank the 2,115 carers who took the time to complete the survey. Your contributions are invaluable in supporting the work of Carers Week and guiding its activities for the campaign in 2013 and in the future.

¹ *In the Know* (2006) Carers UK

² *Census 2011* (2012) Office of National Statistics

³ *Valuing Carers* (2011) Carers UK

⁴ This survey was carried out for Carers Week 2013 by a partnership of charities: Age UK, Carers Trust, Carers UK, Independent Age, Macmillan Cancer Support, Marie Curie Cancer Care, MS Society, Parkinson's UK and Skills for Care.

2. Recognising yourself as a carer

2.1 Being a carer

Every caring role is unique. The carers who shared their experiences in this survey ranged from parents caring for a disabled child; friends looking after a friend with an illness or mental health conditions, partners caring for each other with cancer, Parkinson's or MS; children caring for siblings with autism, or adults caring for their parents following a stroke, a dementia diagnosis or needs that arise from getting older.

Just because you are a wife and mother why should you be expected to take on a caring role without professionals questioning if you can manage.

A caring role can begin at any time in a person's life. School children juggle caring for a parent or sibling with their homework and maintaining friendships, parents find themselves caught between caring for an elderly parent while still bringing up their own young children⁵ and many people care for someone when they too have an illness or disability⁶.

More must be done to help people prepare to care, and to support them in their caring roles. Most of us are untrained, without any medical background at all, just ordinary people from every walk of life; and it can be very frightening to find yourself confronted with the serious illness, or slow deterioration of a loved one.

Again and again, the message from carers is that the most important thing for anyone starting a caring role is being given the support, advice and information they need, from day one.

2.2 Length of time it takes to identify yourself as a carer

Becoming a carer can change the relationship you have with the person that you care for. People continue to see themselves as the parent, child, partner or friend but when you start providing personal care or practical help for someone, you are often taking on responsibilities outside what many of us expect from these relationships. To help people with these roles, carers can benefit from identifying themselves as carers and accessing specialist support, advice and information from the very beginning.

I'm a daughter not a carer but I've had to become my mum's carer, accountant, legal representative, her dementia consultant because otherwise nobody listens.

It's important to remember that carers are people - I am my husband's wife - not just his carer. On numerous occasions I have been introduced by health professionals as 'the carer' and not the patient's wife. I have a right to keep my identity.

Previous research has identified that it took two-thirds of carers more than a year to first identify themselves as a carer⁷. The people who responded to the survey took varying amounts of time to recognise their caring role.

⁵ Sandwich Caring: combining childcare with caring for older or disabled relatives (2012) Carers UK

⁶ 13.2 per cent of carers caring for over 50 hours a week were in 'bad' or 'very bad' health. This compares to 5.3 per cent of people without caring responsibilities. So full-time carers are two and a half times more likely to be in bad health. *Census 2011* (2012) Office of National Statistics

⁷ In the Know (2006) Carers UK

Nearly **six in ten** people who responded to our survey recognised themselves as a carer **within a year** and just over a **quarter** took **one to five years**. **One in six** took **over five years**.

The survey identified that the length of time it took people to recognise themselves as carers has reduced over time. Of those people who responded to the survey they shared that:

- Two in five (38 per cent) people who had been caring for more than 15 years took over five years to recognise themselves;
- One in five (18 per cent) people who had been caring for 10 to 15 years took over five years to recognise themselves as a carer;
- Just over one in ten (12 per cent) people who had been caring for five to 10 years took over five years to recognise themselves.

It is 44 years since my son was born. At that time there was little or no support, but things have moved on a lot, and I am aware that a lot more support is available now.

There is more information out there since I started caring and issues such as dementia are more widely spoken about. I had no idea of the impact this would have on me, my relationship, my family, my job etc. or even how long it would last.

During my role as a carer for my wife over the past five years, the help, assistance, guidance, facilities provided by the local council... have improved considerably... 25 years ago when we were caring for my widowed, mother in law, who must have been suffering from dementia.....(not recognised then) the help and assistance was NIL, it was only after 15 years of caring that we found out we could have claimed Carer's Allowance, that was an expensive 15 years for us.

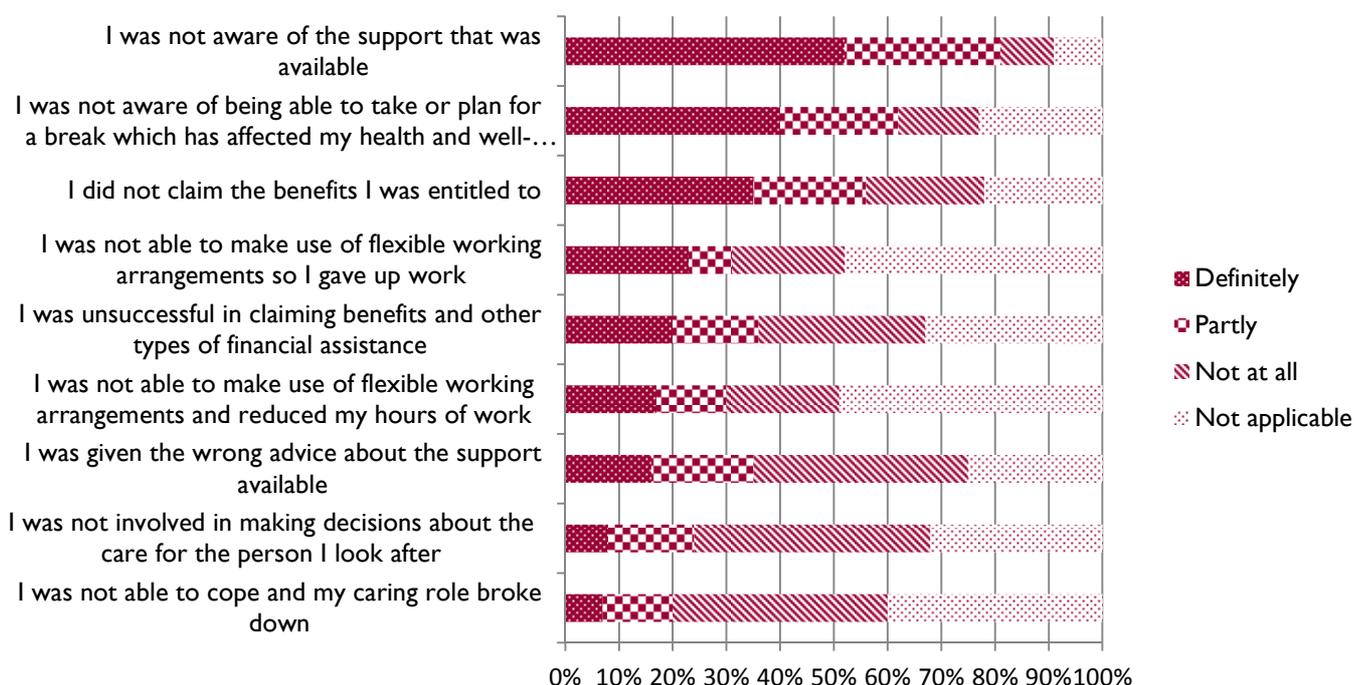
The longer it takes you to identify yourself as a carer the more likely it is that you are missing out on support, advice and information that can help you with your caring role and importantly potentially reduce some of the negative impacts of caring.

2.3 The impact of taking time to recognise your caring role

Looking after somebody can be very demanding. It takes up a lot of time and can leave you exhausted, stressed and can cause injury (from lifting etc). The costs of caring are not just physical, they can be financial, as people dip into savings, get into debt or reduce their working hours or give up work altogether. We will explore some of these impacts later on in this report.

Caring grows on you.... needs creep up. Change can be very quick!! What began as the need for extra help grew to needing 24/7 support. My life-style changed completely... now very narrow... personal aspirations shrank.

Carers shared what they believed the impact on their lives had been on not recognising their role as a carer sooner. The chart on the next page identifies what carers believed the impact on their lives had been of not identifying themselves sooner:



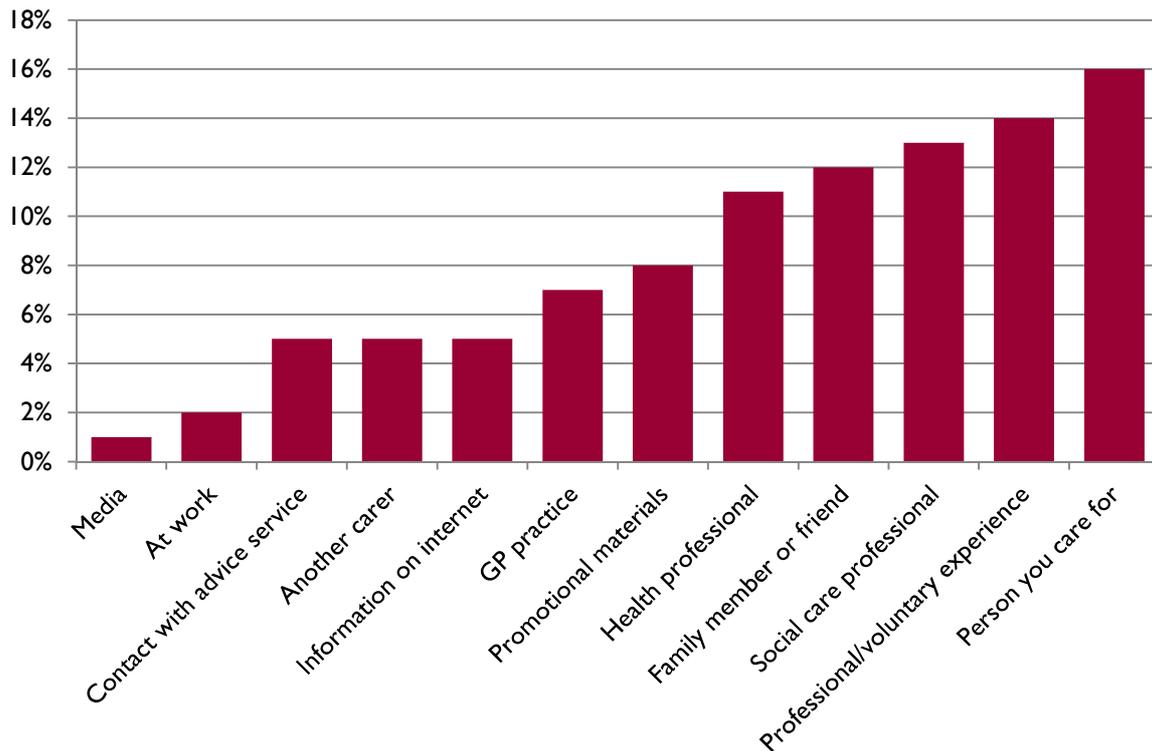
It is worrying to see that so many carers were simply not aware of the support available to them. However, carers expressed that there were opportunities on their caring journey for professionals, family, colleagues and friends to help them find out about support that might be beneficial. The role of caring is not recognised enough and, as a result, carers are left to muddle through with insufficient information and lack of understanding of their rights – in the workplace and also from statutory services.

2.4 Role of professionals and others in identifying carers – understanding and recognition of caring role

Due to the nature of the caring role, carers potentially come into contact with a number of health and social care professionals. As frontline workers, these professionals are ideally placed to recognise the role that carers are taking on and also identify if they would benefit from knowing about local support and services.

My Mum had asked me to attend the Parkinson's clinic with her right from the start. It would have been useful for the healthcare professionals, when they were told I was her daughter, to have acknowledged me as her carer/potential carer, or to enquire if there were any other family members who might be caring for my Mum's needs at times. At that time I did not see myself as my Mum's carer, but now I realise I was, as she was unable to attend the clinic or hospital without my support. As time has gone on (and it's only in the past year) I have gradually had to help my Mum more when she has had falls etc. She is determined to be independent but I realise I still have to be prepared to help her when she's having bad days or yet another fall. I was mistaking her independence as not needing a carer, when in fact her independence is maintained because I do have to take on the role of carer at times to help her regain the independence.

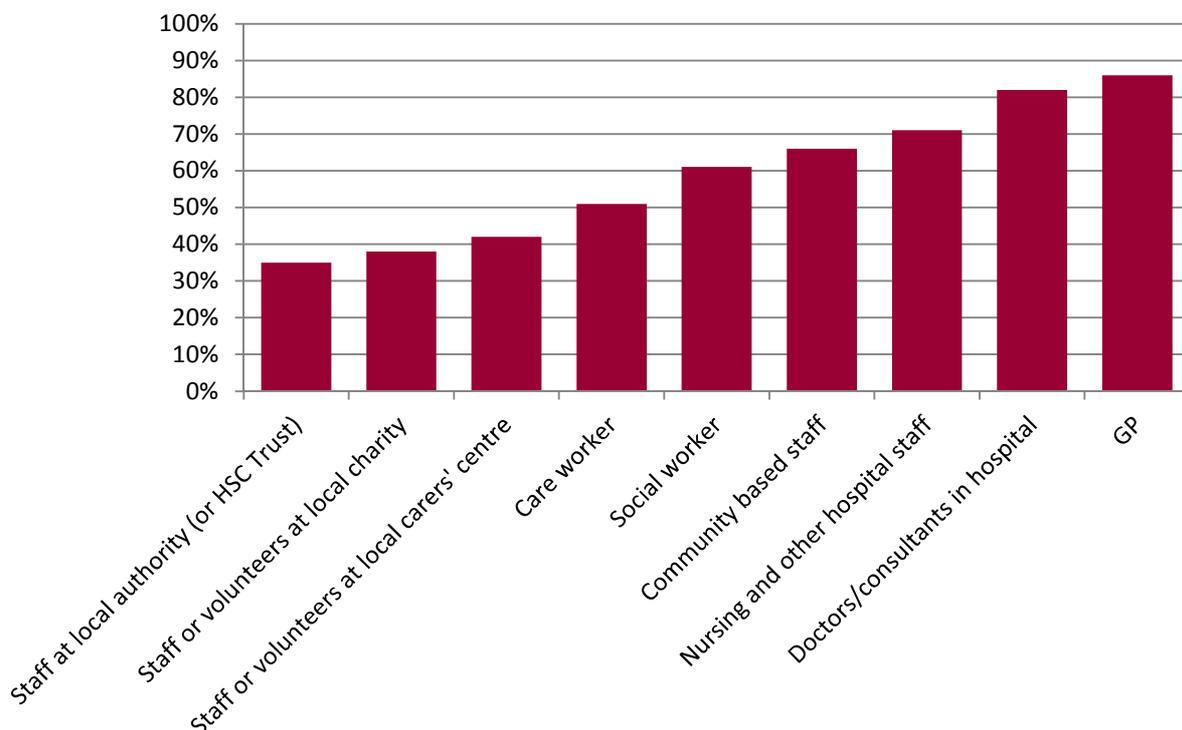
The survey asked carers to identify who first helped them to recognise that they were a carer. The following chart shows the range of responses given by carers that responded to our survey:



It is perhaps not surprising that in most instances the person that they were providing care for helped them identify – perhaps as a means of gaining support for them both or because more of the information is designed with them as its intended audience. It is disappointing that health and social care professionals are not ranking the highest.

Improved recognition and understanding of the role of carers right across frontline roles is required. Carers shared their views on the level of understanding they felt professionals had in their experience. As much as patchy access to services is recognised, carers found wide ranging levels of understanding too.

The following graph shows the percentage of carers who had had contact with a range of professionals:



There are a number of projects and initiatives taking place around the UK to improve the understanding of frontline health and social care staff. One such project is a Department of Health funded joint project with the Royal College of GPs, Carers Trust and Carers UK⁸ to improve the early identification of carers. They are working with GP surgeries and other health professionals across England to support them with working with carers. Resources on this topic are also available for social care professionals produced by Skills for Care⁹. In Northern Ireland, GPs are proactively identifying carers within their surgeries and the Social Security Agency is targeting carers in its 'Make the Call' benefit take up campaign.

In Wales as part of the implementation of the Carers Strategies (Wales) Measure 2010, the West Wales Hywel Dda Health Board has been working with GPs to roll out an Investors in Carers programme. In addition, Health Boards across Wales have been undertaking Carer Awareness training with frontline staff. In Scotland, each Health Board has developed a Carer Information Strategy to identify and provide information to carers, working in partnership with local Carer Support Services. NHS Education Scotland and the Scottish Social Services Council are working together with partners to develop core values, skills and knowledge to help staff work with carers.

However, many carers remain frustrated as they do not feel that their knowledge and understanding of the needs of the person they are caring for are fully considered by professionals when making decisions about their care needs and planning.

While healthcare professionals are the medical experts, we are the ones, in our bodies and our minds, who experience the entire cancer journey.

Carers shared how they felt that, right from the very moment they started their caring role, they would have benefited from receiving a pack of information. This would include information about the illness, condition or disability of the person they were caring for, information on any medication and side effects and advice on how to cope with behaviour. Carers shared how they felt in the dark about what lay ahead and although there might be some information for the person they care for it was not necessarily geared to their role.

I think it would have been useful to have had somebody tell me before my brother left hospital, exactly who to turn to for advice and perhaps had the opportunity to have some kind of interview whereby ALL the options for support were shared with me. My main source of advice initially, was a friend who had gone through the same situation. She told me to contact Macmillan and to talk to my brother's GP. After that I had splendid support and was able to access leaflets and online information. However, I do wonder what would have happened had I not had that friend to advise me in the first place.

It was also highlighted by a number of carers how having a handy list of all useful local numbers (and if available out of hours numbers as for some caring is a 24/7 role) and support groups would make a big difference.

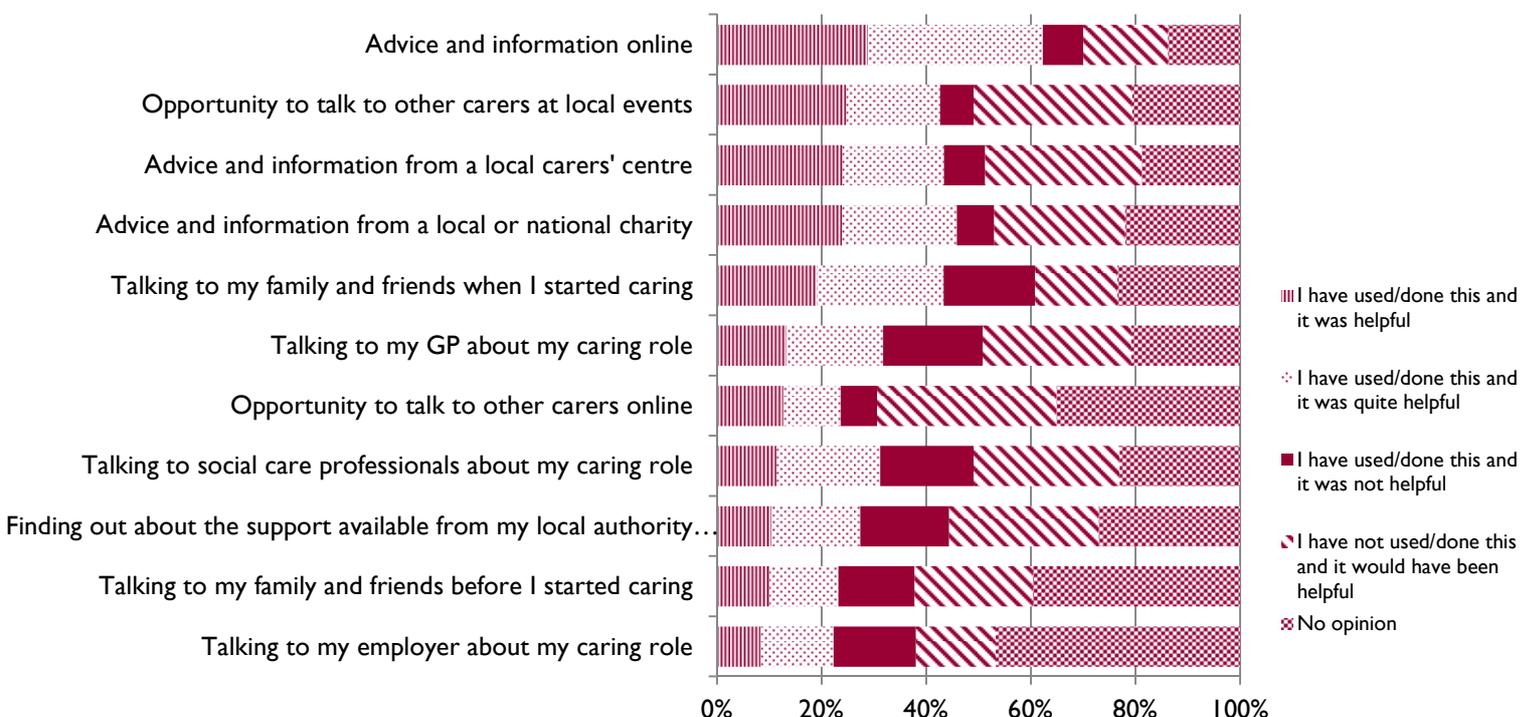
⁸ For more information visit carersuk.org/get-involved/carer-ambassadors and professionals.carers.org/health/articles/primary-care-and-community-links-project.7080.PR.html

⁹ For more information visit www.skillsforcare.org.uk/carers

3. Accessing support, advice and information

3.1 What has made a difference to help you Prepare to Care?

Carers shared in the survey the advice and support that has made the most difference to them. Detailed below is a chart that shares their views.



The above graph shows definite opportunities for frontline health and social care staff to improve their signposting to local or specialist support, advice and information – Carers Week in June provides the ideal opportunity to find out about support available locally:

Two out of five had accessed advice and information from their local carers' centre and found that either helpful or quite helpful.

Over half had received advice and information from a local or national charity either helpful or quite helpful.

Two-thirds of carers accessed advice and information online.

Support can come from a host of places – dedicated services for carers, specialist organisations, other carers, family and friends, employers and health and social care professionals. Some will be statutory and others commissioned and provided at a local level – there is variation throughout the UK of the range of support and assistance available to carers.

The findings also highlighted how some carers are talking to their GP and social care professionals but that also carers are not at the moment. It will be important to further explore the barriers to discussing their role with these professionals.

Caring can be very isolating and particularly if you are providing significant hours of care a day, difficult for people to get out of the house and meet up with friends or attend support groups. With the growth

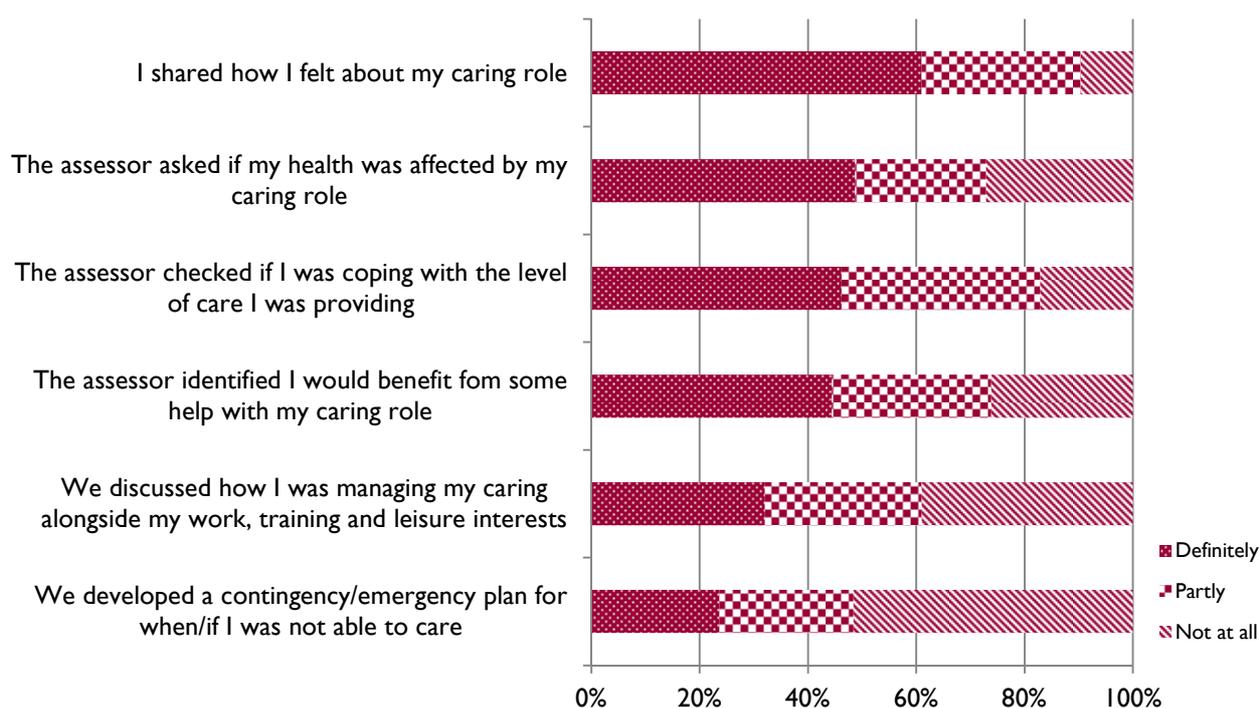
of information online and the development of online communities it is anticipated that a growing number of carers will seek support and advice from this route. However, this is still not accessible to everyone.

3.2 Carer's Assessments

Carer's Assessments are available for people who provide 'regular and substantial' care. They are designed to look at the needs of a carer and are usually provided by the local council (or health and social care trust in Northern Ireland). However, the way the assessment is carried out varies widely – ranging from a self-assessment form to complete to a face-to-face assessment at home – and a range of other approaches in between.

Nearly **half** (46 per cent) of the carers that responded to the survey had been offered a Carer's Assessment but nearly **one in five** (19 per cent) had never heard of it¹⁰.

Carer's Assessments are designed to identify the impact that caring is having on a person's life and whether they are coping and would benefit from additional support and assistance either for the person they are caring for or themselves. The following chart details what carers shared happened during their Carer's Assessment.

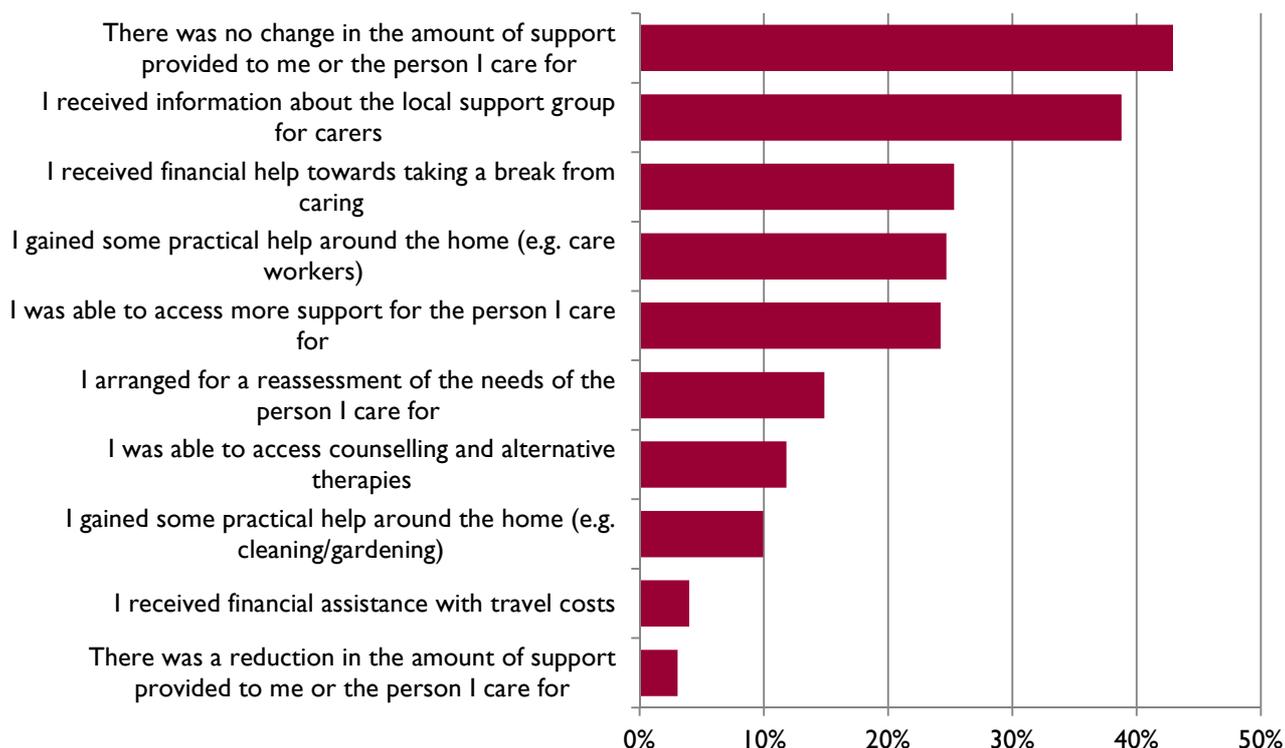


It is worrying that carers are missing out on the opportunity to share the impact that caring is having on their lives. As a result people could end up having to reduce their working hours or give up work if additional support is not identified as being required to help them stay in work.

Furthermore, not having the time and space to think about what plans could be put in place in case of an emergency could leave carers feeling burdened with worry about their responsibilities.

¹⁰ Research carried by Macmillan/Ipsos Mori found that only five per cent of cancer carers had had a local authority carer's assessment. More than a million (2012) Macmillan/Ipsos Mori

Carers shared what the outcome of their Carer's Assessment had been. This include the following:



Carers had a wide range of experiences and views on the helpfulness of their Carer's Assessment.

Nearly **one in five** (17 per cent) **did not find their Carer's Assessment helpful** but a **third** did rate it either **really helpful** (15 per cent) or **helpful** (17 per cent).

It is no surprise that carers sometimes question the purpose of assessments if as many as two in five are seeing no change in support either for themselves or the person they care for, despite having one. Furthermore, Carer's Assessments should be reviewed regularly as the condition of the person someone is caring for, as well as the carer's circumstances and wishes can change over time. This can particularly be the case with long-term conditions such as Parkinson's, MS or cancer.

4. Impact of caring on people's lives

4.1 Are we Prepared to Care?

For three in five of us¹¹ it is anticipated that we will be a carer at some point in our lives. Caring can happen gradually over time as you take on more responsibility for someone in older age or with a long-term condition or it can happen overnight following an accident or stroke. Although it is something as a society that most people would take on without thinking – caring can come at a cost to a person's own health and well-being, finances, career prospects, retirement plans and relationships.

In the survey we asked carers if they were prepared for any of the impacts that caring had had on their lives.

Three out of four (75 per cent) of carers were not prepared for all aspects of caring (both emotionally and physically including the impact on relationships, health and well-being, finances, career and lifestyle.

Sadly I did not have any opportunity to prepare in any way at all - my husband's stroke was a complete bolt from the blue. Life was turned upside down and we had to just think on our feet as a family. Perhaps there needs to be a lot more awareness generally that anybody could find themselves having to be a carer at any time due to all sorts of situations. It is obviously quite an alien concept for most people especially when young but it might be useful to ponder on the 'What if....'? question, how would it affect me and my life?

My experience came as a complete shock with a cancer diagnosis so there was no time to prepare. There was an overwhelming sense of shock and loneliness.

Carers shared in the survey some of the unexpected ways that their life had changed some found new friendships or separated from their partners, others started volunteering alongside caring to support other carers or had no alternative but to give up the job they loved.

Eight out of ten (78 per cent) carers were not prepared for changes to their lifestyle because of their caring role.

What carers take on is so huge it is really hard to describe in words. You really have to experience it to know how much it affects every part of you.

When taking on a caring role the impact can be overwhelming. Lack of sleep, distress, handling the regular crisis means it is virtually impossible to find time for the carer to think about the impact on them and how to handle this.

Eight out of ten (81 per cent) carers were not prepared for the emotional impact of caring.

Carers were asked to share in more detail how caring had impacted on four aspects of their lives – relationships, career, finances and health and well-being the following explores their responses.

¹¹ It Could Be You – A report on the chances of becoming a carer (2001) Carers UK

4.2 Relationships

When you start caring for someone it is difficult to comprehend how this change in roles could alter the relationship you have with the person you are looking after.

Just over **seven in ten** (71 per cent) carers were **not prepared** for the **change in relationship with the person they care for**.

Of course every caring role is different and can change over time. Parents shared how caring for their child born with a disability or long-term condition (diagnosed at birth or a later date) had different stages as their child developed and required more care or grew more independent. Other carers shared the grief of seeing the impact on their partner of an illness and as the intimacy and friendship they had shared was replaced by the caring role that could be difficult to 'turn off' or differentiate from their other role as wife, husband or partner. Children caring for a parent also shared how the increased responsibility led to a full role reversal which was difficult to be prepared for.

People are generally already in a relationship with someone who develops a caring need and the caring is assumed of them – some can manage it for a while...some can manage it for a lifetime.

For some carers they found having the opportunity to care for someone improved their relationship with the person they were looking after. This could have been due to previously living some distance apart or not having as much time to spend together due to work commitments and now having more opportunity to do things together as a couple or parent and child.

Just over **two out of five** (43 per cent) carers had seen their relationship improve with the person they care for.

In some ways it has brought my partner and I closer together (though at times it has done nothing to improve our tempers!). However, our relationships with many friends and family have suffered due to it.

Nearly **six out of ten** (57 per cent) carers have experienced difficulties in their relationship with the person that they care for.

My husband's illness had made him completely dependent on me and he sees me as his carer and not his wife anymore which for me is very sad.

With the responsibility of caring comes the need to prioritise and delegate. The difficulties of making decisions about the care needed for a family member does not always fall equally on each member of that family. Carers shared how family fractures and lack of support put huge pressure on, or even led to a breaking off of relationships with siblings and other family members. Some shared how family members could not cope with the behaviour or disability of the person they cared for and chose to walk away.

Two out of five (42 per cent) carers have had a breakdown in the relationship with family members

It is very time consuming as a carer and no one can prepare you for this role. I devote more time to my mother than my two children.

Caring is incredibly isolating. I cannot emphasise enough how important it is to try to hold on to your own friends, your own life.

Not understanding your friend's caring responsibilities and the potential for them to be unreliable or cancel at the last minute can lead to friendships drifting apart and further increase a carer's feeling of isolation. However, through the caring role some people shared how they had made new friends through local support groups as well as online communities.

Six out of ten (61 per cent) carers have found it difficult to maintain friendships. Over a third (36 per cent) have made new friends because of their caring role.

Caring has put a lot of stress on my relationships with people as I find sometimes I don't have the time to see my friends. I have to cancel plans a lot as things crop up. I am very lucky to have an understanding partner as he get pushed to the bottom sometimes as I have no choice but to.

Half (52 per cent) of carers have experienced difficulties in their relationship with their partner because of their caring role.

Because of the amount of time I spend caring, my partner is becoming very bitter and resentful.

I have given up work to care for my husband. More time together has brought us closer, but has also caused tension. His dementia, diagnosed after I gave up work, is a real challenge to our relationship and a source of much more sadness than the Parkinson's diagnosis.

My husband and I got divorced 28 years ago when our son was five. It wasn't because our son had Down's syndrome but because our lives had changed so much.

For many working age carers, their friendships and contact with colleagues are a much appreciated break from the pressures of caring as long as they are able to remain in work or adjust their hours around their caring responsibilities.

4.3 Careers

The majority of the carers that responded to our survey are working age (83 per cent). In the UK over three million people juggle working and caring¹².

Just under **two-thirds** (63 per cent) of carers were **not prepared for the impact of caring on their career**.

Depending on the nature of the caring role it can take up a lot of time and mean it is impractical to continue working – sometimes you need to travel distances to look after the person you care for requiring night time stopovers, accompanying the person you care for to regular hospital appointments or lack of public transport can leave you in a position where you cannot work full-time and have to reduce working hours or take an alternative role that provides the option to work shifts or flexi-time to fit around your caring role or give up work entirely.

¹² Census 2011 (2012) Office of National Statistics

Just under **half** (45 per cent) of carers in our survey have **given up work** because of their caring role.

Nothing prepared me for the loss of identity that jumped me when I had to stop working – overnight I stopped being superwoman and became a nonentity, a scrounger living on benefits. I feel that I am invisible now – as soon as you mention that you are a carer, whether talking to a professional or a stranger at the bus stop, their eyes glaze over. Once you are a carer it is as if you cease to exist, or only live as a shadow. It is hard.

Just over **two in five** (42 per cent) carers have **reduced their working hours** because of their caring role. Nearly **half** (48 per cent) of carers have had to **change their working patterns because** of caring responsibilities.

Employers are increasingly seeing the benefits of supporting their staff to remain in work alongside their caring responsibilities and there is a strong economic argument to support this as skilled and trained staff are left with no option but to leave the workforce to care for family members and friends. Flexible working and policies that understand and recognise the pressures of caring alongside work are being adopted by a growing number of employers but it is still far from the norm. With increased openness and support in the workplace carers could be less likely to miss out on opportunities for promotion.

I gave up work for 10 years, as there was no way that my younger son's disability, which affected his sleep pattern, would allow for both parents to get a good night's sleep and be fit to work a full week. We therefore had to decide which of us would give up work and only after ten years did we manage to get the support we really needed (via changes to carers rights and also flexible working legislation) so that I could consider going back part, and I have now built up to a 4 day week of different self-employed roles. This is a very admin-heavy way of working, so does not leave as much time for leisure as would a full-time employed position, but it is more flexible around the care and support needs of my sons.

A **third** (34 per cent) of carers stated that they had **missed out on the opportunity for promotion** because of their caring role.

Giving up work or reducing your hours to care has an immediate impact on your household income. Carers shared with us how their finances were fairing as a result of their caring responsibilities.

4.4 Finances

Becoming a carer can significantly impact on your finances and very few people will have considered preparing for the increased costs.

Over **seven out of ten** (72 per cent) carers were not prepared for the **financial impact of caring**.

Carers felt that there was not sufficient advice and information to help them prepare for the costs of caring and as a result were not prepared for the additional costs of caring or had no time to prepare.

No amount of information or preparation makes the reality of caring induced poverty any easier. It is just a reality. Caring means you are poor. You eke out what you have and cut expenditure.

Just over **seven out of ten** carers either definitely (44 per cent) or partly (28%) felt that there was **not sufficient advice and information** to help them prepare to care.

Caring can come at a cost as carers purchase specialist equipment, face higher household bills and invest in adaptations on their home or the home of the person they care for. Although there are grants to help with these costs not everyone will be eligible or due to lack of information and support carers are not always aware of the assistance available. Paying for additional care at home, a day care centre or short-term residential care is sometimes a cost to the carer as can be access to breaks from caring. Although if you are eligible for a support from social care services, this need could be identified as a requirement and funded by the local authority (or health and social care trust in Northern Ireland).

Seven out of ten carers had not planned to care so had either definitely (46 per cent) or partly (24 per cent) **not prepared for the additional costs of caring**.

A family member or friend could need caring for with no warning following a stroke, accident or discharge from hospital. In such instances carers can find themselves paying out in an emergency while financial support is arranged through benefits and support from the local authority (or health and social care trust in Northern Ireland).

For **seven out of ten** carers caring had come as a shock so they either definitely (45 per cent) or partly (24 per cent) **had not time to prepare financially**.

From this evidence we learned about the number of carers who had reduced their hours or given up work to care. Others may have taken a lower paid job with fewer responsibilities to help them manage their caring role so their income would be reduced.

Six out of ten (60 per cent) carers in our survey have had a **reduction in their income/salary** as a result of caring.

It is no surprise, therefore, that carers have found themselves in financial difficulties.

Two out of five (42 per cent) carers have **struggled/found it difficult to pay for essentials** such as heating and food.

A **half** (49 per cent) of carers had **used their savings to pay for essentials** such as heating and food.

A **quarter** (26 per cent) of carers had taken out a **loan** or **fallen into debt** because of their caring role.

Furthermore, recent Carers UK research has indicated that carers' financial situations are worsening¹³ - as greater numbers find themselves in fuel poverty and struggling to pay basic bills, while the Westminster Government's cuts to the Welfare System including to disability benefits is a cause of increasing anxiety.

¹³ State of Caring 2013 (2013) Carers UK

As well as providing personal care, carers can find themselves helping the person they look after with the practical aspects of their life such as their finances. With this responsibility can come legal implications and the need to call on solicitors to arrange Power of Attorney, for example. This can be a difficult time for carers as they see a shift in the relationship of the person they care for – looking after their parent's finances or seeing to the household accounts which was previously their partner's responsibility.

Seven out of ten (69 per cent) carers have taken on increased responsibility for the finances of the person they care for.

Taking on the financial responsibilities of another person, alongside the impact on their own family finances, can cause additional anxiety and stress and become contributors to poor carer health and well-being.

4.5 Health and well-being

Caring can be physically and emotionally demanding. As a result, it can take its toll on a person's health and well-being.

Over **eight out of ten (84 per cent)** carers were **not prepared** for the impact caring had on their **health and well-being**.

After 22 years of caring responsibilities I would say that the role evolves quite drastically as the person you care for gets older and their health deteriorates. I surprisingly never considered that in tandem of course I would age and my health would deteriorate! I never knew what old age would mean for me both in terms of career and health and consequential lifestyle changes.

Some carers find themselves having to do a lot of heavy lifting and manual handling as they help the person they care for in and out of bed, chairs and the bath and shower. In addition wheelchairs and medical equipment can be cumbersome and difficult or very heavy to manoeuvre. Some carers had benefited from some manual handling training but, for others, hernias, slipped disks and back injury were a list of ailments that caring had resulted in.

Six out of ten (60 per cent) carers have **experienced injury** or their **physical health has suffered** because of their caring role.

Worrying about the health and well-being of the person they care for, finances and the future puts a huge burden on carers.

Over **nine in ten (92 per cent)** carers feel **more stressed** because of their caring role. **Nine in ten (89 per cent)** carers **feel more anxious** because of their caring role.

Caring can be very isolating and the nature of caring for a family member or friend can result in carers feeling isolated, unsupported and questioning if they are able to continue to cope. Their own mental health is a growing concern as the financial and physical pressures of caring have an effect on their well-being.

My health has been affected in so many ways. Firstly with stress, great stress of juggling everything, fighting his corner for health, education, and social. Secondly with anxiety as I struggle with self esteem ,

I'm always kicking myself on how I should have done better with him. Stress probably adds to the anxiety and lack of sleep. I seem to be fighting someone or something along with everyday struggles. Nothing is easy! I did have a massive breakdown years ago and I promised myself nothing would get me to that point again. Even if it means losing everything, job, home etc as nothing is more important than being a good mum. Hopefully, I know now when things start to go downhill and I speak up and ask for help. It's not pleasant asking for help, but if it saves me from going under, then I will suffer the embarrassment of asking for help rather than my children suffer without me.

Over the years I was anxious with each relapse and deterioration. I realise now I began the grieving process and one of the strongest stages in the beginning was denial. I shut people out when they talked about MS - this resulted in severe depression.

Six out of ten (61 per cent) carers have suffered from depression because of their caring role.

The above conditions can be worsened by not having enough time to rest, exercise and maintain a balanced diet. Due to the time constraints of caring and the challenging of juggling a number of responsibilities a carer's own health and well-being can slip down the list of priorities.

Seven out of ten (72 per cent) carers have had to reduce the amount of exercise they take and **six out ten (59 per cent) carers have found it difficult to maintain a balanced diet.**

Carers also report their sleep being interrupted by the person they care for, not having enough hours sleep or the worries and anxiety of their caring role keeping them awake at night.

Eight out of ten (78 per cent) of carers have found it difficult to have a good night's sleep.

Make time for yourself. Plan it. Make your life as easy as possible even if you have to lower your standards. Pamper yourself. Make time to relax. Make time to play. Remember, this is not selfish. If you do not care for yourself, you will end up not being able to care for anyone else.

4.6 Preparing for a caring role ending

Throughout the caring journey carers are confronted with a wide range of emotional and practical challenges most of which are unlikely to have been prepared for. Preparing for a caring role ending is very important whether this is end of life care, a move to assisted living or residential care - the carer being unable to provide the required level of care, or the person you are caring for no longer requiring your support. For those carers looking after someone with a terminal condition they cannot afford to lose time waiting for support. They need to be supported from the prognosis of the patient if not before.

The survey asked carers if they had experienced a caring role ending. A total of 305 people shared that they had.

After my caring role ended I felt out on a limb, you live in a bubble each day you have a rough idea of what is ahead.... Even when you know it's going to happen it is a change in lifestyle and is very frightening just as frightening as when the caring begins. You feel lost and alone and no idea what to do with your time. After caring long term carers especially should be given time to grieve and get their head back in some sort of order.

For many people caring for a family member or friend you are focused on their day-to-day needs with little time or opportunity to look to the future.

For those carers that had experienced a caring role ending nearly **half** (47 per cent) had **not had time to plan**.

Going it alone, without specialist advice or the support and the help of other carers, family and friends can be a challenging time – making decisions about alternative care, planning for end of life can be difficult.

I should have done more research before I needed it. My mum was a very private person and wouldn't discuss end of life until the last few days. I wish there had been a dedicated counsellor that could've talked us through these things.

I have been researching and planning for most of my daughter's life, but she continues to live far beyond anyone's expectations. We have come to learn living for today is far more important than planning for her demise, so positive thought and living life to the full are paramount whilst she is with us.

A **third** (36 per cent) of carers stated that they had not given this enough thought and **wished they had planned it better**. Nearly **two in five** carers (37 per cent) were not aware that they should have planned for this.

Being a carer came as a big shock but I am gradually adjusting. I would have liked to have had knowledge of the different stages of dementia and what to expect rather than being upset at the progress and stages that occur.

The survey asked carers who had experienced a caring role ending if there is anything with hindsight they would have done differently.

Nearly **three in ten** (28 per cent) carers **wished they had researched in advance** options for assisted living, residential care etc.

A **third** (35 per cent) of carers would have **planned for end of life care** and also a **third** (34 per cent) would have **planned for end of life care with the person they cared for**.

As well as dealing with the practicalities of a caring role changing or ending, carers also have to come to terms with life after caring, coping with the loss, change in lifestyle and the opportunity to pick up on hobbies, activities, friendships and careers which might have slipped down the list of priorities while they were caring for someone.

Nearly **half** (46 per cent) of carers who had experienced a caring role ending **had kept up with their hobbies and tried to stay in touch with friends**.

A **quarter** (23 per cent) had **thought about options for getting back into employment or remained in work while caring**.

People cope with bereavement and loss in all manner of ways, some go it alone, with no professional help or take on the role of supporting others to come to terms with what has happened. Accessing the right support and specialist help through your GP, counselling services such as Cruse or a local service can really help.

Nearly **six in ten** (56 per cent) carers had **accessed support to help them with the emotions** of their caring role ending.

Coming to terms with a caring role ending due to end of life, a move to assisted living or a reduction in caring responsibilities as the person you care for moves into residential care are developments that we should be better at preparing for or at least start looking into options. A more open recognition of this stage in our lives and the options available should be encouraged and sought in families and relationships.

Two out of five (41 per cent) of carers who have not experienced a caring role ending are worried about this but do not know how to prepare.

Although you can be aware end of life is coming you have to balance this out with keeping up hope and being positive for the person you care for. Also you just don't have the time to think ahead. With hindsight I can see that the signs that end of life for the people I was caring for was approaching, but as a carer in that situation at the time I could not see them. I wish the GP had spent some time with me to discuss these things.

5. Conclusions and recommendations

The UK's Governments have strategies which focus on ensuring carers are 'recognised, valued and supported'. However, the carers that responded to our survey shared experiences and opinions about how, at times, they felt anything but.

This report is published at a time of significant change in the support for families and carers receive. The devolved responsibility for health and social care means different developments across the UK; NHS England has just taken up its responsibilities and a new Health Secretary has brought new priorities for the health and social care system including a focus on dementia and improving the quality of services.

In May, the Westminster Government announced that it will be publishing legislation to put in place a new framework for delivering care and support services in England, giving new rights to carers to be assessed for support. The law will also establish a new system for paying for care services, placing a cap on the amount individuals will have to contribute to the cost of their care.

In Scotland, new legislation is about to be introduced to bring the delivery of health and social care together. In 2014 new legislation will also come into force to make it a duty to offer self-directed support to all people who use services and a power to offer this to carers too.

In Wales, Assembly Members are already considering legislation to make significant changes to the way that social services are delivered in Wales through the Social Services and Wellbeing (Wales) Bill. During this year's Carers Week a Refresh of the Carers Strategy for Wales is due to be launched.

Northern Ireland's Carer's Assessment legislation is in place and changes from the Government's new Transforming Your Care strategy are starting to be felt. The Who Cares? Consultation into adult social care provision with a focus on 'home as the hub of social care' could mean carers face even greater strains as the changes roll out.

Added to this, carers and disabled people across the UK are starting to see the impact of the Welfare Reform Act 2012. Changes to financial support with housing and council tax in some areas mean many families experiencing reduced financial support from more than one of the changes.

The economic downturn, a squeeze on wages and the increasing costs of essentials like food and fuel are all making it more difficult for carers to manage. The coming year will see other changes to the benefits system being introduced as the transfer of Disability Living Allowance to the Personal Independence Payment and Universal Credit are introduced.

Many of these legislative changes include positive measures for carers. In order to deliver this change for carers and the people they care for, and to understand where their lives are being made harder by reductions in support, the Governments of the UK must listen to carers and build and develop communities that recognise, understand and support carers – the UK's 6.5 million carers need *caring communities*.

This report highlights the importance of listening to carers and respecting and acting on their views and requests. Carers shared with us their wish list to help current and future carers be prepared for or manage their caring role. Their list of recommendations to help carers prepare to care included:

Prepared to Care? recommendations

1. Better public understanding and recognition of carers

All situations are different as we and the people we care for all have different needs, challenges and lifestyles but I wish that everyone thought more about the caring role in the same way as we think about stages of life—education, going to work, getting married, having children-taking maternity leave. So my biggest wish is that caring was something everyone talked about and recognised.

2. Access to information and the right support from the beginning

For many carers the greatest asset is 'Time'..... some things take so very long - quick access and speedy advice would be a huge bonus. It is very hard to sift through and find the sort of advice you need. I think GP surgeries should be better prepared to flag up other agencies that could help advise.

Accept the role of "CARER" in the early stages, not deny that you are a carer. Seek information and sift out that which is relevant to YOU and NOW. Join a support group when the time is right for you, Talk to family and friends about how you feel. Accept help from family and friends when offered. Don't feel guilty. Educate GPs to understand carers roles and the difficulties they face. Understand the fluctuations in many neurological conditions, eg Parkinson's and therefore understand the fluctuations that may occur for carers and the amount of care needed.

3. Professionals understanding the role of carers, sharing information, decision making and planning with them.

Professionals need appropriate up to date, regular, reviewed research, education, information and training to be made available and given to them so they know and can further recognise and improve carer's responsibilities in every way and in all aspects of a carer's caring duties to enhance their caring for whom they care for and for caring for the future, for all and in all communities.

To help people avoid crisis instead of only helping out when in crisis. Professionals need to be more of an ally instead of having to fight them for everything, when you are exhausted from your caring role I found that to try and get any help was a massive drain on my already limited energies.

4. Access to good quality practical and emotional support and information as well as breaks from caring.

It would make such a difference to be able to have regular respite rather than feeling that the world will fall apart because I am exhausted. If one can put down a small weight one carries for a short time, regularly, one can carry on for very much longer. Crisis management is the worst of all worlds.

Respite is my main concern - this needs to be of much better quality, more local with more availability on a more regular basis - this would assist hugely in enabling people to build and maintain relationships outside their caring role - this is currently sadly lacking.

5. Flexible working practices and understanding from employers.

A lot of the reason for my being able to maintain my job and hours is due to a very understanding and flexible manager. I could not have got through the last few years without her support.

I am extremely lucky that my current position is part-time in a job that I like and the manager in our tiny company is absolutely first class at allowing me to make up time whenever I need to and to dash off whenever I need to. But my income is severely reduced. I was made redundant from my previous role,

where I commuted to work 60 miles away. There is no way that I would have been able to sustain this type of job combined with caring.

6. Financial support – fair and easy to navigate welfare system.

When my daughter was diagnosed at the age of three I was unaware of any benefits we could claim. We struggled since her birth for many years and spent all savings. Did without holidays and my husband had to work night shifts constantly to cope and care for my daughter who never slept. We did get into debt as my husband lost his job and was unemployed for 6 months. We have no debts now and try not to get into debt again. We do without.

6. Methodology

To assess the impact of caring on carers' relationships, career, finances and health and well-being Carers Week surveyed **2,115** carers between March and May 2013. The majority of respondents completed the survey online, with eight respondents completing paper versions.

1,303 of the respondents were from England, **75** from Northern Ireland, **151** from Scotland and **92** from Wales (the remainder did not state their location).

39 per cent were aged between 40 and 54, **33 per cent** were aged between 55 and 64, **17 per cent** were over 65, **nine per cent** were aged 25 to 39 and **two per cent** were aged under 24.

79 per cent of respondents were women and **19 per cent** were men.

61 per cent of respondents had been caring for more than five years.

Respondents were weighted towards heavy-end carers, with **65 per cent** caring for 50 hours a week or more. **23 per cent** were caring for more than one person.

28 per cent were caring for a parent or parent in law, **36 per cent** for a spouse or partner, **25 per cent** for their son or daughter, **four per cent** for a sibling and **four per cent** for a friend.

92 per cent of respondents were White British and **three per cent** from Black, Asian and other minority ethnic (BAME) communities.

7. Appendix

Four nation and regional split of executive summary statistics

	UK	Northern Ireland	Scotland	Wales	England	North West	North East	Yorks and Humbs	West Midlands	East Midlands	Eastern	London	South West	South East
Total number of carers	2,115	75	151	92	1,303	290	74	118	153	79	70	86	151	283
Were you Prepared to Care?														
Number of carers not prepared for all aspects of caring.	75%	79%	77%	81%	78%	74%	75%	74%	75%	74%	72%	83%	78%	81%
Number of carers not prepared for the emotional impact of caring.	81%	81%	83%	86%	83%	81%	81%	75%	85%	81%	84%	83%	83%	88%
Number of carers not prepared for changes to their lifestyle because of their caring role.	78%	81%	79%	82%	81%	80%	77%	78%	75%	77%	75%	88%	78%	85%
Number of carers not prepared for change in relationship with person they care for.	71%	73%	67%	77%	73%	74%	69%	71%	68%	64%	69%	71%	74%	77%
Number of carers not prepared for impact caring had on career.	63%	67%	67%	62%	64%	64%	65%	57%	64%	61%	58%	74%	65%	63%
Number of carers not prepared for financial impact of their caring role.	72%	72%	74%	74%	75%	73%	75%	64%	74%	78%	69%	78%	75%	77%
Number of carers not prepared for the impact caring had on their health and well-being.	84%	86%	82%	88%	86%	84%	85%	80%	86%	90%	88%	87%	86%	89%
Receiving support (definitely and partly)														
Number of carers not aware of support available	81%	84%	83%	80%	81%	83%	79%	80%	84%	82%	78%	77%	76%	82%
Number of carers given wrong advice about support available	35%	31%	35%	39%	35%	35%	30%	28%	34%	42%	39%	33%	31%	39%

Relationships (strongly agree and agree)														
Number of carers who have experienced difficulties in their relationship with their partner because of their caring role	52%	51%	61%	62%	54%	55%	46%	51%	54%	58%	61%	53%	48%	57%
Number of carers who have found it difficult to maintain friendships	61%	62%	60%	76%	64%	60%	59%	64%	66%	56%	53%	75%	70%	62%
Number of carers who have seen their relationship improve in some ways with the person they care for.	43%	56%	38%	40%	40%	46%	45%	47%	38%	40%	44%	35%	38%	36%
Career (strongly agree and agree)														
Number of carers who have given up work because of their caring role.	45%	41%	45%	47%	47%	46%	48%	48%	41%	46%	54%	51%	49%	50%
Number of carers who have reduced working hours because of their caring role.	42%	48%	44%	42%	42%	39%	46%	44%	37%	41%	39%	40%	49%	42%
Number of carers who have missed out on a promotion because of their caring role.	34%	35%	36%	41%	35%	36%	35%	38%	31%	29%	30%	34%	37%	33%
Health and well-being (strongly agree and agree)														
Number of carers who are more stressed because of their caring role	92%	88%	94%	98%	92%	89%	96%	92%	90%	87%	94%	95%	93%	92%
Number of carers who have suffered depression because of their caring role	61%	62%	59%	66%	61%	58%	61%	60%	60%	61%	60%	65%	60%	63%
Number of carers who have reduced the amount of exercise they take because of their caring role.	72%	76%	71%	84%	72%	72%	76%	82%	70%	63%	53%	69%	68%	75%