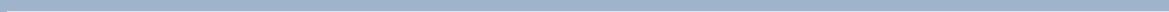


Surrey Carers Health Survey Report 2011



Surrey Carers Health Survey Report 2011

Carers:

“Carers look after family; partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.” This includes adults looking after other adults, parent carers looking after disabled children, and young carers under 18 years of age looking after siblings, parents or other relatives.

February 2012

Acknowledgements

NHS Surrey would like to acknowledge the support of all the carers who gave generously of their time to respond to this survey.

Specific thanks to the 10 Carers support organisations across Surrey and Action for Carers (Surrey) who helped to circulate and promote the survey and the various Disease specific/condition related organisations which included:

- National Autistic society
- Alzheimer's
- Parkinson's
- Headway Surrey
- Rethink
- Multiple Sclerosis
- Epilepsy

Our appreciation to all the Public Health Administration staff that helped enter data onto the Survey Monkey.

Specific thanks to Ron Critcher, Surrey County Council Carers policy officer, for all his technical and practical support.

Finally the authors of this report are especially grateful to all partners of the Surrey's Joint Carers Commissioning Group, including Surrey County Council and Action for Carers (Surrey), for their advice guidance and support.

Published by NHS Surrey

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Date: February 2012

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Executive Summary

Foreword

Carers have been telling us for many years that they feel the effect that caring has on their own health has gone largely unnoticed by health professionals - "ignored and invisible".

National studies, as well as the stories we hear from carers locally, indicate that caring can take a huge toll on a carer's health, both physical, mental and emotional.

We are delighted therefore that Surrey NHS has recognised that they need to know more about the health needs of carers in Surrey by undertaking this survey and committing to addressing the issues it may raise.

The response to the survey was both surprising and unsurprising. Surprising because the response was so great – even more in numbers than some recent national surveys on this issue. Unsurprising because we know, having listened to carers locally, that the effect that caring has on their health can be huge yet is often not understood or recognised by health professionals. The survey has enabled the many carers in Surrey who responded to share, often for the first time, their anxieties about their own health and to comment on the support they currently receive from their GP in particular.

One of the unsurprising, but still shocking, responses was how many carers neglect their own health because they are too busy putting the needs of the person they care for first.

Action for Carers (Surrey) worked closely with Surrey NHS and Surrey County Council in the design and distribution of this survey. We hope to continue this effective joint working to seek solutions to some of the health issues which carers have very clearly stated in their responses. Some of the solutions will be for Surrey NHS to consider directly; others we can work on together. It is the intention that the recommendations will form part of the revised Surrey Carers Commissioning Strategy, a joint document currently being revised by members of the Joint Surrey Carers Commissioning group and which will form the wider plan for actions by all the main agencies providing support for carers.

Carers in Surrey have sent a clear message that the health service needs to both recognise the often severe effect which caring can have on a carer's their health, and also take some responsibility for enabling them to maintain their health. No one wants a breakdown in a carer's health to result in two patients instead of one, so it is in everyone's interest – carers, those they care for, health services- to improve the health of carers.

Jane Thornton
Chief Executive, Action for Carers Surrey and
Chair, Joint Surrey Carers Commissioning group

Introduction

In partnership with Surrey County Council and Action for Carers (Surrey), NHS Surrey launched an adult carer's health survey between January and April 2011. This report outlines the findings and provides recommendations for the Joint Surrey Carers Commissioning Group.

Background

The Surrey Joint Strategic Needs Assessment (JSNA) 2011 reports the following level of needs for carers.

The 2001 census updated in line with 2008 population projections¹ indicates that in Surrey there were over 106,000 carers of all ages, which equates to:

- ❖ 9.6% of the population.
- ❖ 51,234 carers providing over 20 hours care a week (48% of the carers).
- ❖ Of these, 32,021 provide over 35 hours a week (30% of carers) and 23,482 were providing 50 hours a week or more (22% of the carers).
- ❖ Just over 60,000 carers reporting struggling to balance work and caring (57% of the total number of carer's).

The 2001 census figures updated for population growth show that in the county there were just over 106,000 carers who save the public purse an estimated £1.595 billion² a year.

Current Health Responsibilities

In November 2010, the Government published 'Recognised, valued and supported: Next steps for the Carers' Strategy'³, which focuses on improving health and social care support for carers in England. Four priority areas for improvement were identified:

- supporting early self-identification and involvement in local and individual care planning; enabling carers to fulfil their educational and employment potential;
- personalised support for carers and those receiving care;
- supporting carers to remain healthy.

In the Carers' Strategy of November 2010 Government allocated an additional £400m over four years (2011–14) to the NHS for primary care trusts (PCTs) in England to provide breaks for young and adult carers. The Government requested PCTs to work with local authorities and carers' organisations to develop policies, plans and budgets to support carers and make provision available to local people.

¹ Source: 2001 census updated by 2008 population projections

²Source: "Valuing Carers - Calculating the Value of Unpaid Care" Leeds University 2007.

³ HM Govt 2010, 'Recognised, valued and supported: Next steps for the Carers' Strategy

National Picture

The Government has highlighted carers as a group experiencing health inequalities within their plans to promote public health⁴. Evidence of comparative poor health of carers includes:

- A four year study of 392 carers and 427 non-carers aged 66-92, which found that carers who were reporting feelings of strain had a 63% higher likelihood of death in that period than non-carers or carers not reporting strain;
- Carers providing high levels of care being associated with a 23% higher risk of stroke;
- 52% of carers providing substantial care in one study being treated for stress-related disorders. In another, over half the sample said they were in good health, but General Health Questionnaires (GHQs) indicated that 94% could be identified as having psychiatric disorders;
- More than 80% of carers saying that their caring role has damaged their health;
- Carers providing more than 50 hours of care per week are twice as likely to report ill-health as those not providing care.

Evaluation of the National Carers' Strategy Demonstrator Sites Programme - Nov 2011

The National Carers' Strategy Demonstrator Sites (DS) programme was developed by the Department of Health (DoH) as part of the commitments made in the 2008 National Carers' Strategy (HMG, 2008). The DS programme, delivered across England, comprised 25 partnerships. With a delivery period of 18 months, each site was expected to develop new, innovative services for carers, or to extend existing provision if effective arrangements were already in place. The recently published report⁵ sets out the aims of the National Carers' Strategy Demonstrator Site programme which was for Demonstrator Sites to develop and enhance the local support available to carers and, where possible, to measure the quality and effectiveness of the new provision. The national evaluation of the DS programme was commissioned to assess the extent to which these goals were achieved, with a particular focus on: mapping the Demonstrator Sites' activities; assessing the effectiveness of their initiatives; examining the impact on carer health and well-being; outlining the cost of initiatives; and assessing the extent of carer engagement in the planning, delivery and evaluation of the programme.

The findings of this report reflect the evidence gathered as part of the Surrey Carers Health Survey.

The report provides commissioners with policy recommendations which are outlined in the Section 4.

National Profile - Who's at risk and why?

The impact of caring can be detrimental to carers' health. Carers UK's analysis of the 2001 Census findings, 'In Poor Health', found that those caring for 50 hours a week or more are twice as likely to be in poor health as those not caring (21% against 11%). This can be due to a range of factors including stress related illness

⁴ HM Govt 2010, Healthy Lives, healthy people: a strategy for public health in England'

⁵ Department of Health (DoH) 2011 - New Approaches to Supporting Carers' Health and Well-being: Evidence from the National Carers' Strategy Demonstrator Sites programme

and physical injury. Nearly 60% of those who responded to the Surrey Carers Health Survey reported they were providing 50 hours or more care per week.

Over half of carers providing more than 20 hours a week are likely to sustain a physical injury such as back strain ("Ignored and Invisible - Carers Experience of the NHS" Melanie Henwood⁶). A further 17% of those who responded to the Surrey Carers Health Survey reported they were providing over 20 hours of care per week. More than 80% of carers stated that their caring role had damaged their health.

NHS Operating Framework 2012/2013 – Carers⁷

States the following:

2.11 Carers play a vital role in our system and must receive help and support from local organisations. Following a joint assessment of local needs, which should be published with plans, PCT clusters need to agree policies, plans and budgets with local authorities and voluntary groups to support carers, where possible using direct payments or personal budgets. For 2012/13 this means plans should be in line with the Carers Strategy and:

- be explicitly agreed and signed off by both local authorities and PCT clusters;
- identify the financial contribution made to support carers by both local authorities and PCT clusters and that any transfer of funds from the NHS to local authorities is through a section 256 agreement;
- identify how much of the total is being spent on carers' breaks;
- identify an indicative number of breaks that should be available within that funding; and
- be published on the PCT or PCT cluster's website by 30 September 2012 at the latest.

Link:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131428.pdf

⁶ 1998 - Ignored and Invisible - Carers Experience of the NHS (Melanie Heywood)

⁷ http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131428.pdf

Surrey Adult Carers Health Survey 2011

Key Findings:

- Nearly 2000 responses were received in total.
- 70% of respondents were woman and 30% men.
- 60% said they were caring over 50 hours a week
- Almost 100% identified a health condition they suffered from.
- 35% said they thought their condition had worsened due to their caring role
- Over half were caring for someone with a physical disability. 40% were caring for people with mental health issues including dementia.
- 75% lived with the person they were caring for
- 45% had not registered with their GP as a carer although over 65% had told their GP they were caring
- 50% did not complete the section asking them what help their GP had provided
- Over 30% had not had a carer's assessment and a further 20% were not sure.

(Percentages have been rounded up)

What Carers Asked For (in order of priority):

- Carers Breaks, night time, weekend, palliative care trained staff
- Health Checks often referred to as MOT's
- Counselling services, including bereavement, future planning, and emotional support.
- More Training in the Disease/Condition of the cared for person, and back care.
- Recognised and valued as carer during Hospital Discharge
- Flexible appointments with GP.
- Support from Employers.
- Access to leisure activities, including sports centres, pampering days.

Methodology

Who commissioned the survey?

NHS Surrey, in partnership with Action for Carers (Surrey) and Surrey County Council, developed an Adult Carers Health Survey to help understand the impact that caring has on the health of carers – and to help in the development of services for them.

Surrey's carers were asked about their health and their health needs by way of an adult carers' health survey. The questions have been included as graph titles in the main findings section of this report. The findings in this report will allow commissioners to take a fresh look at the services provided for adult carers and to seek opportunities to improve carers own health and wellbeing.

The Surrey Carers Health Survey was launched in January 2011 and closed on 10th April.

6000 hard copies of the survey were distributed via the 10 Surrey carers support organisations. 1622 hard copies were returned.

The Survey was also made available on line using Survey Monkey and was shared with many of the disease specific and condition related organisations such as National Autistic Society, Alzheimer's Society, Parkinson's, Surrey Headway, Rethink. 325 were completed via Survey Monkey. The survey allowed for free text answers to 5 questions. The responses have been analysed and entered on to Survey monkey and are represented as findings in table format.

In total 1,947 were completed, giving a return rate of 33 %.

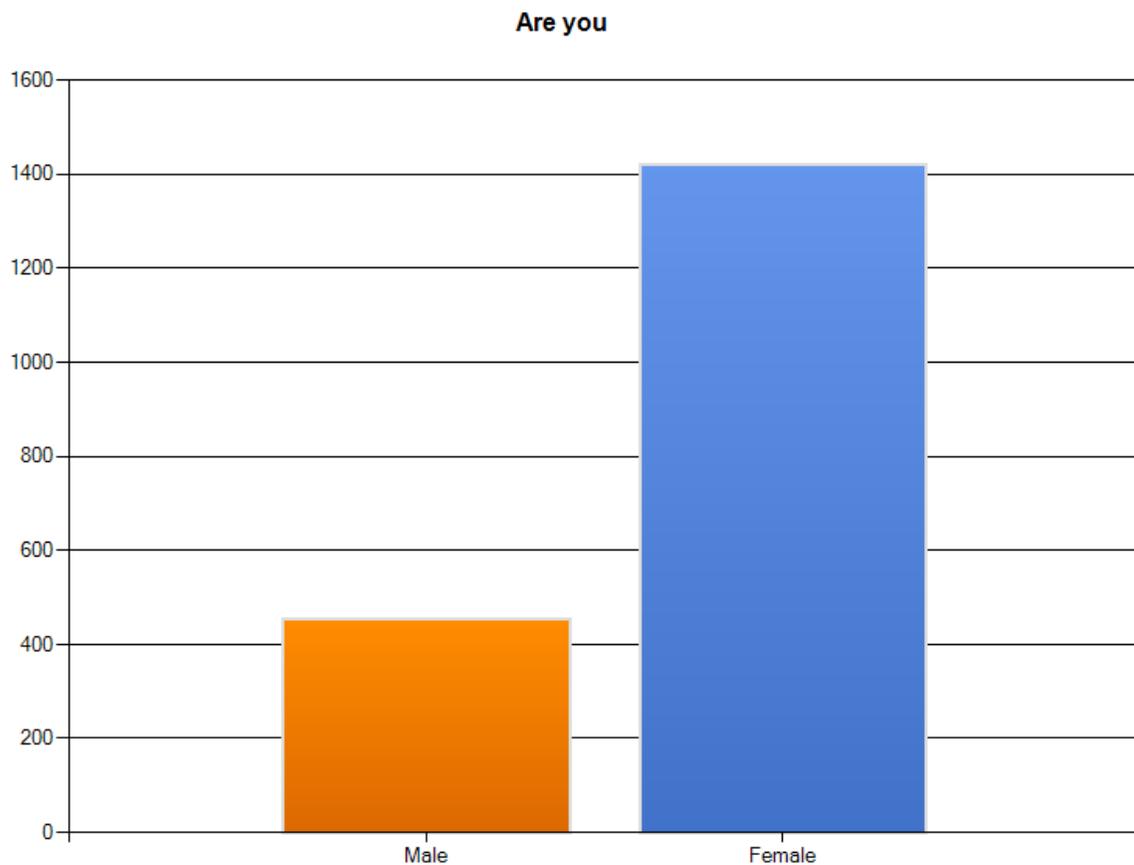
1 in 8 people are thought to be adult carers, meaning there's an estimated 106,000 carers in Surrey.

National evidence suggests that caring can impact adversely on carers' health. The findings of this survey help paint the picture in Surrey.

Consideration to the profile of those who completed the survey is important as this largely reflects those carers who already have had access to carers' services and who are providing high end care. It is important to bear in mind that caring may be just one part of the carer's responsibilities and a carer may also be juggling other caring responsibilities to their family, work commitments and multiple caring roles. The impact on carers who live with the person(s) they care for or who provide remote caring can carry different stresses and anxieties.

Surrey Adult Carers Health Survey Findings

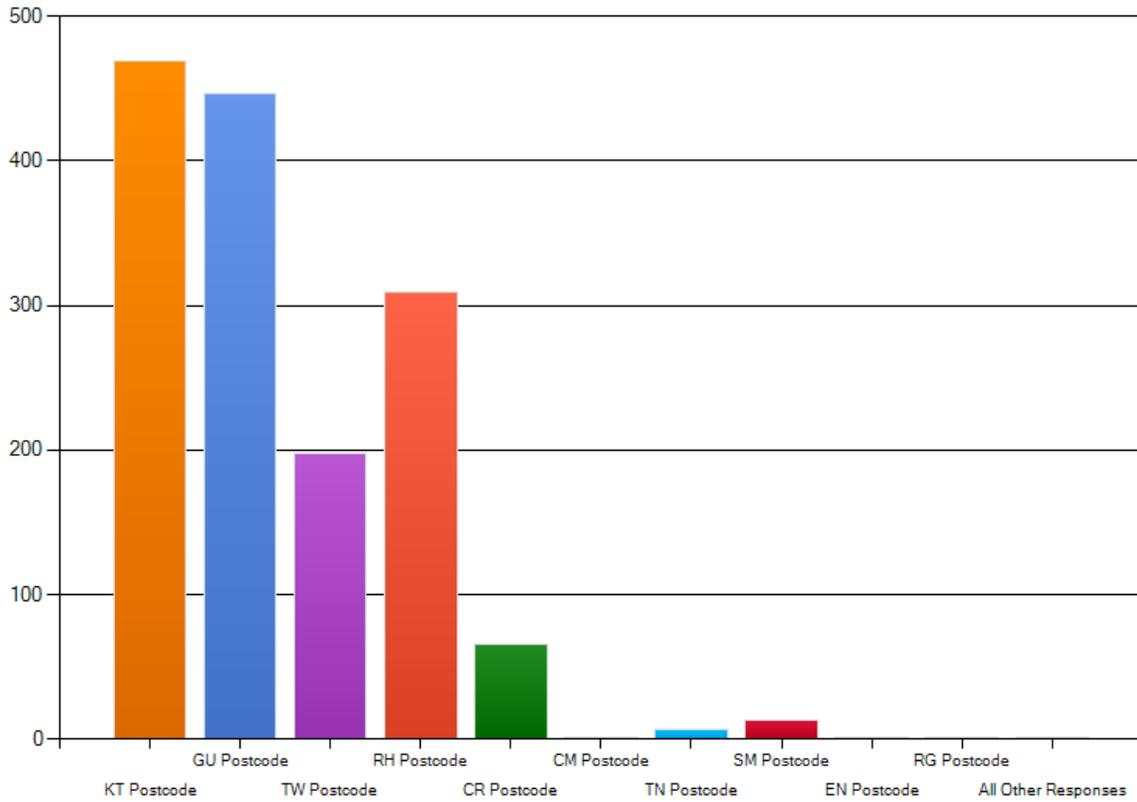
About the Carer



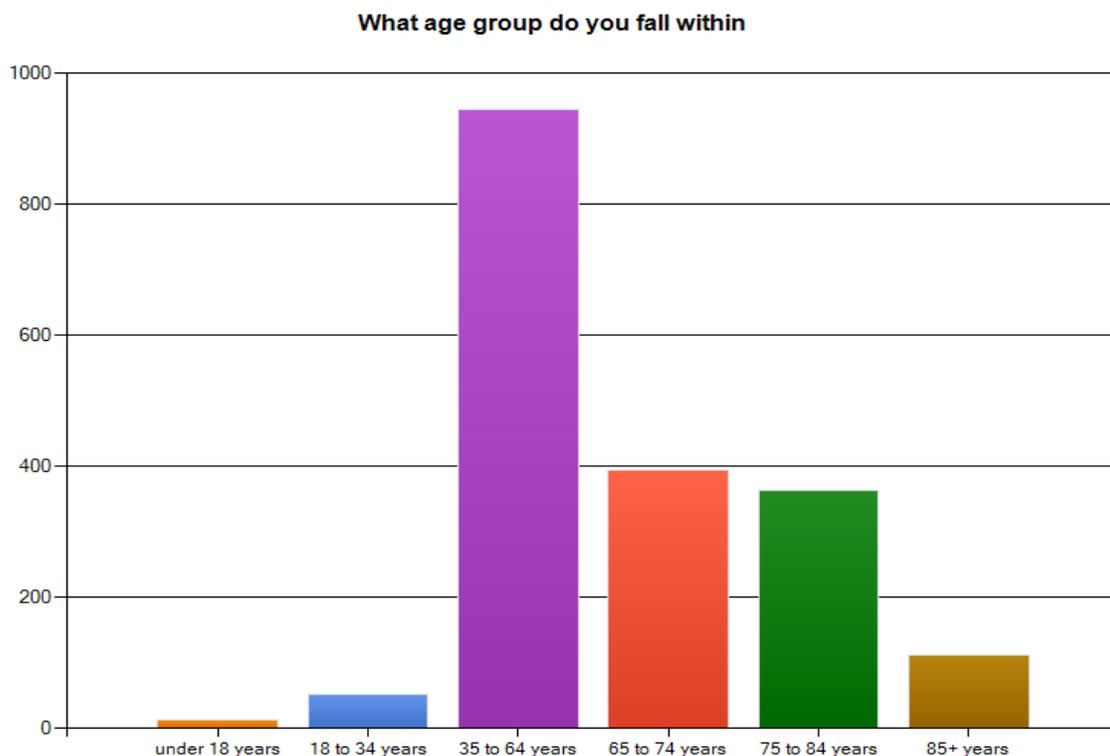
This reflects the national profile according to the Survey of Carers in Household 2009/10 in which:

Nationally women were significantly more likely than men to be carers overall (14% compared with 10%). Six per cent of women and five per cent of men provided care for someone living in the same household. Women were also more likely than men to provide care for someone living elsewhere (8% compared with 5%).

Location of response



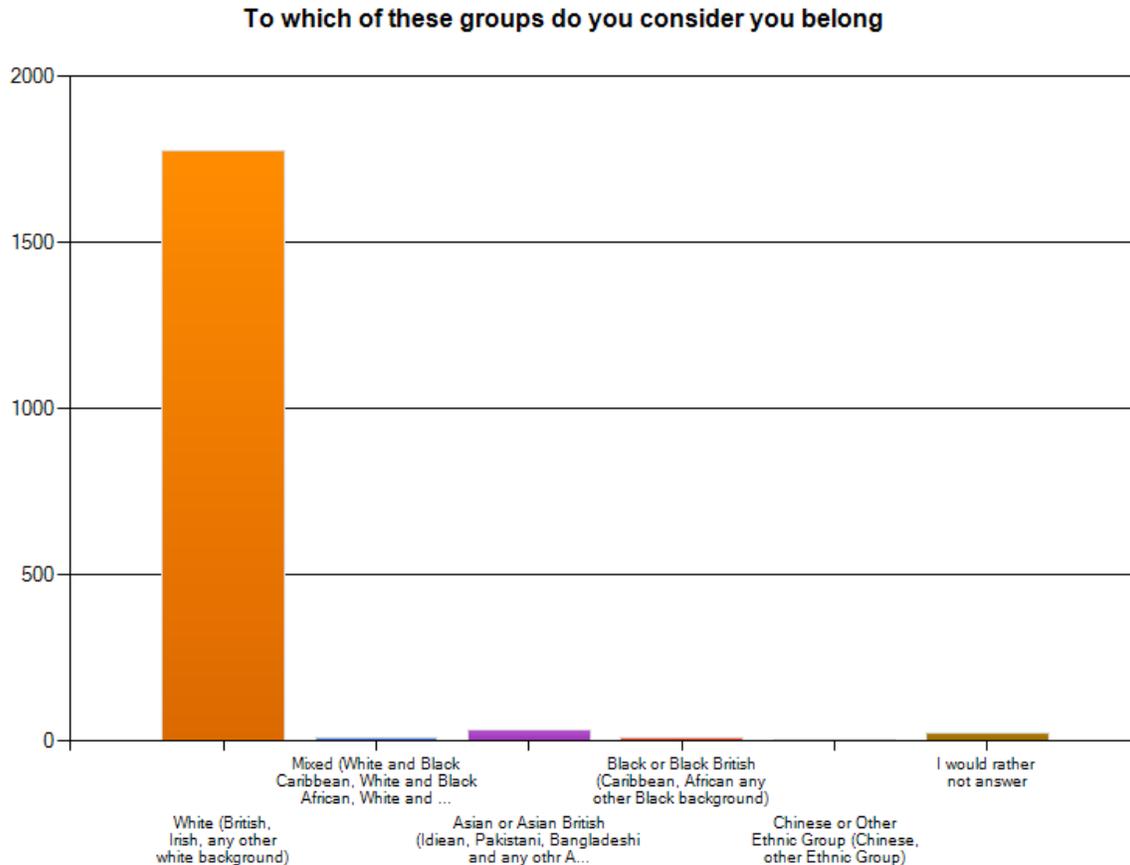
- KT – Kingston upon Thames
- GU – Guildford
- TW – Twickenham
- RH – Redhill
- CR- Croydon
- CM – Chelmsford
- TN – Tonbridge
- SM – Sutton
- EN- Enfield
- RG- Reading



According to the Survey of Carers in Household 2009/10 this reflects the national profile, in which:

Caring was least common amongst younger age groups and most common amongst those aged 45-74. Only 6 per cent of 16-24 year olds and 7 per cent of 25-34 year olds provided care for someone; in comparison 18 per cent of 55-64 year olds and 16 per cent of 45-54 and 65-74 year olds provided care. People aged 65-74 and 75 or over were most likely to provide care for someone in the same household (9% and 10% respectively, compared with 3% for groups under 35). Adults aged between 45-54 and adults aged between 55-64 were most likely to care for someone in another household only (9% and 12% respectively).

The largest age group reflects working age carers in Surrey.



According to the Carers UK 'Half a million voices' report 2011:

The research shows that BAME carers provide more care proportionately than White British carers, putting them at greater risk of ill-health, loss of paid employment and social exclusion.

It is important that a reformed NHS actively works to overcome the additional health challenges that are faced by BAME communities. There is an urgent need for the NHS to clearly understand and respond to the needs of carers and, within this, they need to understand BAME carers.

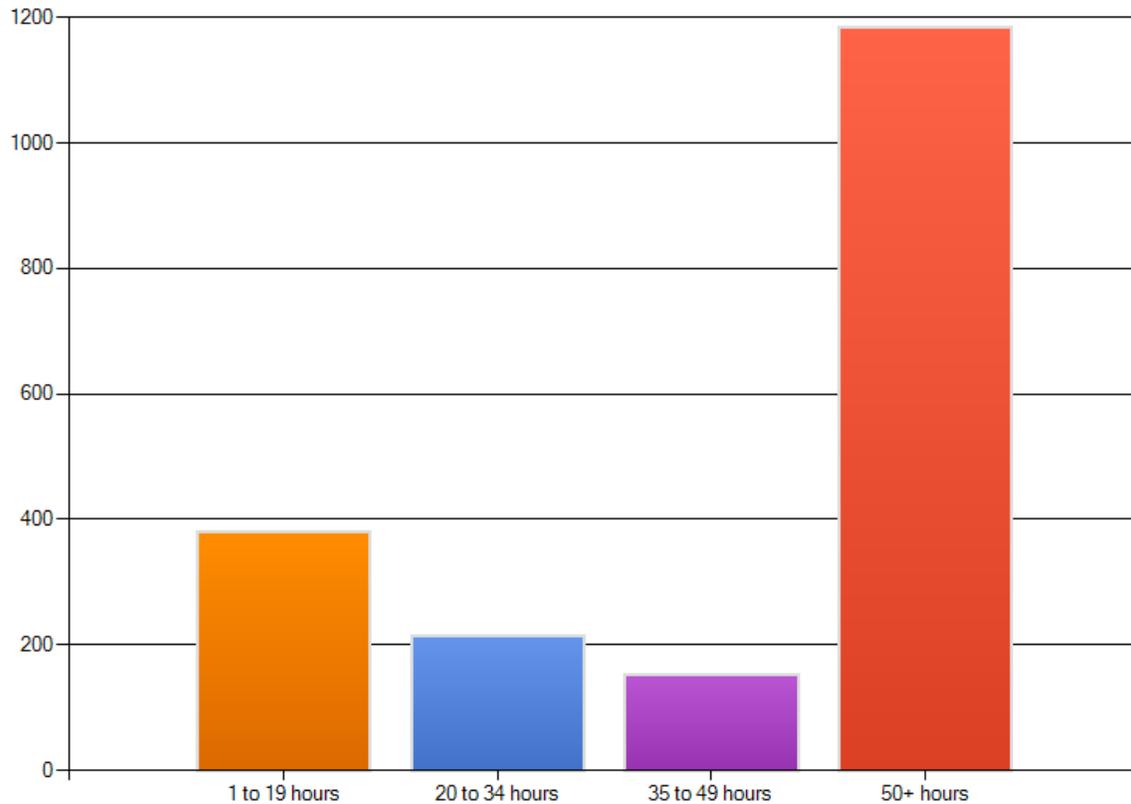
BAME carers are more likely to be in poor health compared with White British carers.

The relative response rates reflects the Surrey's Black, Asian minority ethnic groups (BAME) profile.

Carer quote

'There are assumptions made by professionals which place additional stress and difficulties on Carers. Lack of culturally sensitive services; lack of confidentiality (due to language and translation issues) add to the stress'.

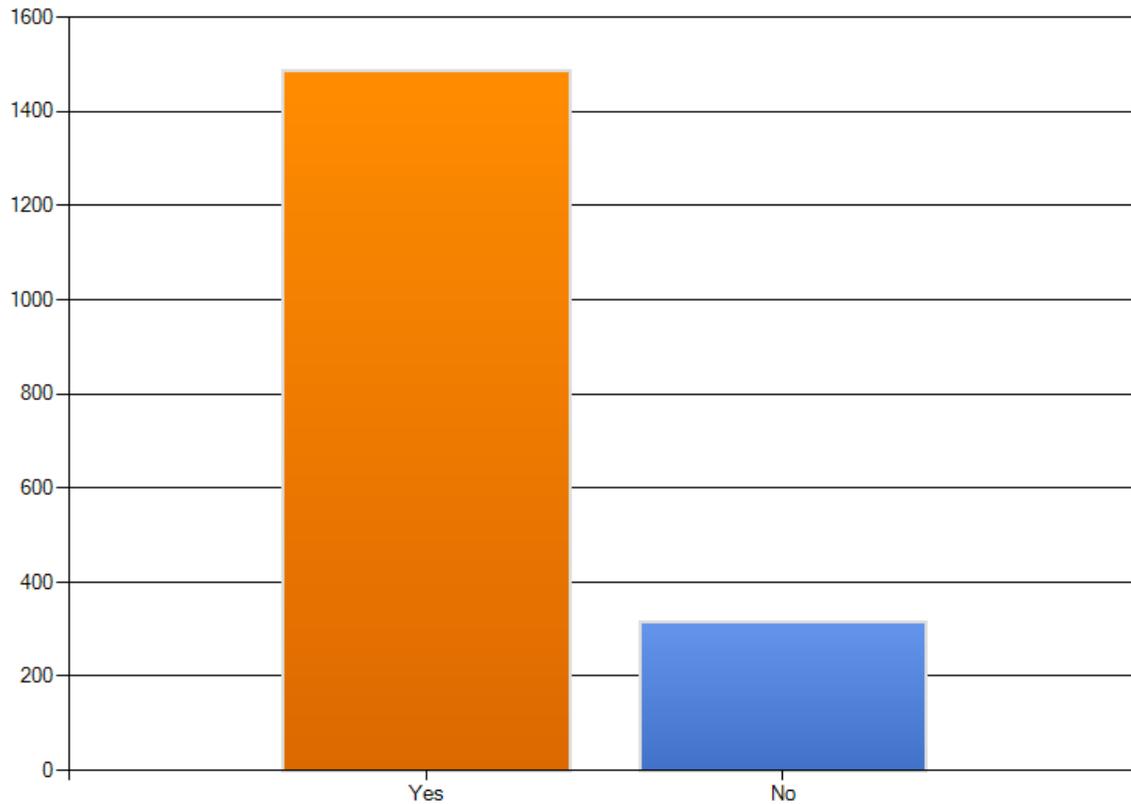
How many hours do you care for the person you look after per week?



According to the JSNA, 23,482 carers in Surrey were providing 50 care hours a week or more (22% of the carers). This health survey reports that 60% of the survey sampled reported that they were providing 50hrs of care a week, suggesting a much larger percentage of carers are at risk of poor health than previously reported.

It is possible that the reason the current survey does not reflect the national profile is as a result of the survey sample which may be skewed by the fact the majority of carers taking part came via the carer networks, rather than the "general public", and were "Heavy end" carers who are more likely to be in touch with Carers' Support organisations and disability organisations.

Do you live with the person you care for?

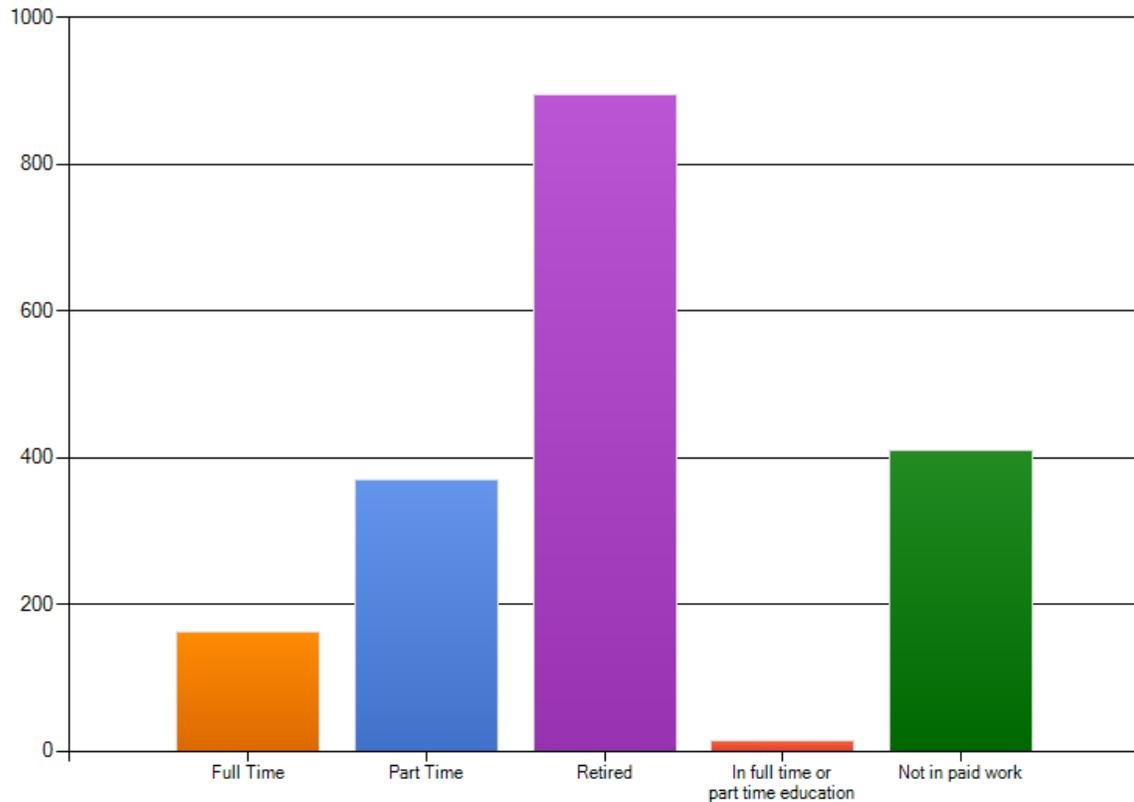


Although most carers reported they lived with the person they care for it's important to note that those who provide remote care may not be registered with the same GP practice. This can cause issues around GP carer recognition.

The survey does not reflect the national picture reported in the Survey of Carers in Household 2009/10⁸ that more carers care at a distance than live with the person they care for. The problems caused by non-registration at the user's GP are likely to be a greater problem than appreciated.

⁸ NHS Information Centre for health and social care – Survey of Carers in Household 2009/10 Dec 2010, Figure 2.2 shows the percentage of households in England containing a carer. One in seven households in England (15%) contained a carer. This represents around 3 million households in England. Seven per cent of households contained someone who cared for someone else in the same household, while 8 per cent contained a carer who was looking after or giving special help to someone in another household only.

Outside of your caring role do you work



It is worth noting that this table reflects the age range evidenced in the earlier graph. Approx. 900 of respondents are within retirement age range.

'Always On Call, Always Concerned – A Survey of experiences of older carers' Princess Royal Trust for Carers (PRTC)⁹ 2011 reported the following key findings:

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 depression.

⁹ The Princess Royal Trust for Carers (PRTC) was created on the initiative of Her Royal Highness in 1991. At that time people caring at home for family members or friends with disabilities and chronic illnesses were scarcely recognised as requiring support.

For nearly 20 years, The Princess Royal Trust for Carers has been fighting to provide carers with the support they so desperately need.

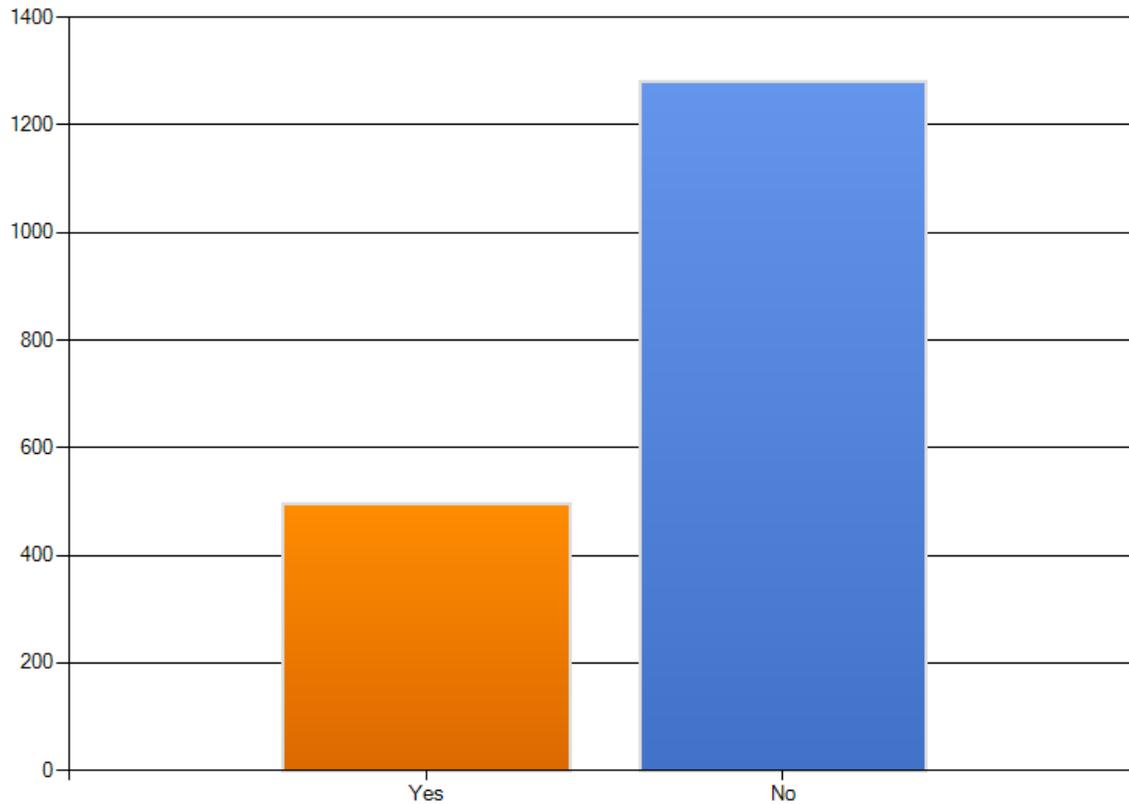
At the heart of The Trust is a unique network of 144 independently managed Carers' Centres, 89 young carers' services and interactive websites (www.carers.org and www.youngcarers.net) which deliver around the clock support to over 424,000 carers and approximately 28,500 young carers.

For more information click on this link: <http://www.carers.org/>

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

Half of all older carers reported that their physical health had got worse in the last year and 7:10 said caring had had a negative impact on their physical health. A quarter of carers aged 60 - 69 said caring had a negative impact on their mental health.

When you become a carer did you give up your paid employment?



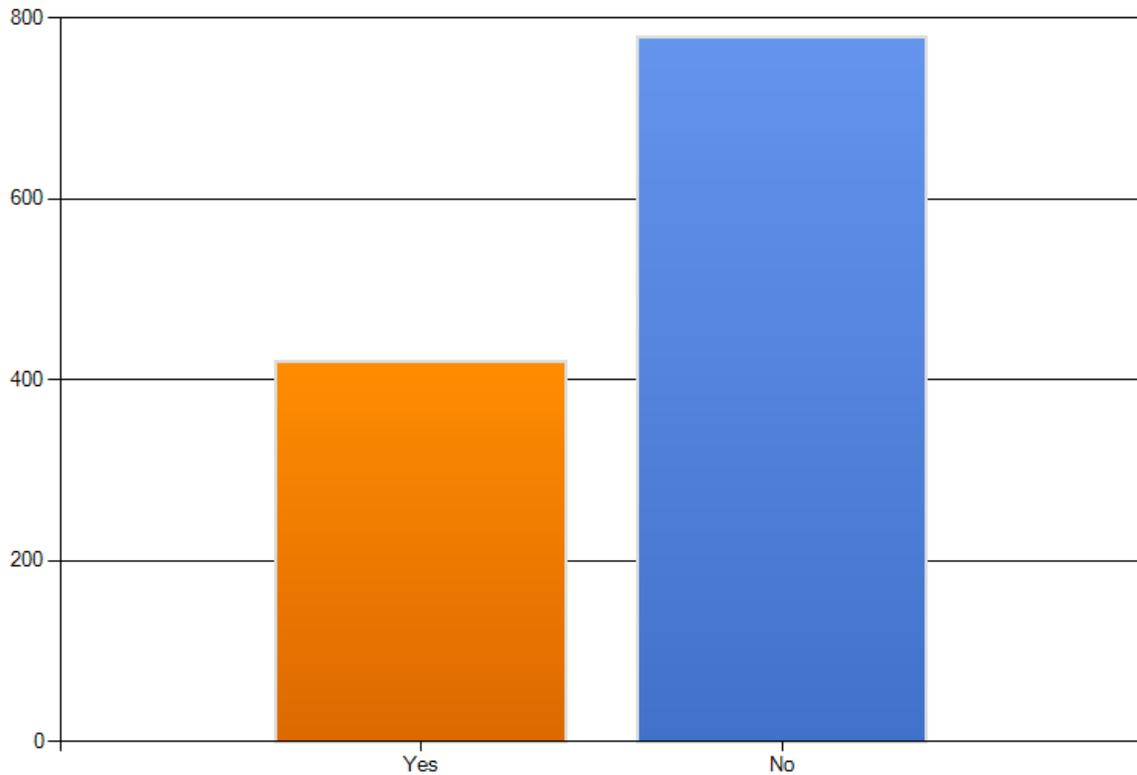
Worthy of further note were the number of carers who had given up employment due to their caring role. There was reference made to lack of employer support especially during episodes of crisis. Men and women with 'heavy' caring responsibilities are known to have lower economic activity rates.

According to the findings of the Carers UK and Leeds University 2007 report "Carers, Employment and Services in their Local Context":

If in the future working carers are to sustain their caring roles and also to make their contributions in the workplace, while avoiding damage to their own health and wellbeing, it will be essential for strong emphasis to be placed on the development of better support and services which take full account of the realities of their working and caring lives.

With 500 carers in Surrey having given up work to meet their caring responsibilities, the vision of our policy of a 'life outside of caring' has still to be realised for many.

If you did not give up your job did you reduce your hours to accommodate your caring role?

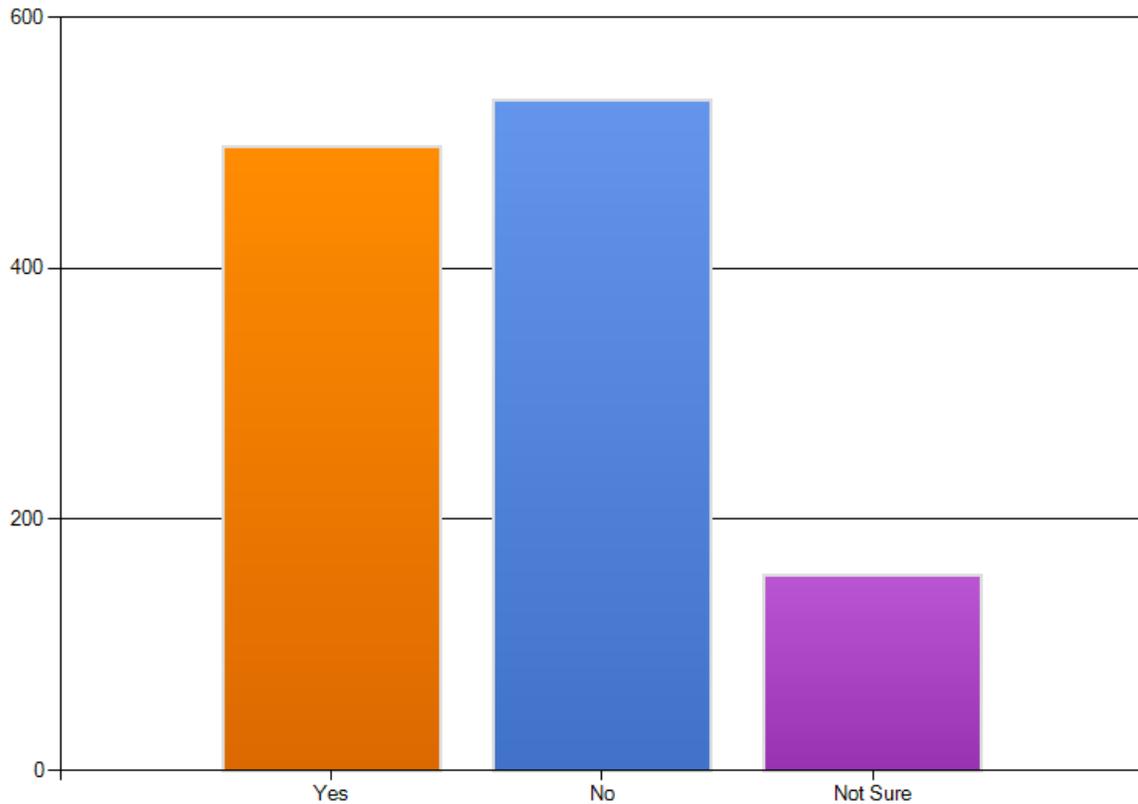


Currently 3 million people in the UK juggle paid work with unpaid caring responsibilities – one in seven people in any workforce – and this number is set to increase by half as much again in the next 25 years¹⁰.

The position in Surrey reflects the national profile, according to the Survey of Carers in Household 2009/10. There were clear differences in terms of working status and caring prevalence. Around one in five (22%) of those who were looking after home or family reported they were carers compared with only one in ten people (10%) who were working. Provision of care was also higher than average amongst retired people (16%).

¹⁰ Survey of Carers in Household 2009/10

If you did give up your job since becoming a Carer have your work aspirations changed?

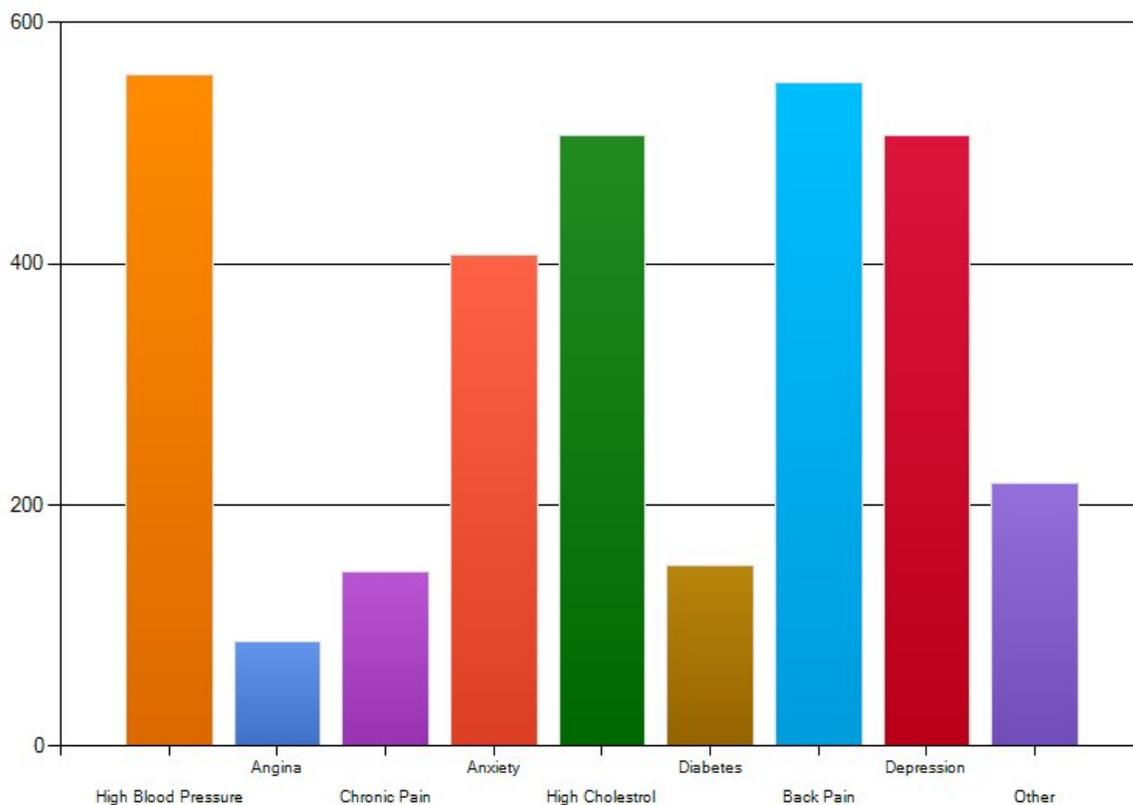


According to Carers UK report 2004 'In poor health'¹¹:

The role of paid employment and training and learning is often overlooked in relation to carers' ill-health. Research has shown that lifelong learning can have a positive effect on carers' health and, for some, provides a vital stepping stone into work. Working also reduces many of the negative factors that affect health. Carers in employment are less isolated, less likely to become depressed and less likely to be trapped in poverty long-term.

¹¹ Carers' UK report (2004), 'In Poor Health' click here: <http://professionals.carers.org/health/articles/in-poor-health-the-impact-of-caring-on-health,904,PR.html>

Have you been diagnosed with any of the following conditions



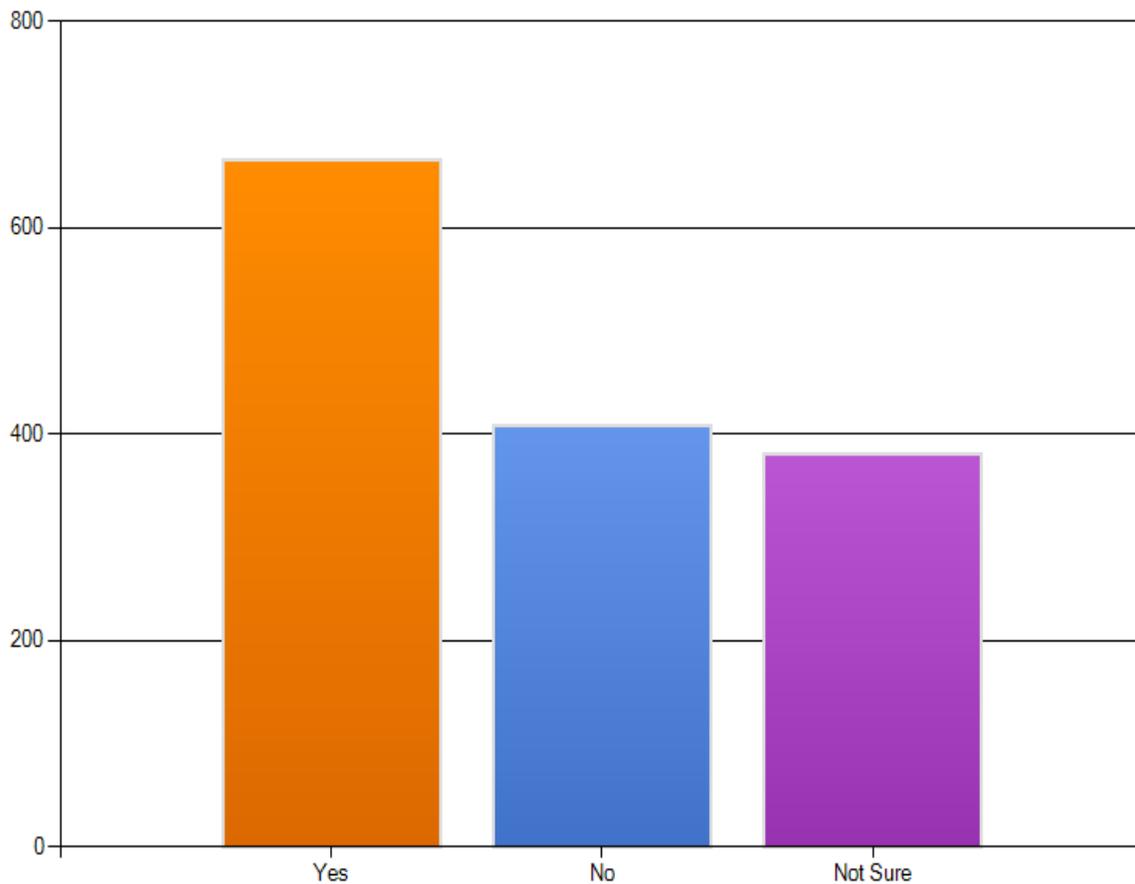
According to Carers UK report 2004 'In poor health' : Physical Health

The General Household Survey found that 24% of carers caring for 50 hours a week or more reported "physical strain". Carers UK's own research found that half of the respondents providing substantial care had suffered a physical injury since they began caring often due to having to lift or handle the disabled person. Carers also report other physical health problems associated with stress such as high blood pressure, heart problems, etc.

Mental Health

Caring also has a negative effect on carers' mental health. A recent report found that mental health problems were more likely to be associated with caring, than physical ill-health. The representative study, based on analysis of the British Household Panel Survey, also found that carers were more likely to report high levels of psychological distress, including anxiety, depression, loss of confidence and self-esteem, compared to non-carers. This research also found key times when caring was more likely to make you ill – at the beginning of caring and once caring had ceased. Women were also more likely than men to suffer from mental ill-health if they were a carer. Research published in 1998 by Carers UK found that 52% of respondents providing substantial amounts of care had been had been treated for a stress-related disorder.

If you have a diagnosed medical condition(s) do you think this has become worse since you started caring for someone?



According to Carers UK report 2004 'In poor health':

Carers are twice as likely to suffer from mental ill health if they do not get a break from caring.

Carers should not have to ignore personal health concerns and needs because their caring role does not allow time to address them. The services and support available to carers should be such as to enable them to stay as mentally and physically well as possible throughout their caring role. (DH, 2009:20)

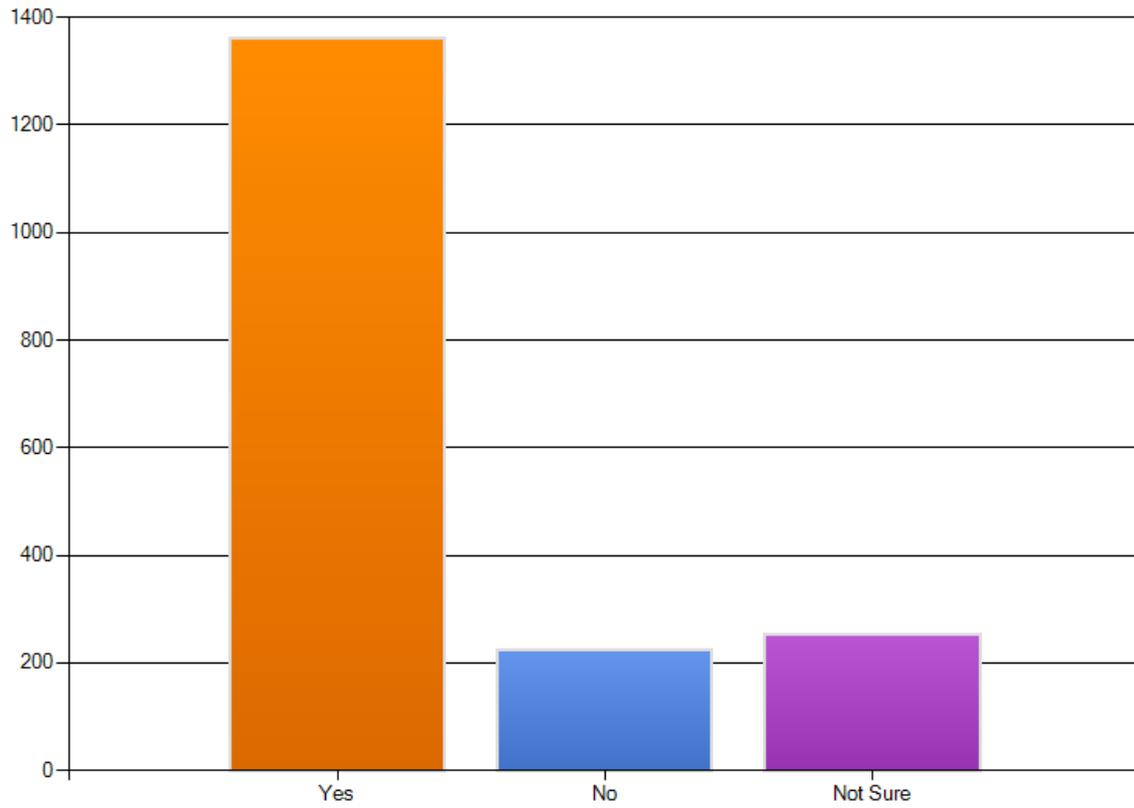
According to the Survey of Carers in Households 2009/10 with regards to the impact of caring upon carers' health and quality of life¹²

Carers were asked whether their own health had been affected in a number of ways because of the care they provided. For this question carers were prompted with a show card, which featured a number of health effects.

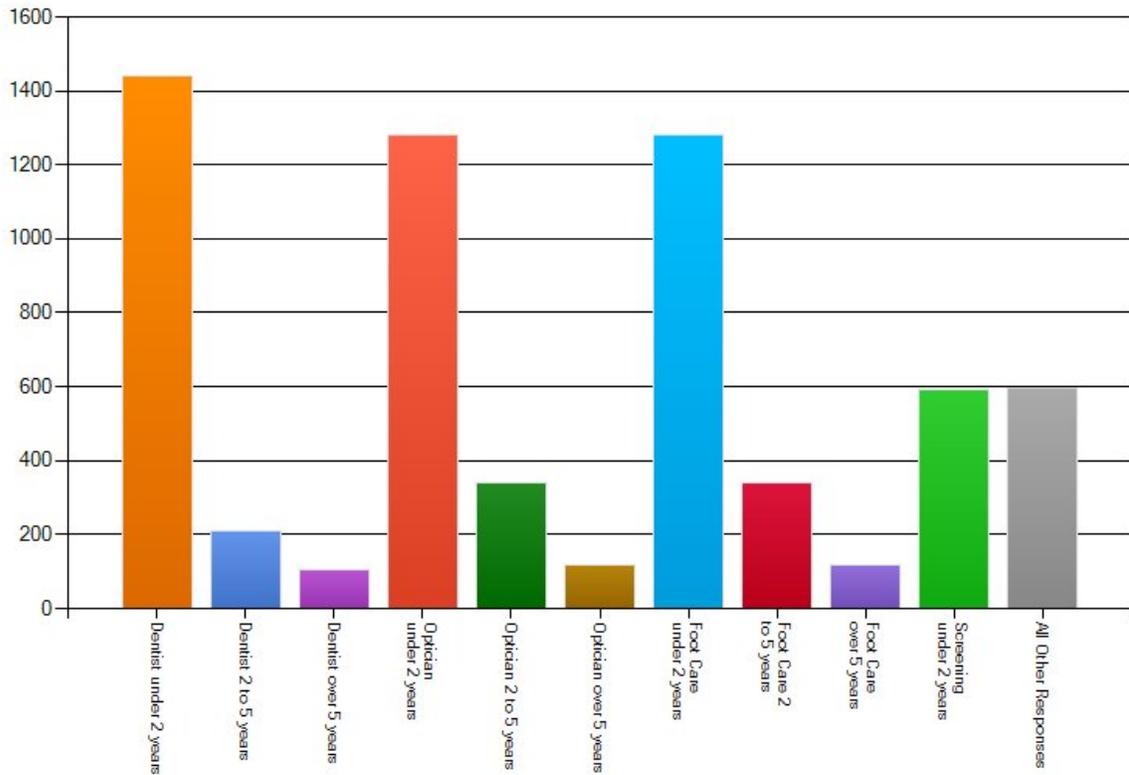
¹² Figure 4.1 Survey of Carers in Households 2009/10 Negative effect of caring upon health was reportedly more prevalent in women than men and in those looking after home or family than those in full time work.

Overall, just over a half (52%) said that their health had been affected in some way. The most common effects upon carers' health were feeling tired (34%), feeling stressed (29%), having disturbed sleep (25%) and being short tempered or irritable (22%).

Do you feel that caring for someone else has impacted on your own health?



Carers often neglect their own health and find it difficult to take up routine appointments. When was the last time you attended check ups for the following?

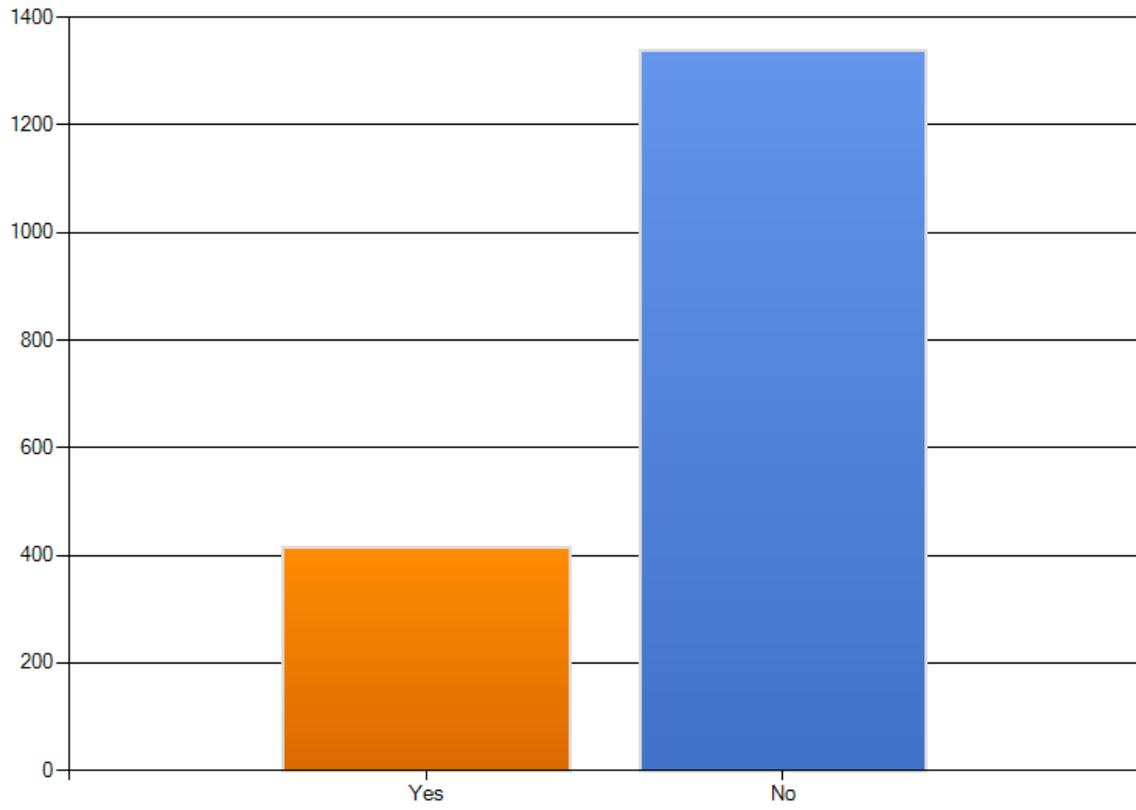


Recommendations from Carers UK 2004 report 'In poor health'

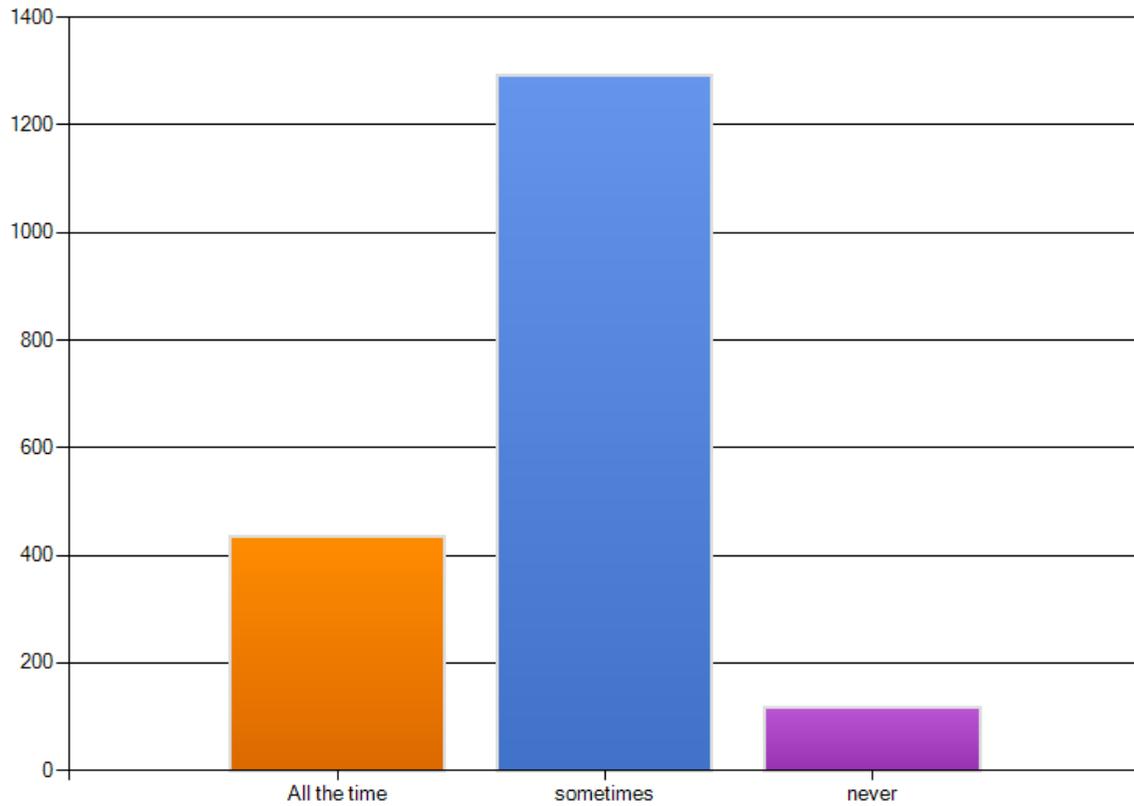
Practical support:

Local authorities and health bodies, in particular, should ensure as much flexibility in services for disabled people and carers as possible in order to minimise negative health impacts.

Has this been a problem for you?

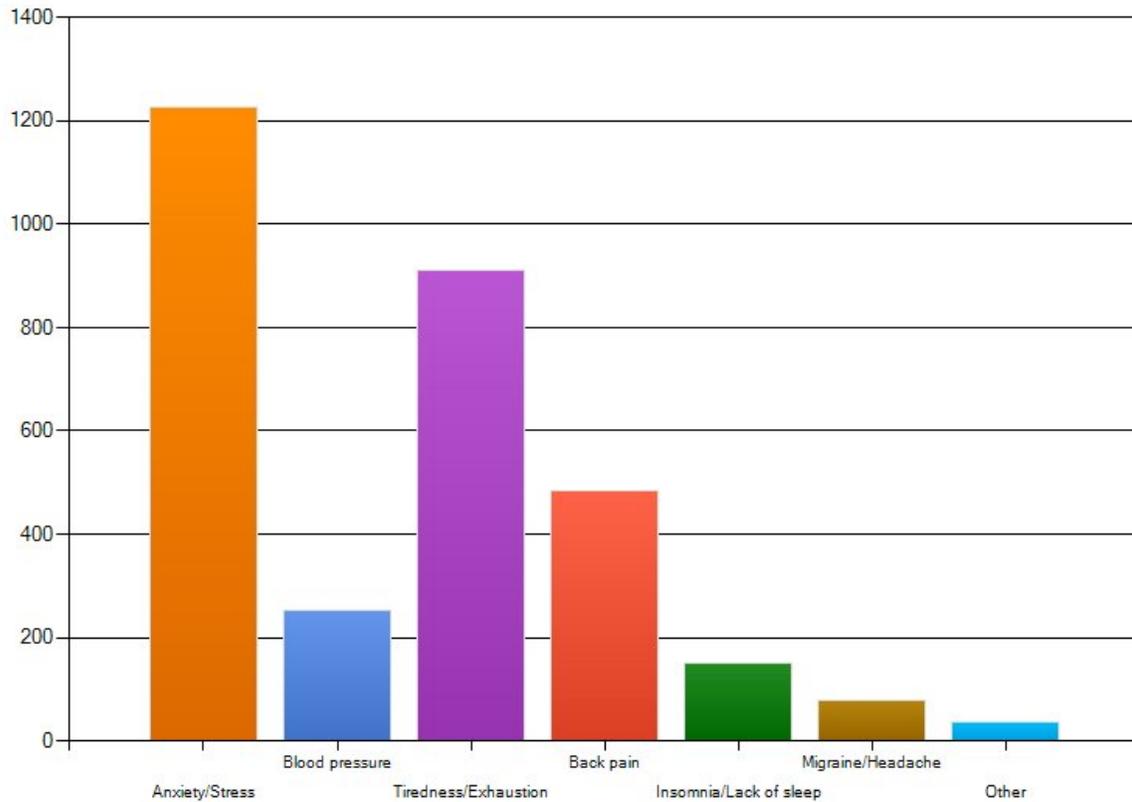


Do you worry about your own health



There is an overwhelming body of evidence that demonstrates that carers are more likely to neglect their own health. The carers in Surrey reflect this national trend and focus mainly on the cared for person.

What health symptoms have you experienced since you took on a caring role?



Nearly every carer who responded reported that they had some symptom. The vast majority reported that they were 'Tired, stressed and anxious'.

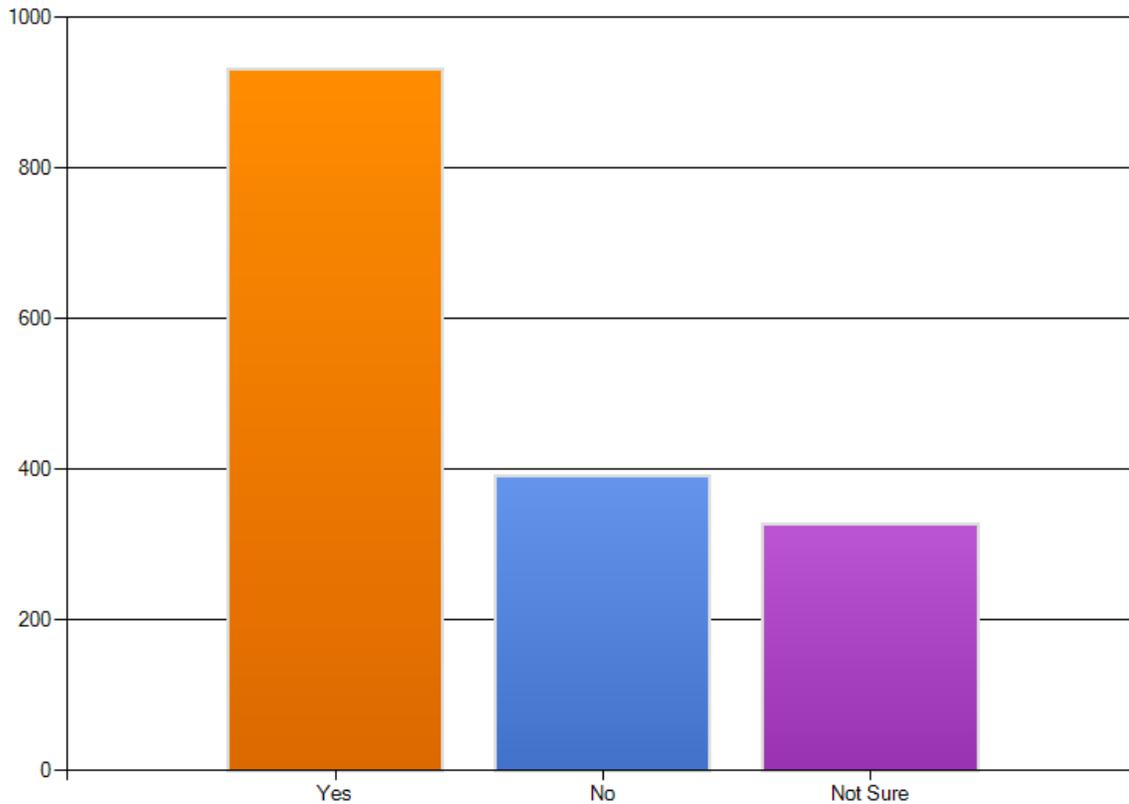
Many carers referred to their increase in weight and an inability to access sports and leisure facilities. Some requested concessionary rates for local amenities.

A further number stated that they were experiencing symptoms of Vitamin D deficiency.

Many of the carers wrote about being prescribed antidepressant and many suffered from sleep deprivation.

It is worth noting that for some carers who are providing sporadic and/ or cyclical care typical in cases where the 'cared for' person has a mental health illness, their caring responsibilities may not meet the substantive and regular eligibility criteria of the local authority but can nevertheless cause continuous worry, anxiety and stress which may result in illness or conflict for a carer holding down a job.

Do you think your caring role contributed to any of these conditions starting?



Many carers made reference to the strain that caring has placed on their marriage and other relationships.

Many carers experienced sleep deprivation due to disturbed nights.

Many Carers stated they experienced loneliness and had difficulty accessing carers' services, some due to distances needed to travel or lack of funds to cover public transport.

Carers emphasised the enormous stress that often comes with the caring role. Sometimes carers are expected to take on the work of professionals without the necessary training or support.

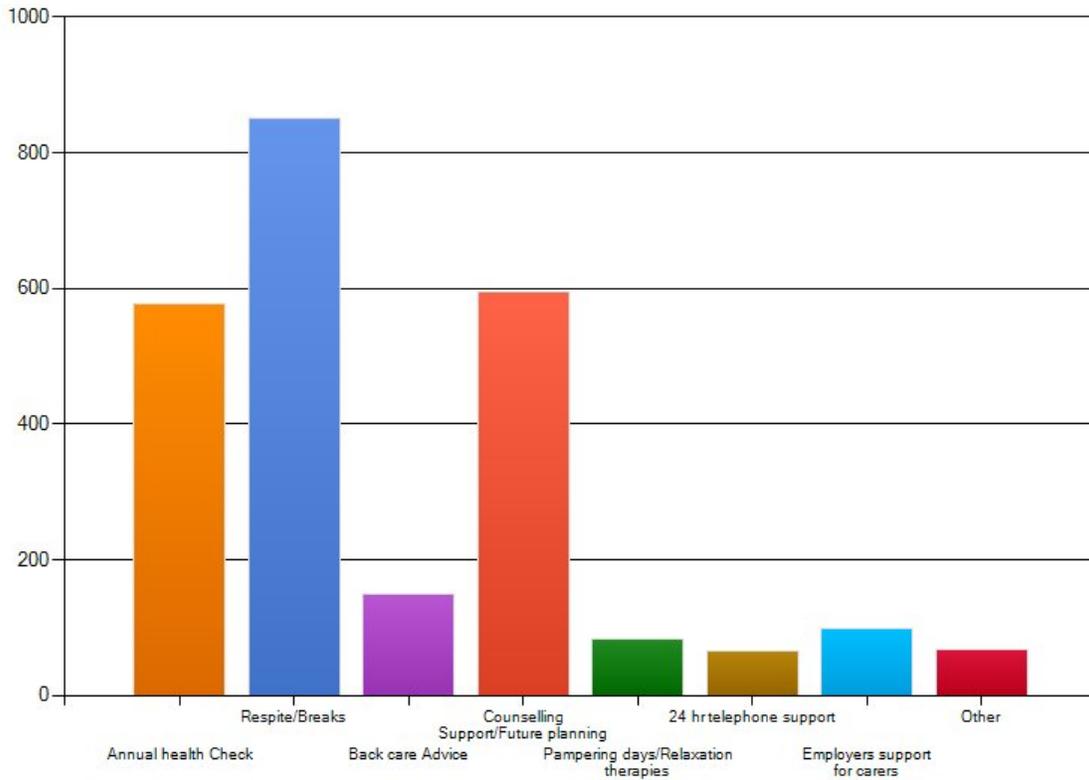
Caring remotely also causes stress and anxiety.

Parent carers have to juggle other family commitments with that of the needs of a disabled child.

Those carers who are working can face difficulties juggling work commitments with their caring role. Employers who are sympathetic to parents of young children do not always apply the same level of support to their working carers who may also be called away in times of crisis.

Carers made the correlation to poor diet and nutrition and the impact that this has on their health.

What do you think would improve your health as a carer?



The three key areas of importance to Surrey carers were:

- Carer Respite including evening, weekend and overnight respite with palliative care trained staff
- Counselling. This could be divided up between bereavement, emotional support and future planning especially for parent carers, Stress and anger management training were also cited.
- Annual health checks often referred to as annual MOT's

Other services requested included more opportunities for training, especially in the disease condition that the cared for person had been diagnosed with, and more back care.

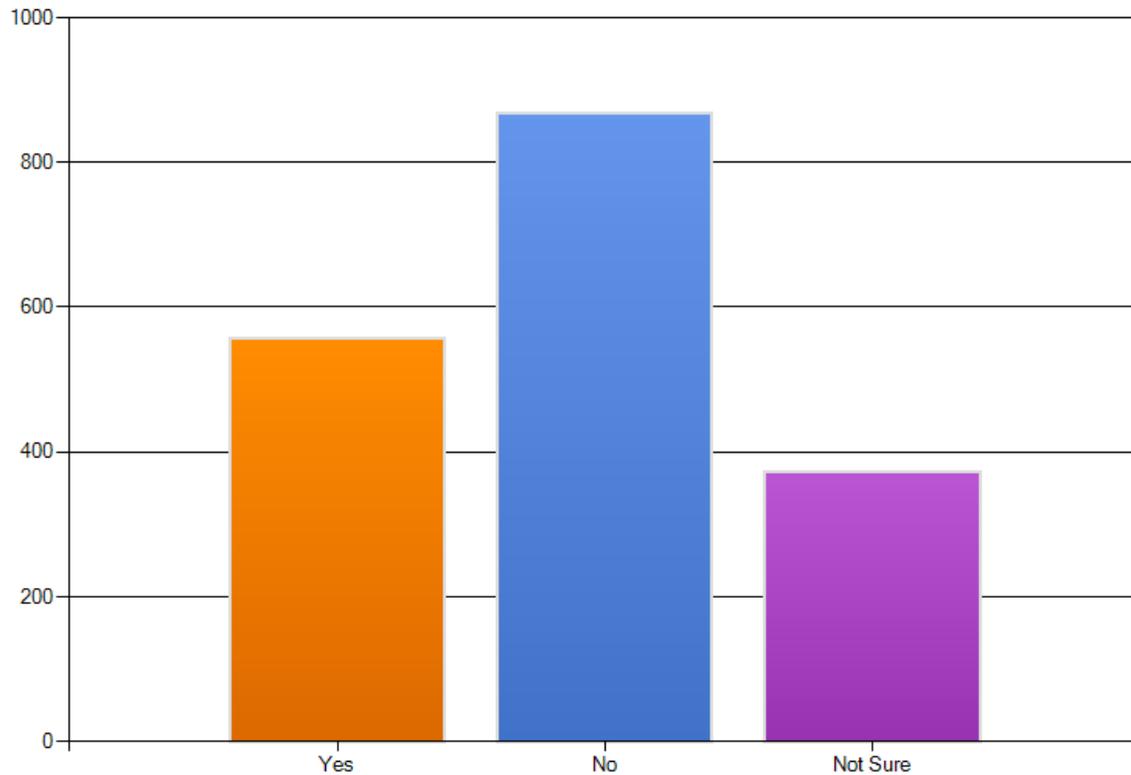
The Government acknowledge in 'Recognised, valued and supported: next steps for the Carers Strategy' 2010:

'Stress busting' therapy sessions for carers offering massage and reflexology have also been popular.

Surrey Carers reported how much they valued stress busting and pampering days.

Many carers reported on the fact that they were being treated for depression and taking antidepressant medication. It is possible that by providing more breaks and other support services the causes of the depression could be treated rather than the symptoms.

Have you completed the registration form to inform your GP you are caring for someone?



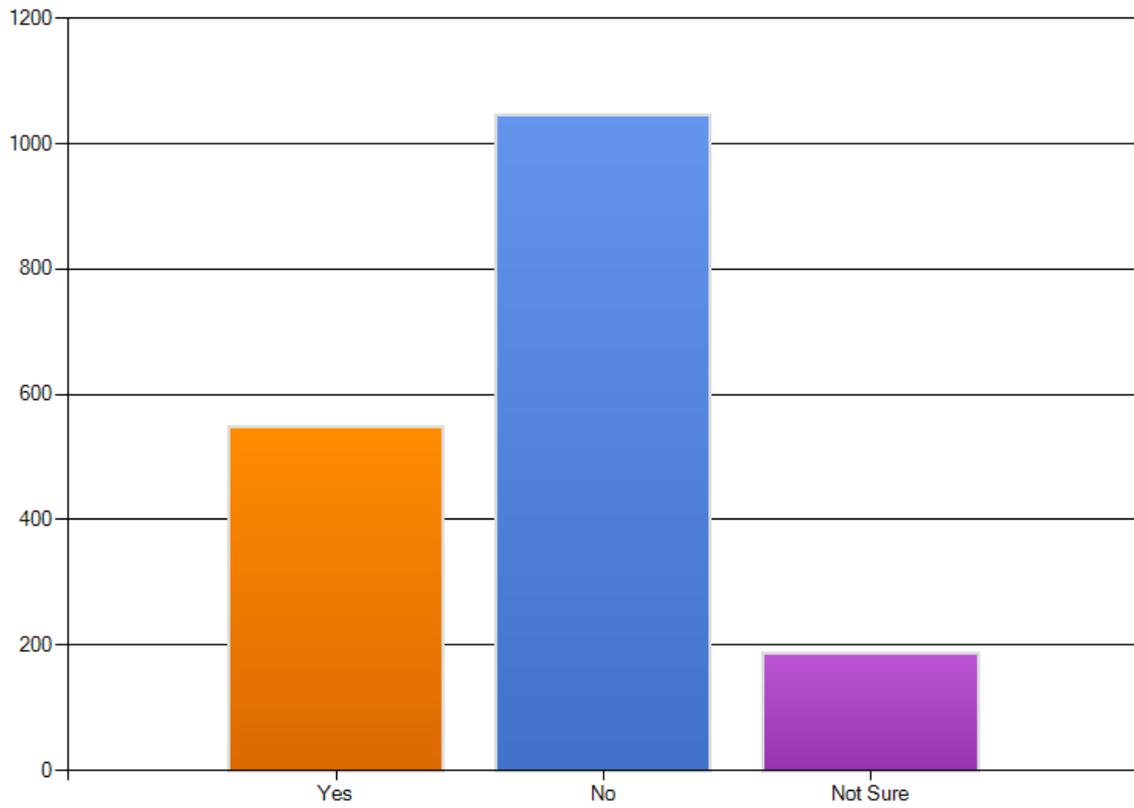
The Quality and Outcomes Framework (QOF) is part of the General Medical Services (GMS) contract for general practices and was introduced on 1 April 2004.

The QOF rewards practices for the provision of 'quality care' and helps to fund further improvements in the delivery of clinical care. As part of QOF surgeries are asked if they hold a carers register

The table reflects the findings of the Surrey GP Carers Recognition Worker (CRW). The original pilot ran in the South West Surrey area evidenced that the best surgery had 6.7% of the 10% they should have had registered against their practice size. The Princess Royal Trust for Carers (PRTC) states that at any time a practice list will be made up of 10% carers.

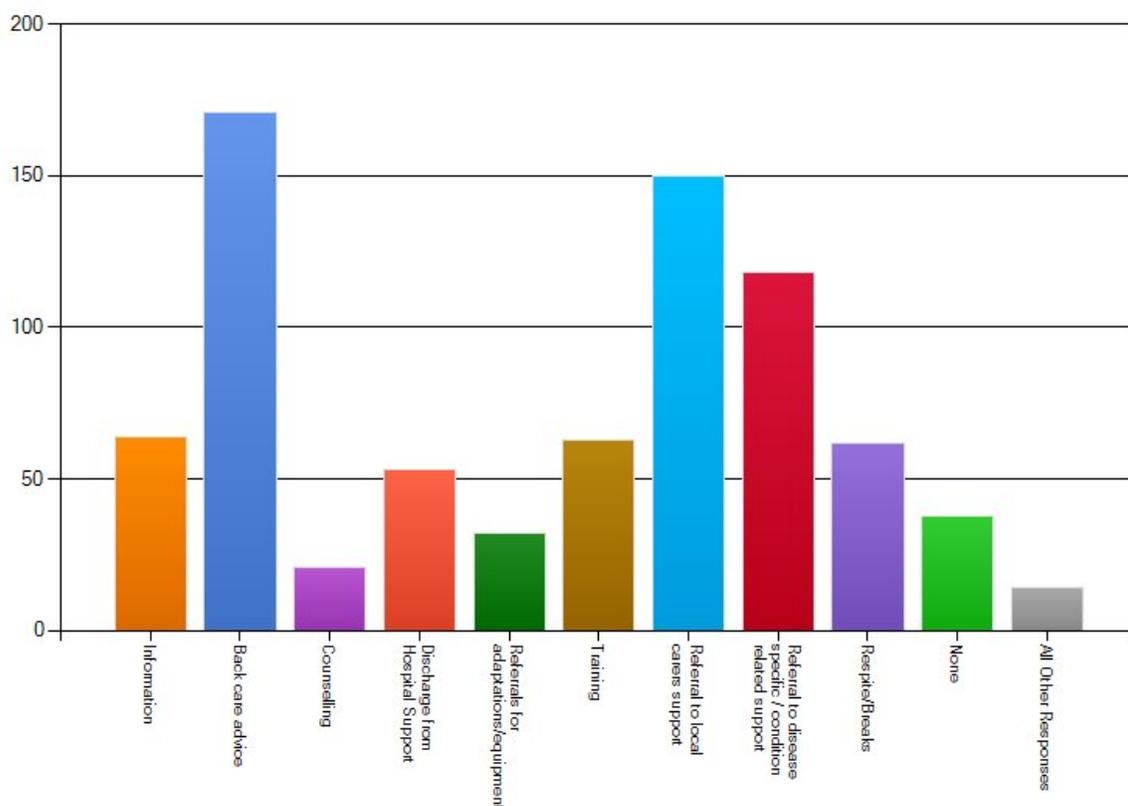
It is possible that in the past neither the carer nor GP has seen or understood the value of registration. It is hoped that the new Surrey-wide CRW service run by Action for Carers (Surrey), launched in October 2010, will promote better awareness of carers within primary care.

Have you used any services / health treatments to support you as a carer



The British Medical Association and the Royal College of General Practitioners provide guidance on working with carers.

What Help/Support has your GP provided?



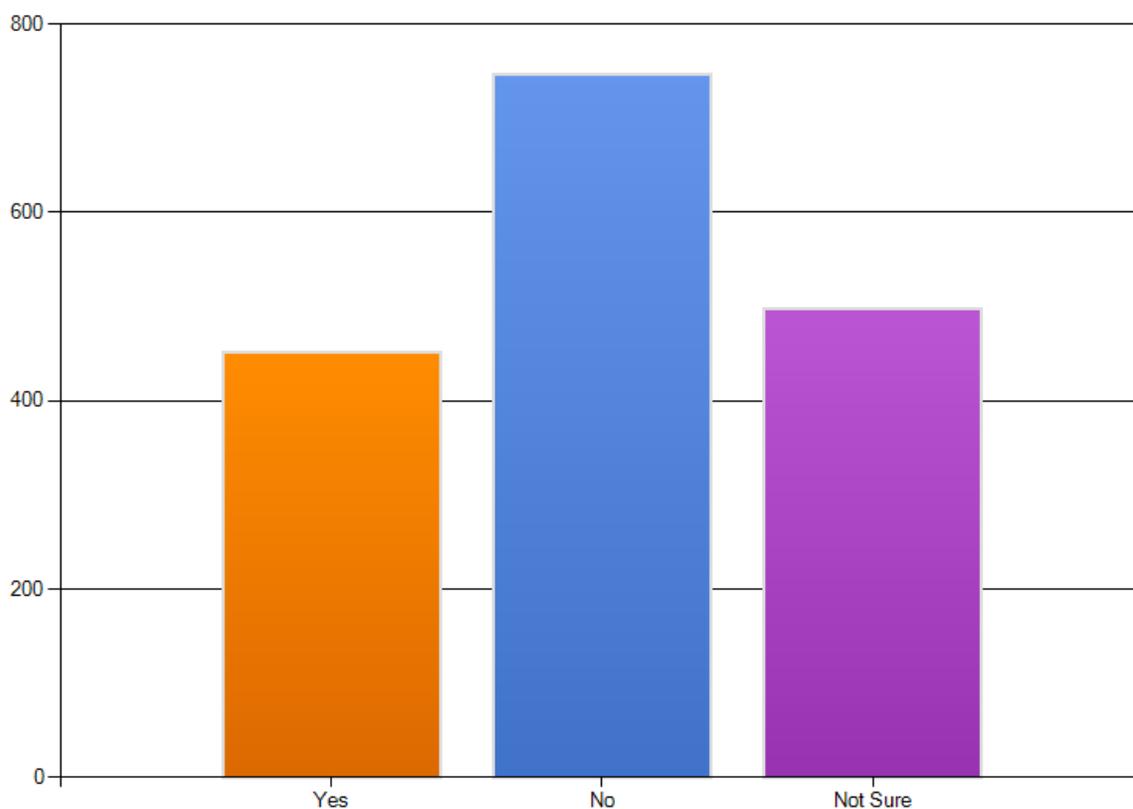
Routine Appointments

The vast majority of carers stated that they were unable or had difficulty attending their routine health appointments. The following examples were reported: Dentist, Optician, Foot care, Cervical smear tests, Mammograms, Retinography screening, Blood pressure and other blood tests.

It appears to be the case that where the "Cared for" person has an appointment, carers prioritise their needs but neglect their own health.

Carers also reported that, where they had to attend external routine appointments, consideration needed to be given to how best to provide replacement care for the cared for person, e.g. a carer who required regular blood testing herself and who cared for her husband with advance stage Parkinson's had her home visit service withdrawn because the surgery said she was fit enough to attend the appointment without taking into consideration her caring role.

Has your GP acknowledged your health needs as a Carer?



Consideration is required as to why there is disparity between the 45% of Carers who report that they have registered with their GPs and the 65% who have spoken to their GP about their caring role.

According to the NHS Operating Framework 2011:

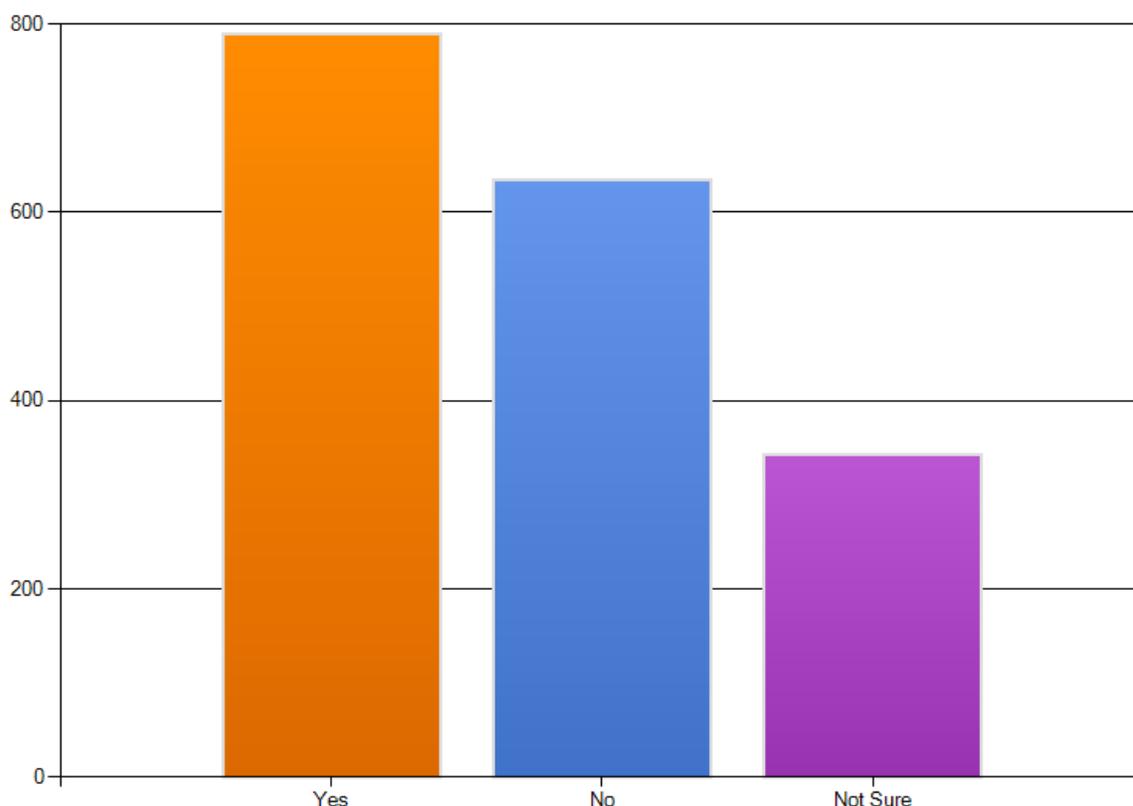
4.21 NHS organisations should consider 'Recognised, valued and supported: next steps for the Carers Strategy' which focuses on four priority areas and states the need to:

Identify carers earlier;

Carer quote

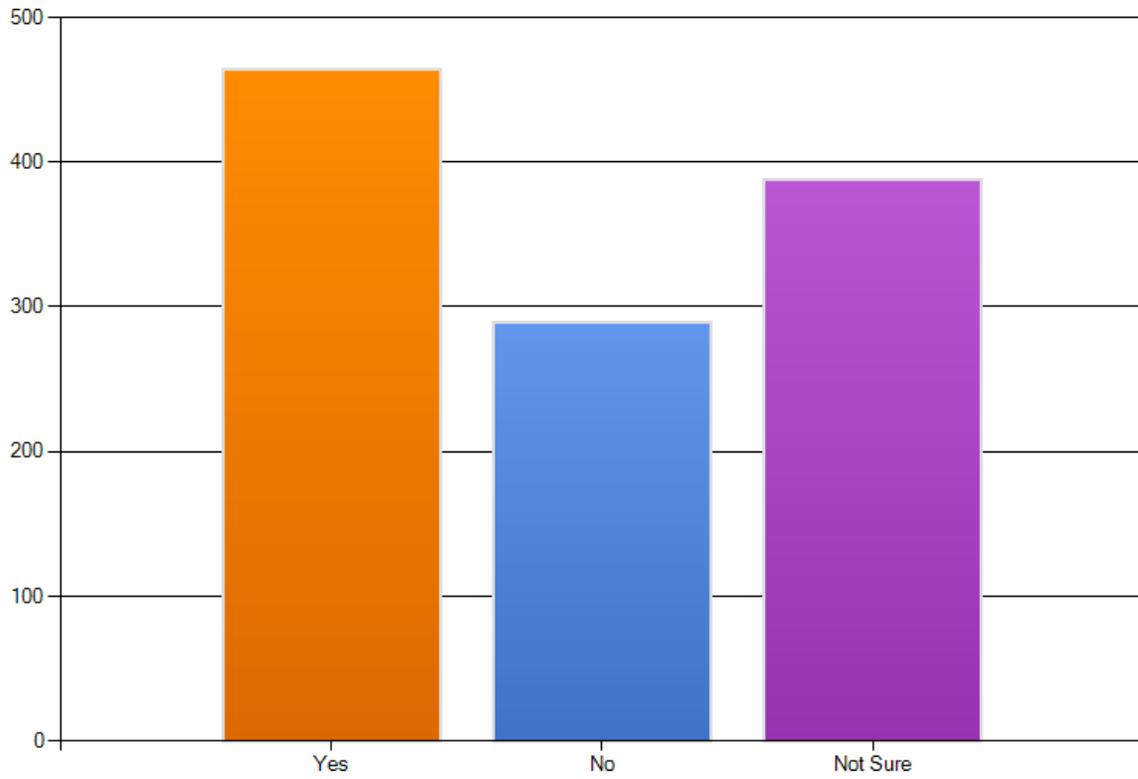
'Yes we have the GP projects but the basic problem in every day practice is that Carers remain ignored and our role is not universally respected. Carers can be seen as trouble makers and people who deny patients their privacy and rights. The fact that Carers provide the lion's share of the care has been missed and we have not to date been seen as an essential part of the network of care – often the only care!'

Are you aware if you have had a Carers Assessment?

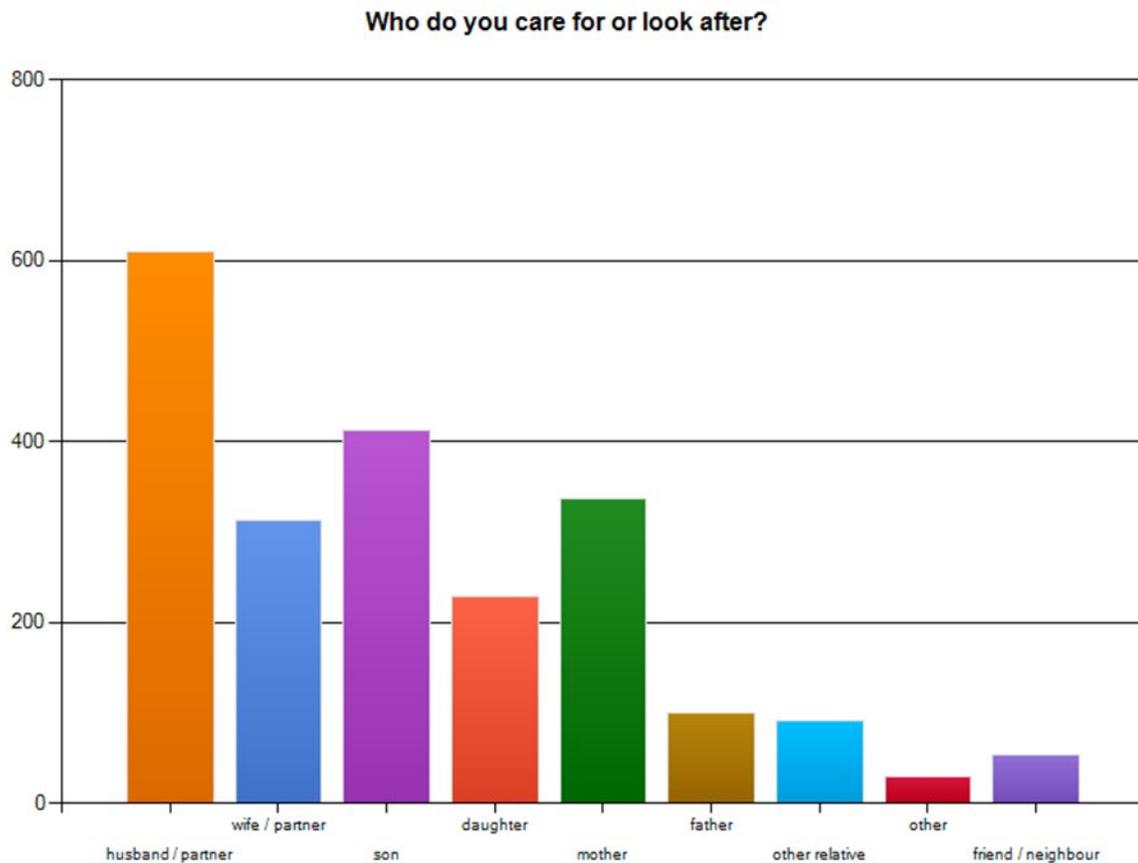


A Carers' Needs Assessment is based on the legal right of a carer to have an assessment of their own needs, under the Carers Recognition and Services Act 1995 or the Carers & Disabled Children's Act 2000. It is the carer's chance to discuss with the social care team, what help they need in caring for someone. Carers who undertake regular and substantial care are entitled to ask the local authority to undertake a carer's assessment. The definition of "regular and substantial care" is linked to the impact of caring, rather than a specific volume or set of tasks. However, it is often assumed that those caring for more than 20 hours a week are likely to be seen as undertaking regular and substantial care. The respondents to this survey included a substantial majority of "heavy end" carers who would have been entitled to a carer's assessment. The responses to the survey highlight that there are still many carers who are not accessing assessments of their own needs. Health professionals in both Acute and Primary Health settings can play a valuable role in highlighting the value of carer's assessments to their patients. Many people who are new to caring may be unaware that the term "carer" applies to them and health professionals have a key role in explaining this to patients with caring responsibilities. Health professionals can also help by making referrals to Social Care services or by providing carers with information and sign posting. As part of carers' needs assessments, a question relating to the carer's health is included.

When having your Carers Needs Assessment were you asked about your own health needs?



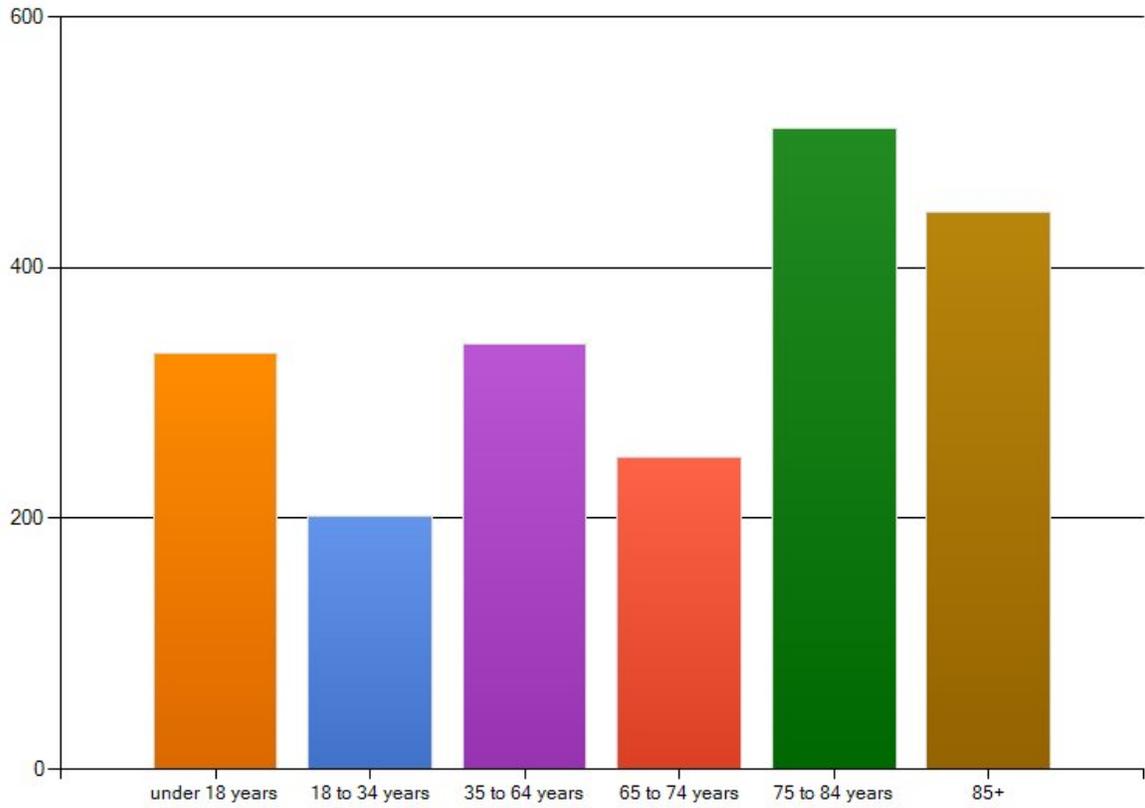
About the 'Cared for'



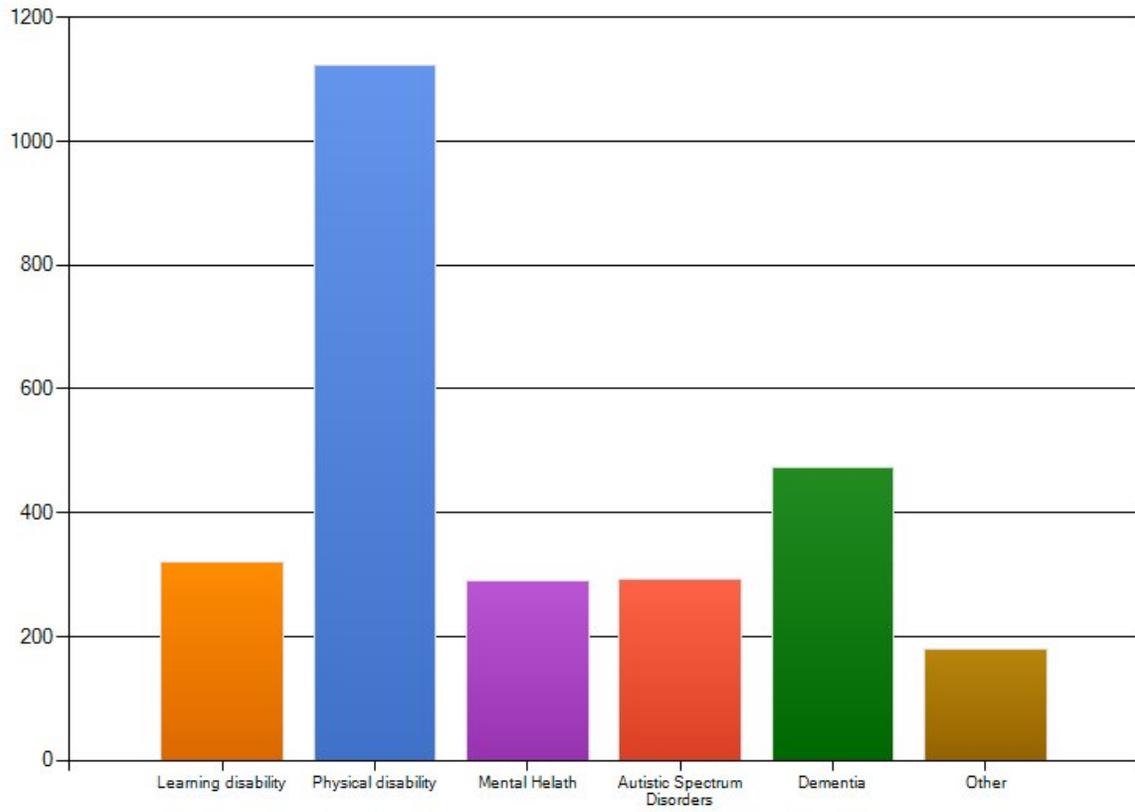
Quote from Carer

A Carer may be undertaking smaller amounts of care to a number of individuals, or juggling caring with work and other family responsibilities such as child care. The caring role to each individual may or may not be regular or substantial yet essential in maintaining a supportive network to them. The Carer may be struggling to sustain this multiple or complex and demanding caring role and the impact is affecting the Carer's life outside of caring e.g. their health may be breaking down either/ or physically or mentally; their employment may be in jeopardy; their relationships and social life outside of caring may be affected – and so it's the impact that should be considered not just "regular and substantial"

What is the age of the person you care for or look after?



What is the main illness or disability of the person you care for?



Quotes from Carers

Counselling, counselling! A support network is vital..... talking to those who care to be bothered

No time to attend appointments nowhere to leave my disabled child

Some counselling for parents of disabled children is desperately needed. I have tried for years to access this through my GP with no success. I wouldn't ask for it if I didn't think I needed it. But because I'm generally competent all together, efficient sort of person (because I have to be) no one knows how it feels to be a parent of a disabled child every day..... and one day I might go over the edge, but where would that leave my child?

Had to give up job, employer not sympathetic

Can't afford to attend dentist – local dentist private no NHS dentist near enough

I have sacrificed my career, health and marriage and financial security by being a carer for my son

No energy permanently tired and short tempered

For my needs to be taken seriously before I commit suicide or put M into care

Need help preparing for the worst i.e. Death and bereavement counselling

My main anxiety is focused on when we are no longer around

I need help with the district nurse calling to do blood tests as I'm currently taking warfarin. The GP surgery is saying that as I am mobile I must attend the surgery for these tests. I cannot leave my husband unattended. He has severe Parkinson's

People with severe difficulties are often bad tempered and aggressive. This can be the worst part of being a carer to be made to feel worthless by the person you love.

I have arthritis in my neck and knees and spine, which has obviously got a lot worse since caring for my wheelchair bound husband

I have been caring for 31 years I am getting very tired. Get rid of my husband!

He is doubly incontinent and I get no help

Being a male carer I've been ridiculed for living with my mother, which I didn't bargain for. I am angry but I'll do my best by her.

My employer hasn't helped and increased my hours.

I need more respite and one million pounds in my bank account see what you can do please!

I feel that once initial fire fighting is over the NHS loses track. No one seems to check up on our well-being. As always it's up to us to be pro active

I am the walking dead

I have been made to feel as a waste of space

There is no light at the end of the tunnel

Many carers raised their anger and frustration with regards to carers' assessments.

To those who responded to the question relating to support they had received from their GP's a significant few reported on a positive hospital discharge experience.

Carers Health and Well being

It is important that carers take care of their own health and wellbeing so that they are better able to cope with the demands of caring for someone else. The findings of this report evidence that Surrey adult carers often neglect their own health needs.

Carers have a key part to play in supporting the care which the NHS provides, and in helping the NHS understand the needs of the person they care for. The critical role of carers as main care-providers must be recognised, acknowledged and acted upon at all levels in the NHS. Being a carer can also bring its own health costs. Many carers find their health suffers as a direct consequence of the physical or emotional strains of caring and this is true also for carers who provide 'remote' caring. To help protect their own health and well-being, carers need to know early on in their caring role that support is available. GPs and other primary care professionals are well placed to identify carers and alert them to sources of help and advice. The benefits of this service has been evidenced by the development of a Surrey wide GP Carers Recognition Worker (CRW) project which aims to identify carers within primary care and to sign post them on to support services.

Recognised, valued and supported: Next steps for the Carers Strategy November 2010

The "refresh" of the National Carers' Strategy recognises that one of the greatest challenges facing the NHS is its ability to identify, recognise and acknowledge Carers. Listed below are the priority areas relating to Health checks from the National Carers' Strategy. The Surrey Adult Health Carers survey identified carers' health checks as the second priority for development.

Priority area 4: Supporting carers to remain mentally and physically well

Health Checks

4.11 The Government is committed to the future of the national NHS Health Check programme. As part of the programme, 40 to 74 year olds will be offered a free NHS Health Check that will help carers, among others, stay well for longer. Everyone receiving an NHS Health Check will receive a personal assessment and individually tailored advice and support to help them manage their risk of heart disease, stroke and diabetes. The assessment can be carried out locally and in a variety of settings, including pharmacy and community settings, to help to ensure that the service is accessible to all those eligible, including carers who may find it more difficult to access some health services. Carers should be encouraged to take up their offers of a free NHS Health Check when they receive them.

4.12 The carers' demonstrator sites focusing on health and well-being checks are testing different ways of reaching out to carers, including those in ethnic minority communities, and offering structured consultations to discuss their own health and well-being. The final report from the independent

evaluation of the demonstrator sites, particularly around accessibility for carers, will be fed into the on-going policy considerations for the NHS Health Check programme.

According to the DH evaluation of the National Carers Strategy Demonstrator Sites Programme, four months after the check about a quarter of respondents felt the way they looked after themselves, took care of their health, and the exercise they took had improved.¹³

Evaluation of the National Carers' Strategy Demonstrator Sites Programme Nov 2011

The National Carers Strategy Demonstrator Sites programme of support for carers, developed and funded by the Department of Health (DH), was one of the commitments made in the July 2008 National Carers Strategy for Carers. The programme comprised 25 sites across England, focusing on three areas of support for carers:

- Breaks for carers: these aimed to measure the quality and effectiveness (including cost effectiveness) of a range of new approaches to offering breaks to carers.
- Health and well-being checks for carers: here the intention was to deliver annual health and / or health and well-being checks for carers.
- Better NHS support for carers: these were to explore ways of providing better support for carers in NHS settings.

The report makes the following policy recommendations:

1. In all localities, efforts to bring local authorities, NHS organisations and voluntary sector organisations together to develop and deliver effective support for carers, in partnership, should be strengthened.
2. Local carer support partnerships should involve a diverse range of carers in service development.
3. In delivering support to a wide range of carers and reaching carers not already in touch with services, local partnerships should work flexibly, and sometimes on an ad hoc basis, to engage carers in specific target groups.
4. Effective carer support at the local level should always include a varied portfolio of carer support services, which can be adapted to meet individual needs.
5. Portfolios of carer support need to be agreed locally between local authorities, NHS organisations, voluntary sector organisations and other organisations where appropriate.
6. Hospitals should routinely provide mechanisms to identify and support new carers, centring their efforts on wards where patients have received a new diagnosis or are due to be discharged and on out-patient clinics where patients are likely to be accompanied by those who care for them.

¹³ P87 New Approaches to Supporting Carers' Health and Well-being: Evidence from the National Carers' Strategy Demonstrator Sites programme

7. Every GP practice should be encouraged to identify a lead worker for carer support, who can assist in carer identification, help in referring carers to suitable local services, and ensure carers' access to health appointments and treatments is not impeded by their caring circumstances.
8. All staff who interact with carers, in hospitals, GP practices, local authorities and in the voluntary sector should be trained to consider how caring responsibilities can impact on a carer's health and well-being and equipped to advise on how a carer can access a health and / or well-being check.
9. All relevant organisations should regularly offer carer awareness training to their staff.

The report¹⁴ provides a substantial body of evidence that in all 3 areas of support provided to carers there has been a significant health gain for the carer.

It also provides evidence relating to cost benefit. Although precise measurement of cost savings was not possible, the study found evidence that many of the types of carer support introduced had the potential to result in cost savings within the health and social care sector. Potential savings were identified in the national evaluation study and in the local evaluation reports, relating to:

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

Carers and their Health

The evidence for supporting carers is clear at national level. Evidence from national surveys include:

36% of carers suffered mental health issues compared to 17% of carers who had taken a break of more than a few hours since beginning their caring role;

35% of carers without good social support experienced ill-health compared to 15% of those with good support.

As detailed on the Office for National Statistics website, the 2001 Census found that:

¹⁴ Department of Health (DoH) 2011 - New Approaches to Supporting Carers' Health and Well-being: Evidence from the National Carers' Strategy Demonstrator Sites programme

- Over 225,000 people providing 50 or more hours of unpaid care per week stated that they are in 'not good health' themselves. More than 50% of the people providing this much care are over the age of 55, and it is at these ages that the 'not good health' rate is highest. However, there are nearly 80,000 people aged 54 and under providing more than 50 hours of unpaid care per week, who state that their health was not good. Joint Commissioning Strategy for Carers 2009-2013

Of the almost 2 million people aged 16-74 who are permanently sick or disabled, 273,000 provide some unpaid care for other people and 105,000 provide 50 or more hours care.

Furthermore, the Supporting Carers: An Action Guide for General Practitioners and their Teams, 2008 highlighted the following statistics:

- More than 80% of carers say that caring has damaged their health.
- Out of all carers caring for more than 50 hours a week, one third report depression, a half report disturbed sleep and 25% report back and other strains.
- The prevalence of psychiatric morbidity is significantly higher in those who care for others in their own home.

The DoH has advised that the NHS should recognise the vital role played by carers and make sure that carers remain in good health, and that their health-related quality of life does not deteriorate as a result of their caring responsibilities. The 'NHS Outcomes Framework' includes a carers-specific improvement area measure: enhancing quality of life for carers measured by a health-related quality of life for carers' survey collected using the GP Patient Survey (EQ5D).

The BMA document: "Working with Carers: Guidelines for Carers describes how carers' health suffers:

"This includes not only physical health (primarily musculoskeletal problems) but also mental health, particularly in cases where carers have not been able to take a break from caring. Doctors and primary health care staff have a key role in helping to sign post carers so as to ensure that they get the physical and psychological support they need".

Carers often provide the majority of care that would otherwise be the responsibility of health or social care professionals. In many cases one carer can be providing care that teams of professionals provide; Carers cannot go "off duty" in the same way that professional paid staff can.

The impact of caring can be detrimental to the health of carers. Carers UK's analysis of the 2001 Census findings, 'In Poor Health', found that those caring for 50 hours a week or more are twice as likely to be in poor health as those not caring (21% against 11%). This can be due to a range of factors including stress related illness and physical injury.

This difference is especially marked amongst younger people. In the 18-25 age group, those providing 50 hours care or more per week are three times as likely to be in 'not good' health as people of that age group not providing care (8% against 2.5%).

This backs up earlier research, including a 2002 study, which found that carers were over twice as likely to have mental health problems if they provided substantial care;

- 27% of those providing over 20 hours a week had mental health problems compared to 13% of those providing less than 20 hours of care.

Analysis of the Census also indicates that carers providing high levels of care are twice as likely to be 'permanently sick or disabled' as those not caring.

Altogether 316,000 people in the UK who provide care describe themselves as 'permanently sick or disabled', of these 124,900 care for 50 or more hours per week.

550 carers stating they experienced back strain. Surrey provides a back care service through Action for Carers (Surrey) and White Lodge Centre Chertsey¹⁵.

Support for Carers' Own health in Surrey

Within Surrey the findings of the Adult Carers' Health Survey provide a valuable picture of the impact caring has had on carers' health. This report evidences that caring has far-reaching health implications for Surrey carers. It confirms many of the national findings and also expands on them.

Current Activities

GPs identify carers from among their patients. A network of Carer Champions is being set up in each GP surgery to deal specifically with carers and the issues that they face.

- The ten Carers' Support Organisations in Surrey provide advice to carers on getting support from GPs.
- Carers' Support Organisations offer 'timeout' and therapy days for carers.
- Adult Social Care can provide support following a carers needs assessment: the process may provide carers with a carers break or carers direct payment.
- Exercise on prescription via GP
- Carers' courses offered by Carers Organisations, Disease or Condition specific organisations, Joint Surrey Training, Surrey County Council (SCC) and NHS Surrey include elements such as moving and handling and coping strategies.
- Primary Carers are being offered annual flu vaccinations.
- Co-design and co-production of care pathways include carer involvement to provide better informed service design and delivery.

¹⁵ White Lodge Centre provides a range of flexible and creative activities and opportunities for disabled children, young people and adults, for their families and for carers across Surrey and the surrounding area.

Crossroads Care Surrey – Carers Survey 2010

Data collected by Crossroads Care Surrey during their 2010 Carers survey stated that over 90% of carers believed that Crossroads Care helped them keep going. Almost 80% believed that Crossroads Care kept them in better health. Quality of life: 96% of carers reported that Crossroads Care improved the quality of their life and 85% believe that they improve the quality of life of the person that they care for. 98% of carers reported that they can go out with peace of mind when the care worker takes over. In all 771 carers were sent questionnaires and 325 were returned (42%).

The data was independently analysed by Marin Scott, a consultant for the Disabled living Foundation.

Surrey GP Carers Recognition Service

Carer Quote - 'You feel you can ask for help when you need it, as you know best what you and your family needs. Also, just simply having recognition makes all the difference to how you can cope'.

The National Carers Demonstrator Sites that are exploring better ways in which the NHS can support carers are also testing a number of approaches, including carer assessment support workers based in GP practices who help to identify carers and signpost them to support services, carer liaison teams, carers' leads in clinical teams and a range of support materials. Surrey already has 3 GP Carers Recognition Workers (CRWs) employed by Action for Carers (Surrey) and who are based in primary care settings. Future benchmarking of the number of carers registered with their GPs should evidence improved recognition and support being offered to carers.

Box 3.3 National Demonstrator site¹⁶

Staff in Derby, a local authority-led site delivering a wide range of Breaks services (including alternative care in the home and well-being support/services), anticipated difficulties in engaging with GPs and took several steps to facilitate effective co-operation, including:

- Recruiting a PCT development worker to negotiate with GP practices. This proved very effective and staff in this site wished they had done this earlier.
- Appointing 20 'carer champions', with existing staff in 32 local GP practices allocated this role. The champions provided information and drop-in advice sessions for carers attending appointments, either when visiting a GP alone or when attending with the person they cared for.
- Arranging regular network meetings, including staff from all organisations involved in delivering the DS programme, through which carer awareness could improve and knowledge and experiences could be shared.
- Running awareness-raising sessions for GPs and health workers, including developing an online toolkit they could use.
- Creating an electronic referral system for GPs to use when referring carers to the Breaks service. This was implemented successfully and included a 'feedback mechanism' informing the relevant GP of the outcome of any referral.

Centre for International Research on Care, Labour and Equalities (CIRCLE) and University of Leeds. Nov 2011

The Princess Royal Trust for Carers reports that admission to hospital can be an indication of a breakdown in the caring relationship because the care is no longer able to care, often as a result of caring causing physical or mental ill health. There is evidence to suggest that a significant number of admissions are due to problems¹⁷ associated with the carer rather than the person admitted. In the Surrey Adults Carers health survey, many carers reported on the positive support that had been offered to them during hospital discharge but sadly there remain cases where policy implementation falls short. NHS Surrey is working alongside NHS providers to help improve practice through shared learning on training, information and support.

The Discharge from Hospital regulations 2003 states that the NHS has a “duty to inform Carers” of their rights to request a carers’ needs assessment and an actual duty to collaborate which means the NHS should refer Carers. This of course presumes that the carer will have identified themselves as a carer and also knows what a carers’ needs assessment is.

In Preventing Admissions to Hospital or Residential Care, Evaluation of the National Carers' Strategy Demonstrator Sites Programme Nov 2011¹⁸ recommends that: Hospitals should routinely provide mechanisms to identify and support new carers, centring their efforts on wards where patients have received a new diagnosis or are due to be discharged and on out-patient clinics where patients are likely to be accompanied by those who care for them. Timely and co-ordinated support for new carers and carers with changing care responsibilities, linked to follow-up services, should be available in every acute hospital and advertised in all out-patient clinics.

In the same ‘report’: In helping to avoid carer breakdown and hospital admission the report also found that preventing hospital admissions has clear cost saving implications. Costs avoided may include: £95 for a simple accident and emergency attendance; £345 per 24 hours for a short hospital inpatient stay; £1,571 per 24 hours for a long inpatient stay (PSSRU, 2010).¹⁹

NHS Continuing Health Care

Support for practitioners and for others responsible for NHS Continuing Health care is required around identifying and referring carers on to appropriate support. Assessment of risk is central to providing a holistic multidisciplinary assessment to need. Good risk assessment will include listening and observation, talking to the individual and their carers.²⁰ Practitioners need to understand the difference between a healthcare need and a social care need. Where a person is eligible for NHS continuing health care, the NHS is responsible for meeting their assessed health and social care needs. NHS Surrey needs to ensure that carers are offered breaks and are aware of the other types of carers support available to them.

Continuing Care: NHS and local council’s responsibilities 2001 Guidance -This guidance requires all Strategic Health Authorities (StHAs) to review and agree new criteria for fully funded, continuing NHS

¹⁷ Supporting Carers: The Case for Change 2011

¹⁸ Chapter 7 on p 132

¹⁹ Chapter 6, Page 109

²⁰ NHS Continuing Healthcare Practice Guidance March 2010

health care. Primary Care Trusts and local authorities are required to be involved in agreeing these new criteria and to have only one set of criteria across the Strategic Health Authority. Local Authorities and the NHS should also agree joint eligibility criteria for mixed packages requiring both health and social care.

Following the implementation of the National Framework for continuing care with standard national eligibility criteria, an increasing numbers of people with complex long-term health conditions now receive free NHS continuing care packages. The local authority remains responsible for providing support to carers but there needs to be more joined up service delivery.

Young Carers

Surrey already has a multiagency Young Carers' Strategy. Plans to develop a young carers' health survey to be implemented in the summer of 2012 are progressing in partnership and will enhance commissioner understanding of young carers' health needs.

Support for parent carers of disabled children

Additional to the legislative process which places a duty on councils to commission short breaks services; commissioners in Surrey need to take note of the need to provide support in future planning for parent carers.

Dementia Strategy and Mental Health Strategy

Supporting carers of those with dementia or mental health ill- health is a key component of the National Carers' Strategy. Surrey has both a Dementia and Mental Health Strategy which needs to be reflected in any future commissioning intentions informed by the Surrey Carers' Strategy 2012-15²¹

Section: 2.9 NHS Operating Framework 2012/13. PCT clusters should ensure that all providers have a systematic approach to improving dignity in care for patients, to giving staff appropriate training and to incorporating learning from the experience of patients and carers into their work.

Supporting carers from military families

Surrey needs to recognise that a growing number of military family members are becoming carers supporting Service personnel who have been injured in military operations overseas. Commissioners in Surrey need to work alongside service charities such as the Royal British Legion, to ensure support is offered to carers in military families.

The role of commissioners in promoting health and well-being for carers

21

[http://www.surreycc.gov.uk/sccwebsite/sccwspublications.nsf/591f7dda55aad72a80256c670041a50d/adb65dd2f860d5eb802578100048aaef/\\$FILE/Surrey%20Dementia%20&%20Older%20People's%20Mental%20Health%20Strategy%20-%20July%202011.pdf](http://www.surreycc.gov.uk/sccwebsite/sccwspublications.nsf/591f7dda55aad72a80256c670041a50d/adb65dd2f860d5eb802578100048aaef/$FILE/Surrey%20Dementia%20&%20Older%20People's%20Mental%20Health%20Strategy%20-%20July%202011.pdf)

The broader role in promoting health and well-being of carers has been enhanced by new public health functions that are outlined in the Public Health White Paper 'Healthy lives, Healthy People'

Carers in Surrey need to ensure their voice is heard on the new Health and Wellbeing boards and also through using Healthwatch which is replacing Local Involvement Networks (LINKs).

Carers Breaks

Recognising carers as expert care partners values both their role in providing support and their wider knowledge and skills. The Surrey Adult Carers' Health survey identified carers' short breaks as the number one priority area for carers. NHS Surrey, in partnership with Surrey County Council and Action for Carers (Surrey), has developed a model based on other early adopters to provide GP carer breaks. NHS Surrey has agreed £1.3 m funding to support the pilot which was launched in December 2011. Surrey Independent Living Council will administer the project and allocate carers direct payments. The service will be facilitated through the GP Carers Recognition Project website.

End of Life (EOL) Carers Support

National EOL Intelligence Network Report Feb 2011 indicates that 60% of people would choose to die at home; but only 21% do. Where an end of life care service has been available, this has resulted in more people dying at home because the carer has felt supported. In line with 'Supporting people to live and die well: A framework for social care at the end of life' (DH NEOLCP 2011) it is a key priority for Surrey that we deliver high quality end of life (EOL) care and support to people approaching EOL and their carers, to allow them to live and die well in the place of their choice.

As part of the wider National End of Life Strategy, NHS Surrey in partnership with Crossroads Care Surrey has developed an EOL carers' support service, providing palliative care trained staff. The service is designed to ensure that the provision of breaks services, funded in line with the National Carers Strategy, is accessible to carers in "End of life situations". The aim of this new service, which will be available to all carers, is to address the need, highlighted in the End of Life Care Strategy and in 'Healthier People, Excellent Care', to support carers and patients, enabling them 'to choose where they die and not be admitted to hospital in the last days of life, if that is their preference'. This service is being rolled out across Surrey from November 2011 and is funded by NHS Surrey on an annual basis via a Surrey County Council grant. The funding is for £300,000 annually.

Future Carers Commissioning

NHS Surrey in partnership with Surrey County Council and Action for Carers (Surrey) is currently drafting a new joint Surrey Carers' Commissioning Strategy 2012-14 which will emphasise the need for a 'whole family approach' to carers' commissioning. NHS Surrey recommends that:

1. Once the Strategy is drafted, a consultation document is widely circulated amongst Surrey's clinical commissioning groups and NHS providers.
2. Consideration is given to the findings of the Evaluation of the National Carers' Strategy Demonstrator Sites Programme Nov 2011, including how to implement the policy recommendations within Surrey.
3. The Strategy reflects the requirements of the NHS Operating Framework 2012/13
4. Incorporation of the finding of the Surrey Carers' Health Survey

A multi-agency Surrey Young Carers' strategy was launched in February 2011

5. It is a recommendation of this report that future strategies include the sign up and adoption of the Strategy by all NHS providers.
6. It should also reference the recommendations to be published in the recent Associate of directors of adult social care (ADASS) report on young carers and personalisation.
Click on link: <http://www.youngcarer.com/pdfs/AMOU.%20youngcarers.pdf>

Recommendations

Recommendations are based on best practice and the new policy recommendations in the new requirements in the NHS Operating Framework 2012/13, the Department of Health demonstrator site evaluations (New Approaches to Supporting Carers' Health and Well-being: Evidence from the National Carers' Strategy Demonstrator Sites programme Centre for International Research on Care, Labour and Equalities (CIRCLE) and University of Leeds. Nov 2011) and the National Carers Strategy 'Next Steps' 2010.

Priority Areas and Monitoring Plan

The recommendations made in this report will be referenced in the new Joint Surrey Carers Commissioning Strategy 2012-14. The Joint Surrey Carers Commissioning group will be responsible for implementing and monitoring the action plan.

Priority Area	Organisation Lead
Carers Breaks	
<ol style="list-style-type: none"> 1. Maximise the provision of 'Carers breaks' through carers' direct payments. 2. Monitor the implementation of the GP Carers Short breaks pilot. 3. To roll out the End of Life Care service across Surrey. Monitor the service. 	<p>NHS Surrey</p> <p>NHS Surrey</p> <p>NHS Surrey</p>
Health and Well Being	
<ol style="list-style-type: none"> 1. Promote and raise awareness of carers and the support they need through all NHS services. Identify, recognise and offer support to carers especially those who have historically found it difficult to access services such as those caring for someone with a mental health illness, substance and alcohol misuse problem and those who are BAME and/or young carers. 2. In line with Government and SCC policy, NHS Surrey to adopt a 'family centred approach' to supporting carers. 3. Review future publications and recommendations of national demonstrator sites in reference to Carers Health Checks. 4. Encourage borough and district councils to provide carer concessions to sport and leisure facilities and disseminate information to carers. 5. Investigate the health needs of children who are young carers. 6. Ensure Carers issues are identified and supported within the future plans of Health and Wellbeing boards. 	<p>NHS Surrey</p> <p>NHS Surrey</p> <p>NHS Surrey</p> <p>Boroughs and Districts</p> <p>NHS Surrey</p> <p>Surrey County Council</p>
Emotional Support	
<ol style="list-style-type: none"> 1. Review the provision of counselling services within Surrey and access for carers e.g. bereavement, relationship counselling, first steps service. 2. Work with Children's services to provide support for parent carers on future planning. 	<p>NHS Surrey</p> <p>SCC Children's Service</p>

Training		
1.	Promote the Royal College of General Practitioners guidance on carer friendly services within general practice and primary care settings.	NHS Surrey and Action for Carers (Surrey)
2.	Work with emerging Clinical commissioning groups (CCG's) to raise the level of carer awareness and carers' health needs.	NHS Surrey
3.	Work in partnership with NHS providers to improve carer awareness i.e. dentistry, pharmacy etc.	NHS Surrey
4.	Another area requiring particular attention is dementia, Section: 2.9 NHS Operating Framework 2012/13. PCT clusters should ensure that all providers have a systematic approach to improving dignity in care for patients, to giving staff appropriate training and to incorporating learning from the experience of patients and carers into their work.	NHS Surrey
5.	Work with disease specific and condition related organisations to improve on the provision of information provided to carers.	NHS Surrey and Voluntary sector
6.	Promote E learning on carers' awareness to all health staff.	NHS Surrey
Carers 'Care' Pathway		
1.	Carers' Assessments: Health professionals can help by making referrals to Social Care services or by providing carers with information and sign posting. Surrey Joint Carers Commissioning Strategy group should monitor the number of referrals made between health and social care which would provide a picture of how well the interface is working especially when related to hospital discharge, intermediate care and NHS continuing care.	SCC and NHS Surrey
2.	Ensure carers' needs are reflected in all future development around patient care pathways. Carer care pathways need to be clarified and consideration given to the advantages of developing a generic carers' care pathway to sit alongside all patient care pathways and contain explicit criteria details and acknowledge all the various interfaces within service delivery. All pathways need to reflect the government's commitment to a family centred approach and therefore include children who may have young carer responsibilities.	NHS Surrey
3.	Work in partnership with NHS providers to improve carers' experience of Hospital discharge.	NHS Surrey and NHS providers
4.	Where NHS Continuing Health Care/Intermediate Care applies a more joined up approach to service delivery is required. Review referral protocols where NHS Continuing	NHS Surrey

<p>Healthcare/Intermediate care are applicable in line with Department of Health -Discharge from Hospital regulations 2003 and Intermediate Care guidance (Halfway Home 2009) and ensure children who have young caring responsibilities are included.</p> <p>5. Ensure that other Surrey wide strategies including Dementia and Mental Health reflect carers' needs.</p> <p>6. Consider carer targeted information around existing care pathways.</p>	<p>NHS Surrey</p> <p>NHS Surrey</p>
<p>Employment Support</p>	
<p>1. Promote Carers friendly work practice and raise awareness of the Action for Carers and Employment service</p>	<p>All</p>

Appendices

- ❖ National Carers Strategy 2010
- ❖ Surrey Joint Carers Commissioning Strategy 2008 – 2011
- ❖ Surrey Multi agency strategy for Young Carers 2011 -2014
- ❖ NHS Operating Framework 2012/13
- ❖ Surrey Joint Strategic Needs 2011
- ❖ NHS Continuing Healthcare Practice Guidance March 2010
- ❖ Supporting Carers: An Action Guide for General Practitioners and their Teams, 2008
- ❖ 'Supporting people to live and die well: A framework for social care at the end of life' (DH NEOLCP 2011)
- ❖ New Approaches to Supporting Carers' Health and Well-being: Evidence from the National Carers' Strategy Demonstrator Sites programme Centre for International Research on Care, Labour and Equalities (CIRCLE) and University of Leeds. Nov 2011
- ❖ Discharge from Hospital regulations 2003 -Department of Health.
- ❖ Survey of Carers in Household 2009/10 - NHS Information Centre for Health and Social Care

Princess Royal Trust for Carers (PRTC)

- ❖ Always On Call, Always Concerned
- ❖ A Survey of the Experiences of Older Carers September 2011
- ❖ Supporting Carers: The Case for Change August 2011
- ❖ The Adult Carer Quality of Life Questionnaire (AC-QoL) February 2011
- ❖ Supporting carers: An action guide for general practitioners and their teams 2008 in partnership with the Royal College of General Practitioners
- ❖ Carers Health Survey 2004

Carers UK

- ❖ Valuing Carers 2011: Calculating the value of carers' support in partnership with university of Leeds
- ❖ Half a million voices: Improving support for BAME carers 2011
- ❖ In Poor Health: The impact of caring on health Dec 2004

Other

- ❖ Social Care Institute for Excellence research briefing 11: The health and well-being of young carers Published February 2005
- ❖ Devon Cares: Health and Wellbeing checks for Carers
- ❖ British Medical Association document: "Working with Carers: Guidelines for Carers
- ❖ Ignored and Invisible - Carers Experience of the NHS 1998
- ❖ Crossroads Care Surrey – Carers survey 2010



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