Surrey Young Carers Health Survey Report 2013
Definition:

Young carers are children and young people (up to the age of 18) whose life is affected by looking after someone with a disability or long-term illness. The person they care for may be a parent, a sibling, another family member or a friend, and need not necessarily live in the same house as them. The care they give may be practical, physical and/or emotional.

“Let us not forget about young carers. Officially, there are 175,000 of them, but I think that we all know that that figure is just the tip of the iceberg and that there are significantly more. Young carers are children who do not have a recognisable childhood because of their caring responsibilities. They do amazing things to support parents, brothers or sisters, but they need considerable support themselves. They need tailored and integrated support, with schools, social services and community groups working together to ensure that they have the same opportunities as other young people: a good education; good health; training opportunities; a social life; and, yes, the ability just to be children and have fun, which is what childhood should be about.”

Minister of State for Social Care, Paul Burstow 1 July 2010
Acknowledgements

The author of this report would like to acknowledge the support of all the young carers who gave generously of their time to respond to this survey. Particular thanks to members of the Surrey Young Carers Forum who helped codesign and co produce the survey.

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The subsequent report draws on various other research that has taken place including some specifically work conducted by Prof: Saul Becker at Nottingham University and Carers Trust and The Children’s Society and Carers UK. We are grateful to be able to include their findings in support of our own.

Finally the author of this report is grateful to all partners of the Surrey’s Multi Agency Young Carers Strategy Group, including Surrey County Council and Action for Carers (Surrey), for their advice guidance and support especially Jane Thornton, Chief Executive of Action for Carers Surrey, John Bangs, Senior Commissioning Manager for Carers at Surrey County Council and Gabby Alford, Associate Director previously of NHS Surrey.

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1. Foreword

Young carers in Surrey have been telling staff in our Surrey Young Carers service on an individual basis about how caring has affected their physical and mental health for a long time. Whilst our face to face contact with young carers has undoubtedly given us considerable insight into the health issues faced by them, in our discussions with colleagues in the health service we were clear that for future planning we did not want to make any assumptions. As for the Health survey undertaken with Adult Carers in Surrey in 2011, we needed to hear directly from young carers themselves about their health concerns and the issues in relation to their health that need addressing in order to be able to accurately inform commissioners and providers of health services here in Surrey. Whilst there has been some national work in this area, it is important for us to have a picture of what the world looks like for young carers here in Surrey in relation to their current and future health and wellbeing.

The young carers surveyed shared some very personal and sensitive information about their lives and the impact of their caring role on their health, many for the first time we suspect. Much of what the young carers said comes as no surprise: they want more peer support from other young carers; more breaks; someone to talk to, including health professionals as well as more informal contact; access to counselling services (mirroring the adult carers health survey), and a chance to be like other young people. But there are a few things that we weren’t expecting to see that should give us all concern: the high incidence of self-harm/eating disorders revealed by the young carers who responded; one third stating that they thought their health had worsened as a result of their caring role (and many others maybe not sure how this may impact so not able to articulate in the survey); 11% having sustained an injury as a result of their caring role, but hardly any seeking help for this from their GP.

The National Carers Strategy is very clear that young people should be protected from inappropriate caring and have the support they need to thrive and have a positive childhood experience. This survey shows however that, for this group of young people, their health needs, both physical and emotional, are not being recognised and that the health service is not adequately meeting those needs in order to give them the best start in life. Much of this centres around prevention e.g. avoidance of injury as a result of moving and handling; proactive programmes to enable young carers to keep emotionally well; better identification by all health professionals of how caring may impact on a young carers health and taking some positive action.
I would urge colleagues in all of the Clinical Commissioning Groups in Surrey and the Acute and Community providers to work with us and our partners in the local authority as part of the Surrey wide joint commissioning process and the Surrey Young Carers Strategy to improve their response to young carers in Surrey. This survey provides direct evidence from young carers themselves, so we need to listen to what they have told us and do our best to make sure that their physical, mental and emotional wellbeing is being promoted and supported by all partners engaged in both commissioning and delivering health services in Surrey.

All young carers in Surrey deserve to be happy and healthy and we need to work together to find a solution to some of the very real health concerns revealed by this survey.

Jane Thornton
Chief Executive, Action for Carers Surrey
Chair, Joint Surrey Young Carers Strategy Group
2. Executive Summary

Definition

For the purposes of this report I have used the term ‘young carer’ meaning a person below the age of 18 years who has taken on a caring role but this is a label we give to them and it’s important to remember they are children first. This definition is contextualised by stating that: ‘The term does not apply to the everyday and occasional help around the home that may often be expected of or given by children in families and is part of community and family cohesion.’ Also, that: ‘A young carer becomes vulnerable when the level of care-giving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her emotional or physical wellbeing or educational achievement and life chances.’

It has been argued that if families were better supported these children would be able to live a normal life and have equal access to life opportunities.

Introduction

The 2011 Census tells us there are 108,433 carers in Surrey, an increase of 9% since the 2001 Census; and nearly one quarter (22%) of these carers are providing more than 50 hours caring per week. There are also an estimated 14,030 young carers in Surrey (Nottingham University Research 2013). There is therefore over 14,000 reasons to care and make a difference to young carers.

With the number of young carers set to rise, the national economic situation means thinking differently and helping more people with less money in real terms. However, this is only likely to work if Councils and the NHS pull their resources together to support young carers. Supporting young carers and protecting them against inappropriate levels of caring so that they can thrive should be our key priority and by doing so we help to safeguard the rights of a young carers’ to a childhood and equal rights to life chances. By focusing on ‘family centered’ care planning we can provide help in a manner that many families appreciate and avoid far greater cost for the provision of more expensive, more intrusive ‘care packages’ or other services. In this sense, increasing support for young carers can be seen as investing to save not only in financial terms but also in health terms.

For many years now national research based on adult carers has evidenced that carers neglect their own health. In 2011 NHS Surrey in partnership with Surrey County Council and Action for Carers (Surrey) conducted their own survey to evidence the impact of caring and to seek recommendations to inform future commissioning intentions. One of the recommendations of the subsequent report was to undertake further research on the impact of caring on young carers’ health. This report concentrates on 2 primary areas of investigation, the impact on young carers’ health and the interface between young carers and NHS services.

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1 Carers Trust – Guidance from Carers Trust: Commissioning Services for Young Carers and Their Families
2 NHS Surrey Adult Carers Health Survey 2011.
Finding time to keep regular medical appointments, partake in some sort of physical activity, meet up with friends or simply relaxing can feel like an impossibility to a young carer. Juggling caring responsibilities with school, working either full- or part-time whilst looking after another person/s when caring is no easy task especially if the young carer already has or develops their own disability, illness or health condition. We know from national research on adult carers that their own health is a low priority. The findings of this survey suggest this is reflective of young carers too. Missing medical and dental appointments and regular checkups and vaccinations can have a damaging effect on a young carers’ long term physical health. With their caring commitments young carers are a high risk group.

Young Carers are potentially storing up problems for the future if they delay seeking medical help. Changes in their behaviour due to taking on a caring role can result in poorer diets, lack of exercise and reduced hours of sleep (which can be a side effect of stress and depression) and further more they may become vulnerable to ‘at risk’ behaviours which can lead to a deterioration in the young carer’s mental health.

As with adult carers the number of hours a young carer provides care can vary hugely however unlike adult carers, young carers have to juggle the demands of school life and managing their education while offering care. This builds to a significant number of hours a week which provides additional pressure on the young carer which again can have a negative impact on their health.

The findings of the survey show that young carers are not looking after themselves and many will not be aware of the impact that caring has and will have on their future health. Young carers need to be identified by their GP (General Practitioner) so that this can be noted on their medical records. Knowing their patient is a young carer; GPs can then monitor and check if they are under pressure. They can make appropriate referrals to reduce levels of inappropriate caring and offer advice and support as well as diagnose and treat young carers more effectively. For many young carers just finding the time to make an appointment or finding someone to look after the person they are caring for in order to attend an appointment can prove an impossible task.

Currently there has been no national research on the long term effects that caring has on young carers’ health. This report however evidences that the emotional impact is immediate and it is reasonable to speculate that there is also the potential for physical health problems to manifest themselves later in life. Of course it would not be true to say all young carers will experience a negative impact to their health, a resilience perspective may explain why some cope better with adversity than others. The key to good health for young carers is to build resilience especially where this relates to emotional wellbeing.

Acute trusts and community providers can also play a significant role. By identifying young carers and recognising their status they can signpost to appropriate services and provide age appropriate information and training. Hospitals need to record on medical notes if a patient is reliant on a young carer. Sadly this report evidences the fact that where young carers do come into contact with NHS services they are most likely to be ignored. NHS staff need to remain alert to young carers and their particular circumstances’ so that they can offer appropriate support.
The report will inform health and social care commissioners of their duty towards young carers in both a national and local context. It will draw on a number of recent surveys to provide data that will help to paint a picture of the state of health of young carers in Surrey and make recommendations for future planning.

3. Key Findings

- 87 responses were received in total.
- 74% of respondents were female and 26% male.
- Nearly 50% were aged between 12-15 years.
- 86% came from a British White background with 14% from other groups. (Surrey BME population approx 5%)
- 81% attended school. There may have been some having home education (there are some within the project) or attending sixth form college. It is possible that there are a small number of 16 & 17 year olds in the Not in Education, Employment or Training (NEET) category and possible that some have been excluded from school but this would need further investigation.
- Over 70% said they were sometimes late for school a further 43% said they had missed school due to their caring role.
- 62% find it difficult to find time to socialise.
- 60% find it difficult to do their homework.
- Over 70% of those aged 16 – 24 years had not told their employer of their caring role.
- Young carers were mostly caring for 2 different age groups ‘Under 18 years’ or ’35-64 years’.
- Young carers provided emotional support, domestic support and additional child care as their stated top caring roles.
- The average number of hours spent caring per week was 14.
- 2 young carers were caring 24 hours a day.
- 35% said they thought their health had worsened due to their caring role but 50% were not sure.
- 35% recognised they experienced the symptoms of an eating disorder with 9.6% relating this specifically to their caring role.
- Approximately 50% did less than 1 hour a week of physical activity.
- Over half (53%) were caring for someone with a physical disability. 28% were caring for people with mental health issues excluding dementia.
- 90% lived with the person they were caring for.
- 51% had not registered with their GP as a carer and 59% had not told their school nurse.
- 11% had sustained an injury due to their caring role but out of these over 90% had not sought help from their GP.

(Percentages have been rounded up)
What Young Carers Asked For (in order of priority):

- Peer support from other young carers
- Carers Breaks.
- More time for social, and/or physical activities
- Someone to talk too.
- Organised activities such as holidays
- Support and information of the condition of the cared for person.
- Free counselling services
- Help with getting around such as bus passes
- Time to talk to the Doctor/School Nurse.

Additional data drawn from the Surrey Young Carers Survey 2012-(Action for Carers Surrey) This survey received 265 responses. 56% wanting to know about opportunities for the future and nearly 30% wanting to know more about "coping methods". Around 18% were concerned about bullying while 15% want to know more about medical conditions. Each of the above issues are ones that are likely to be associated with the young carer being anxious and potentially stressed.

4. Introduction

Context of National Strategy/Policy

The United Nations (UN) ‘Convention on the Rights of a Child’ 1989 states that every child has the right to participate fully in family, cultural and social life³; it is an integral part of the primary care team’s role in safeguarding children to uphold this convention.

The 2008 National Carers Strategy “Carers at the Heart of 21st Century families and Communities” acknowledges that many young carers may experience problems with their physical and mental health due to their caring role. Responses to the survey will help improve our understanding of how caring impacts on the health of young carers and will make recommendations to commissioners of young carers’ services here in Surrey. It should also influence the way that adult and children’s services provide support to the whole family i.e. to the disabled adult or child, so that children do not take on a caring role in the first place.

The National Carers Strategy stated its vision that: ‘Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive and to enjoy positive childhoods.’

The National Carers Strategy was refreshed in 2010. The Government’s cross departmental plan “Recognised, Valued and supported: Next steps for the Carers Strategy” (Nov 2010) ⁴ highlights areas for and the actions that the Government will take over the next four years.

⁴ https://www.gov.uk/government/publications/recognised-valued-and-supported-next-steps-for-the-carers-strategy
to ensure the best possible outcomes for carers (including young carers) and those they support.

The National Carers Strategy also highlights the value of a whole family approach to support carers’ health and wellbeing.

From the Government’s Carers Strategy, *Caring about Carers*, issued by the Dept of Health. Chapter 8, pp75-81:

Improving support for young carers

15. To support young carers better, the Government has already indicated that we will:

- do more to make health, education and social services work together on children’s services plans, as set out in our White Paper *Modernising Social Services*.

16. We will also:

- improve awareness training about young carers for General Practitioners, primary health care teams, social workers and teachers at the time of their initial training and subsequently, through providing opportunities for young carers to share their experience with professionals.

Current Health Responsibilities:

The following Strategies/Mandates are inclusive of young carers:

**Healthy Lives Healthy People – Our Strategy for Public Health in England**

1.36 A total of 1:10 people are carers and analysis of census data shows that 1:5 of those providing over 50 hours per week say they are in poor health compared to 1:9 non carers.

1.44 There are an increasing number of frail older people and many over 65 are carers. In winter 2008/9 there were 35,000 excess deaths in England many of which could have been prevented.

3.64 Carers also play a vital role in supporting people to stay at home. The Dept of Health Carers Strategy sets out how we will support carers to recognise the value of their contribution, involve them in how care is delivered, support their mental and physical health and enable them to have a work, family and community life. As part of this the government is making an additional £400 million available through the NHS over the next 4 years to support carers’ breaks.

3.70 (With regards to End of Life (EOL) The taboo about discussing death and dying means that too many people can reach this critical point of their life unprepared without having thought about how or where they would like to be cared for. This in turn affects their carers

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and their families as a poor death can lead to a traumatic bereavement, with associated mental and physical health issues. The Dept of Health will continue to implement the EOL strategy

**NHS Mandate 2013 -15**

The Mandate to the NHS Commissioning Board sets out the objectives for the NHS and highlights the areas of health and care where the Government expects to see improvements.

2.5 The NHS Commissioning Boards Objective is to ensure the NHS becomes dramatically better at involving patients and their carers and empowering them to manage and make decisions about their own care and treatment.

- The 5 million carers will routinely have access to information and advice about the support available – including respite care.

2.8 We want to see improvements in the way care is coordinated around needs, convenience and choice of patient, their carers and families – rather than the interest of the organisations that provide the care.

2.11 (Relating to Dementia and PMs Dementia Challenge) The objective (2.10) is to make measurable progress by 2015, in particular ensuring timely diagnosis and the best treatment available for everyone that needs it including support for their carers.

**Part 2 of NHS Outcomes Framework- Enhancing quality of life for people with long term conditions Enhancing quality of life for carers**

2.4 Health related quality of life for carers

3.1 Helping people to get back as quickly or as much as possible to their everyday lives is not something the NHS can achieve alone, but requires better partnership with patients, their families and carers, social services and other agencies.

3.3 Real consideration on how to make it easy for patients and carers to give feedback on their care and see reviews from other people, so that timely and easy to review feedback on NHS services becomes the norm.

**Part 4 - NHS Outcomes Framework – Ensuring people have a positive experience of care.**

4.6 Improving the experience of care of people at the end of their lives: Bereaved carers views on quality of care in last 3 months of life

10 Transforming how the NHS performs: managing ongoing physical and mental conditions such as dementia, diabetes and depression – so that we, our families and carers can

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[6](http://mandate.dh.gov.uk/)
experience a better quality of life: so that care feels more joined up right across GP surgeries, district nurses and midwifes care homes and hospitals.

The NHS Mandate is underpinned by the Putting Patients First: The NHS England Business Plan for 2013/14 – 2015/16 (05/04/13)\(^7\). The plan describes an 11 point scorecard which NHS England (formerly known as the NHS commissioning board) will introduce for measuring performance of key priorities, focused on receiving direct feedback from patients, their families and NHS staff.

NHS Constitution\(^8\)

The constitution sets out rights for patients, public and staff. It outlines NHS commitments to patients and staff, and the responsibilities that the public, patients and staff owe to one another to ensure that the NHS operates fairly and effectively. All NHS bodies and private and third sector providers supplying NHS services are required by law to take account of this constitution in their decisions and actions. The new constitution was published on the 26\(^{th}\) March 2013 and carers including young carers are referenced throughout.

Guide to the Healthcare System in England; Including the Statement of NHS Accountability

All references above are included in the Guide to the Healthcare System in England Including the Statement of NHS Accountability May 2013 publication\(^9\).

Royal College of General Practitioners – Commissioning for Carers Guide\(^{10}\) (Published June 2013)

Amongst other resources the RCGP have developed a guide for commissioners on the importance of identifying and supporting carers including young carers. Primary care providers can play a key role in a whole family approach to supporting young carers. Successful support programmes are likely to involve many community partners, including schools, and to focus on supporting young people who are carers to thrive and reach their full potential. Emotional impacts such as worry, depression and self harm have been identified in young carers.\(^{11}\) Young carers need support to regain confidence in their own identity to help them to move forward in their lives beyond their caring role.

The responsibility of being a carer early in life shapes a young person’s:

- Emotional and mental health
- Ability to build relationships with others
- Educational achievement\(^{12}\)

Young carers often have many questions that trouble them that they may not share with others.

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\(^8\) https://www.gov.uk/government/publications/the-nhs-constitution-for-england  
\(^{10}\) http://www.rcgp.org.uk/carers  
\(^{12}\) Page 12 RCGP Commissioning for Carers Guide
• Can I catch it? Will it happen to me too?
• What caused it? Why us? Is it my fault?
• Can I do anything to make it better?
• Will the person that I look after get worse or die?
• What should I do in an emergency?

Many carers feel ignored by health professionals\textsuperscript{13}

**General Medical Council (GMC) 0-18 years: Guidance for all doctors\textsuperscript{14}**

Published in 2007 this guidance describes what is expected by Doctors registered with the GMC.

It States:

‘Doctors should be aware of the needs and welfare of children and young people when they see patients who are parents or carers, or who are cared for by children or young people.’

**Report of the children and young person’s health outcomes forum\textsuperscript{15} (Published 15\textsuperscript{th} May 2013)**

In January 2012 the secretary for health launched the development of a children’s and young peoples’ health outcomes strategy. This report which although doesn’t specifically mention young carers does however reflect the same issues and findings of this survey and makes similar recommendations including 4 new outcomes indicators for the NHS outcomes framework:

• Time from first NHS presentation to diagnosis or start of treatment
• Integrated care – developing a new composite measure.
• Effective transition from children’s to adult services
• Age appropriate services – with particular references to teenagers

Further recommendations are made for Public Health.

The focus of the report is about acting early and intervening at the right time, integration and partnership, workforce training and development, knowledge and evidence, leadership accountability and assurance and incentives for driving service improvement. All of which have a read across for young carers.

A further report on mental health\textsuperscript{16} was published through the forum. Listed below are key facts and findings:

• One in ten children aged between 5 and 16 years has a clinically diagnosable mental health problem. About half of these (5.8%) have a conduct disorder, 3.7% an emotional disorder

\textsuperscript{14} http://www.gmc-uk.org/guidance/ethical_guidance/children_guidance_index.asp
(anxiety, depression) and 1–2% have severe Attention Deficit Hyperactivity Disorder (ADHD);

• At any one time, around 1.2–1.3 million children will have a diagnosable mental health disorder;
• Half of those with lifetime mental illness (excluding dementia) first experience symptoms by the age of 14, and three-quarters before their mid-20s;
• The rates of disorder rise steeply in middle to late adolescence. By 11–15 it is 13% for boys and 10% for girls, and approaching adult rates of around 23% by age 18–20 years;
• Self-harming in young people is not uncommon (10–13% of 15–16-year-olds have self-harmed) but only a fraction of cases are seen in hospital settings; Although effective treatments are available only around 25% of those who need such treatment receive it;
• 11–16 year olds with an emotional disorder are more likely to smoke, drink and use drugs;
• Around 60% of Looked After Children and 72% of those in residential care have some level of emotional and mental health problem. A high proportion experience poor health, educational and social outcomes after leaving care;
• Looked After Children and care leavers are between four and five times more likely to attempt suicide in adulthood;
• One third of all children and young people in contact with the youth justice system have been looked after. It is also important to note that a substantial majority of children and young people in care who commit offences had already started to offend before becoming looked after;
• Young people in prison are 18 times more likely to take their own lives than others of the same age;
• The costs of mental health problems for the English economy have recently been estimated at £105 billion pa;
• Children of teenage mothers are generally at increased risk of poverty, low educational attainment, poor housing, poor physical and mental health, and have lower rates of economic activity in adult life;
• Young people in prison are 18 times more likely to take their own lives than others of the same age.

It is reasonable if emotive to interpret the above data as inclusive of young carers.

Context of Local Policy

The vision for Surrey’s\textsuperscript{17} Multi agency young carers’ strategy states:

“We want to ensure that children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes. We also want to ensure that independent young carers services in Surrey and other targeted services who work directly with young carers should be able to provide safe, quality support to those

\textsuperscript{17} Interagency Strategy for young carers in Surrey 2011-14 \url{http://www.surrey-youngcarers.org.uk/}
young people who continue to be affected by any caring role in their family. We want to encourage staff in all agencies to be pro active in recognising and supporting Young Carers and their families and for this to be recognised as being ‘everybody’s business.”

The role of Surrey’s Health and Wellbeing board should ensure that young carers are protected from inappropriate levels of caring and that a family approach to assessment is embedded within all health and social care systems. Surrey publishes a Joint Strategic Needs Assessment (JSNA) for young carers. This helps inform commissioning intentions.

Currently only a small proportion of young carers are identified and supported by services. Accurate data is difficult to obtain, as it is often dependent on the young person self-referring for support. Until recently it was thought that the 1200 young carers supported per year in Surrey represented around 40% of the total number. However new data from the University of Nottingham suggests this proportion may be as little as 10%. (Based on estimated Surrey Y/C population of 14,030)

Carers are typically children or young people living in families with a parent or sibling with an illness or disability for whom they provide care. The average age of a Surrey young carer is 12, which is the same as the national average. Young carers are more likely to live in a family:

- With a single parent – as there is greater likelihood that no adult care support is available
- Suffering social exclusion – where there is little likelihood of outside support
- With unemployed parents or on low incomes – who lack the means to pay for additional support

The Social Care Institute for Excellence (SCIE) has identified a number of risks to young carers based upon research findings including the following health issue:

- Possible mental-health disorders including stress, anxiety, low self-esteem, depression, eating disorders, difficulty in sleeping and self-harm

**Young Carers Census Data 2011**

On the 16th May 2013 new data on the number of young carers was published. The figures released evidence the following:

- **19% increase** in the number of young carers’ aged under 18 nationally. There has also been an
- **83% increase** in the number of 5-7 year olds providing unpaid care.
- **25% increase** in the number of young adult carers’ (aged 16-25) — a group that is twice as likely not to be in education, employment or training.

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Estimated numbers of young carers in Surrey by District and Borough

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<th>District or Borough</th>
<th>Estimated young carers aged 5 – 17</th>
<th>Population aged 5 – 17</th>
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<tr>
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</table>

8% based on University of Nottingham young carers study for the BBC undertaken by Professor Saul Becker and others. This estimates 1 in 12 secondary school pupils. from JSNA

A survey conducted for the BBC in 2010 of over 4,000 school children, showed that 1 in 12 had caring responsibilities, equating to some 700,000 young carers in the UK – four times the number identified in the 2001 census. Further research by Professor Saul Becker Nottingham University Young Carers Study reports this number may in fact be higher again,
evidencing a young carers population of 14,030 living in Surrey. At present our young carers services give some form of support to 1,200 young carers a year, which is just 8.5% of this number.

Research by the Mental Health Foundation suggests that there are an estimated 200,000 young people in the UK living with a parent with a severe mental health problem. This in turn would suggest that out of 12,000 young carers in Surrey, up to 3,400 are looking after a parent with significant mental health concerns.

An estimated 70% of young carers living in Surrey look after an adult in their family; the remaining 30% care for a sibling.

**What do young carers do:**

- **Intimate caring**: 18%
- **Emotional support**: 82%
- **Additional child care**: 11%
- **General caring**: 48%
- **Domestic chores**: 68%
- **Other**: 7%

**Future changes in the law**

Currently whenever an adult has his or her needs assessed by social care, the assessment must take into account whether there are children in the family and what additional services a parent might need to prevent children from becoming young carers - children’s services must do the same. Assessment of needs includes a health and well being component and an opportunity for social care staff to sign post carers/young carers for other services.

Changing the **Children and Families Bill** and the **Care Bill** in parliament could make this happen. The Care Bill at present is not inclusive of Young Carers or Parent Carers however the legal framework should still be to support children where their parent has a disability. The purpose of the Bill is to promote a whole family approach which means looking at the needs of each individual in a family and the impact of disability and caring on all family members within a whole family approach; and the promotion of prevention and wellbeing. This will

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20 These figures are from *Young Carers in the UK: the 2004 report* (Dearden and Becker) www.saulbecker.co.uk
21 http://www.publications.parliament.uk/pa/cm200910/cmbills/008/10008.i-iii.html
ensure that young carers are safeguarded against inappropriate levels of caring and their needs taken into account during the assessment process. Recently Norman Lamb Care Minister has responded to the issue of young carers who will be left without equal rights to services compared to adult carers unless the bill is further modified in a letter to Carers Trust (Appendices) but the details are yet to be agreed.

The Government have confirmed that the “Well-being principles” in clause 1 of the bill will apply equally to carers. There is also a new focus on integrated services. Integrated Care and Support: Our Shared Commitment is the first output from the governments National Collaboration on Integrated Care and Support involving partner organisations. This is a significant policy change which will impact on the NHS especially where is relates to patients with complex needs and hospital discharge. The new duties of integration; a whole family approach; prevention and wellbeing will mean that the NHS needs to consider how they respond to carers/young carers at every point of contact from on the hospital ward; to discharge; to Intermediate Care; to rehabilitation; to ongoing care, including NHS Funded Continuing Health Care (CHC) and “integrated” social care and when caring comes to an end.

To learn more about the consultation click here to link to Carers World Radio podcasts http://carersworldradio.ihoststudio.com/radiolatestprog.html

Think Local, Act Personal (DH) 2011

Think Local, Act Personal sets out the new commitment to moving forward with personalisation and community-based support. Building on the progress from Putting People First (HM Government 2007) which outlined the personalised Adult Social Care System that ‘Agreed and shared outcomes which should ensure people, irrespective of ill or disability, are supported to: Live independently and to sustain a family unit which avoids children being required to take on inappropriate caring roles’.

At the Surrey Young Carers Multi Agency group meeting on the 19th February 2013 a ‘Making it real for Carers’ workshop was held to interpret what this means for young carers in Surrey. Feedback from this event with regards to support from health professionals was clear, “ see us, recognise us and involve us”.

Universal Services

GPs, Health Visitors, School Nurses, Hospital Staff and other community health practitioners have a vital role to play in young carers’ lives. Health staff need to embed their understanding of the pressures and challenges that face young carers into their core operations. These settings must also have the knowledge and capacity to offer support and practical guidance to young carers they meet in their services. Young carers told us that they were frustrated with the fact that doctors can't consult with them, and are not obliged to give them information about the illness, symptoms and medication prescribed to person they care for. This is obviously a big issue, as without all the information, it is difficult to understand the needs and well being of the person they care for. ‘Age is not a number’ one

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23 Integrated Care and Support: Our Commitment May 2013.
24 http://www.puttingpeoplefirst.org.uk/_library/PPF/NCAS/Partnership_Agreement_final_29_October_2010.pdf
young carer said 'Why can’t young carers have the same right to support that adult carers’
get.'

To assist with this, Surrey has developed a comprehensive range of ‘carer awareness
training’ tools and a generic Carers Care Pathway where health professionals can find out
what services are available to young carers and make referrals. The difference this makes to a
young carers life cannot be calculated and truly significant.

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Case study – Carers Trust/Children’s Society

Male young carer cares for his younger sister with ME. She is wheelchair user. The
young carer goes on to describe that his sister lost all her friends and ended up being
home educated. He became her best friend. His sister didn’t like receiving help and he
often had to toilet her himself. He describes this as being an unusual experience and
didn’t know how to handle it. “No one showed me how to lift her or use the
wheelchair”.

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Health Minister Dr Dan Poulter has stated that the 1,200 school nurses can help support
young carers. The minister said ‘School nurses are to become "young carers champions" in a
bid to help youngsters whose lives are overshadowed by looking after their family members,
"Young carers are often under incredible pressure both at home and at school," he said.
"School nurses can do a lot to give young carers a voice and help ease that pressure. Our
plans will help them do just that."
13th April 2012.

At The Children’s Society ‘Prevention through Partnership’ Event held in March this year,
Edward Timpson, Children’s Minister said: 'I'm afraid I have zero sympathy for any teacher
who thinks that their responsibility extends no further than educating their pupils during
school hours. Any adult who has regular contact with a child should take a keen interest in
their welfare.'
This applies to health staff as much as Education staff where identifying and supporting of
young carers is concerned.

The Government has pledged to increase the health visitor workforce by 4,200 to offer all
families support when they become parents and are caring for young children. Health
visitors lead and deliver the Healthy Child Programme, linking with maternity services,
general practices and Sure Start children’s centres, and the evidence-based Family Nurse
Partnership programme, thereby helping to give all children the best start in life. Although
only a small percentage of young carers under the age of 8 responded to this survey it is
known that children as young as 4 years old have been known to take on a caring role.

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25 5.5 No health without Mental Health
Pharmacy and Medicines

Medication causes problems and worries young carers. Many are anxious about the responsibility that they take on when administering medication. *A major worrying task is that most young carers are responsible for giving out medication to the person they care for….They were worried that one mistake could be fatal*  
Community or Hospital based pharmacists are a source of help and support around medicines and general lifestyle advice and need to provide age appropriate advice and support to young carers.

The Surrey Carers Partnership will be running a Community Pharmacists Carers Information week starting on the 2nd September 2013 to help identify hidden carers including young carers.

Mental Health

The government’s ‘No Health without Mental Health’27 strategy published Feb 2011 is a strategy for all ages. For those young carers whose own mental health is affected by their caring roles, quick access to services is vital.

Mental health is important to us all. It is important that people are healthy in their minds as well as their bodies. Mental health is how someone is feeling in their mind. Good mental health is about feeling good about your life and being able to cope with problems when they happen. We call good mental health, mental well-being.

A mental health problem is a problem with someone’s mind that makes it difficult for them to live a normal life. Mental health problems may be small problems or more serious problems. They may last for a short time or a long time.

Having mental health problems is upsetting for the person who is not well, their families, friends, and carers. It seems that some people are more likely to have certain kinds of mental health problems. More young people have problems with their behaviour and the way they feel in their mind.

Stigma and experiences of discrimination continue to affect significant numbers of people with mental health problems. This discrimination is extremely damaging but most particularly for young carers either experiencing mental health themselves sometimes due to the impact of their caring role or caring for someone with mental health. People with mental health problems have worse life chances than other people. Part of this is the direct effect of the condition, but a very large part is due to stigma and discrimination, driven by ignorance and fear, and some people’s negative attitudes towards them. Stigma can also affect the attitudes and behaviours of clinicians, including mental health clinicians, and commissioners.

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Families and carers, young and old, often receive limited help and too often report that they are ignored by health professionals on grounds that they need to protect the confidentiality, and respect the wishes, of the service user. However, families and carers, including children, have detailed knowledge and insight and are often best placed to advise health and social care professionals about what may help or hinder the recovery of the person for whom they are caring. If they are well supported and listened to, families and carers can continue their caring responsibilities for longer and participate fully in decisions about services and how care is delivered. The refreshed carers strategy, Recognised, Valued And Supported: Next steps for the Carers Strategy, sets out the actions that the Government will take over the next four years to ensure the best possible outcomes for carers and those they support.28

Children who are aware of the symptoms of a family member suffering from mental illness may be confused about the illness. This can lead them to feel scared, angry and powerless to change their situation. Predominant feelings vary depending on the child’s age and level of understanding. Fear and guilt are often more common in younger children, while anger and embarrassment tend to be more common amongst adolescents. Some children:29

- are withdrawn.
- appear anxious.
- find it difficult to concentrate on their school work. This can lead to underachievement in education and as a consequence reduced life chances.
- have low self-esteem and become depressed, having a fatalistic acceptance of their life situation.
- show behaviour difficulties, violent or self-destructive behaviour.
- adopt paranoid or suspicious behaviour as they believe their parents delusions.

Children and young people need help to develop their own understanding of mental health problems, and to be relieved of any self-blame that they may have. There may be evidence of genetic factors in some mental illness however the child can be reassured that this is only one risk factor and that their chances of developing a mental health problem can be lessened by talking about their feelings, seeking prompt help, maintaining a healthy lifestyle and being aware of the risks associated with alcohol and drugs.30

A Carers Trust case study from one young carer who cared for her mother with mental health and who was experiencing bullying at school reported that the young carer already had concerns about inheriting her mother’s conditions which were made worse by the continual taunts of the bully who said; “Your mums insane, she’s a freak and you’re going to grow up like her.”

In another case study the young carer said: “I never understood my mum’s illness. The doc never told me what was wrong. He should have told how to cope with her behaviour. He never called to see how I was doing.”

28 4.20 No Health without Mental Health
30 [http://saulbecker.co.uk/v1/downloads/young_carers/young%20carers%20and%20mental%20illness%202002.pdf](http://saulbecker.co.uk/v1/downloads/young_carers/young%20carers%20and%20mental%20illness%202002.pdf)
The Department for Education has introduced an **Early Intervention Grant**, which will provide a new funding stream for early intervention and preventative services for children, young people and families. It is not ring-fenced, enabling significantly greater freedom at local level, to respond to local needs and drive reform, while supporting a focus on early intervention in the early years and up through the age range. It will bring together funding for a number of early intervention and preventative services, including Sure Start children’s centres. Schools and local areas report significant benefits from the Targeted Mental Health in Schools (TaMHS) programme, and the Early Intervention Grant includes funding for targeted mental health support for children and young people.31

TaMHS, which has been rolled out to school clusters in all local authorities in England, provides school-based early intervention and targeted mental health support for vulnerable children (aged from 5 to 13) and their families. This can involve one-to-one work, group work or work with parents and carers.32

In Surrey out of the 385 schools, 235 schools engaged with the TaMHS Approach from November 2011 to April 2013 (61%) with approximately 2,500 staff across 122 Surrey schools having received Mental Health Awareness training so far.33 Further reading available in the appendices.

Around 117,000 families in the UK are experiencing multiple problems (5 or more). Multi-systemic interventions that involve young people, parents, schools and the community have been shown to reduce conduct disorder, improve family relationships and reduce costs to the social care, youth justice, education and health systems. Families often experience multiple problems, such as substance misuse or mental health problems, parenting problems, child neglect and behaviour problems in school, or involvement in offending. Evaluation of family intervention has shown reductions in mental health problems, drug or substance misuse and domestic violence.34

**What the national mental health strategy delivers:**

Invests around £400 million over four years to make a choice of psychological therapies available for those who need them in all parts of England, and expand provision for children and young people, older people and their carers, people with long-term physical health problems and those with severe mental illness.

In the UK 1:10 Children or young people have problems with their mental health or emotional wellbeing. Young Carers’ mental wellbeing is what allows them to cope with all the challenges they face as they are growing up dealing with day to day pressures as well as juggling their caring role. If the young carer is experiencing inappropriate levels of caring this may impact on their mental health.

In Surrey young carers with poor mental health, in difficulty or experiencing problems can be referred to **Child and Adolescent Mental Health Services**35 (CAMHS) for support. Furthermore there are voluntary sector providers who also offer support.

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31 5.9 No health without Mental Health
32 5.10 No Health without Mental Health
33 Babcock 4S Limited www.babcock-education.co.uk/4S
34 5.11 No Health Without Mental Health: Delivering better mental health outcomes for people of all ages.
The Children’s Society and ITV1 survey; 30 per cent of young carers are under 10

In January 2011 The Children’s Society published the findings of an ITV 1 Survey which found:

- 43 per cent of young carers say they have too much responsibility for their age
- 30 per cent of young carers are under 10 years old
- More than two-thirds (67 per cent) said being a young carer made them feel stressed
- Half (52 per cent) said that being a young carer had a negative effect on their school work.
- A fifth (20 per cent) said they had been bullied because of their caring role
- More than two-thirds (68 per cent) said being a young carer made them feel 'depressed'.

The survey was conducted with The Children’s Society’s National Young Carers Forum. Further reading is available in Appendices.

Improving Access to Psychological Therapies (IAPTs)\(^\text{36}\)

Launched in 2011 The Children and Young People's (CYP) IAPT Project is a Service Transformation Project for Child and Adolescent Mental Health Services (CAMHS). The focus of CYP IAPT is on building a more collaborative relationship between children, young people, families and therapists through use of frequent outcome monitoring and extending participation in service design and feedback, extending training to staff and service managers in CAMHS and embedding evidence based practice\(^\text{37}\) across services, making sure that the whole service, not just the trainee therapists, use session by session outcome monitoring. The following conditions and therapies will cover:

- a range of emotional disorders such as anxiety and depressive disorders, Obsessive Compulsive Disorder (OCD) and Post Dramatic Stress Disorder (PTSD) - manualised

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Case Study - Young Carers experience of talking to his GP

A young carer wrote of his experience of talking to his GP about his circumstances at a time when he was experiencing suicidal thoughts.

The GP was aware that the young carer was receiving some pastoral support from school but when asked by the young carer to refer for counselling services it was refused on the basis that the young carer was already receiving support from school.

In fact the teacher providing pastoral care was struggling to manage the support required as the level of need was far higher than she was trained to deal with.

The young carer did manage to access support eventually through Surrey Young Carers Service but the experience has left its scars. It took a huge amount of courage for him to ask for help in the first place and the response left him shattered at a time when he had little resilience to deal with.

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implementation of the evidence based behavioural therapy or Cognitive Behaviour Therapy (CBT) treatment packages, and
• for behavioural problems in 3-10 year olds (Oppositional Defiant Disorder or Conduct Disorder) - parenting programmes such as Webster Stratton.

(CYP) IAPT project is not available in Surrey for 2013/14.38

Quote

"Why can’t children get the same as adults?"

Young Carer

Other support is available through the ‘Young Minds’ Website (20) and there are Emotional Literacy Support (ELS) schemes available in some schools in Surrey. The ELS programme is non labelling/ a non medical model that enables children to be listened to. This is an essential as part of the spectrum of emotional support.

Youth Support Service (YSS)

NHS have appointed a Child and Adolescent Mental Health Service (CAMHS) Primary Mental Health Worker within Surrey Youth Support Services (YSS). The post-holder works closely with Youth Support Officers (YSO) and YSS Specialists including health professionals to achieve positive outcomes for young people with emerging mental health, emotional and behavioural difficulties. The role involves undertaking mental health assessments and delivering therapeutic input to young people and their families as appropriate. The post-holder will also take a lead in the provision of consultation, training and support to front-line staff. This post may provide an alternative referral point for professionals who have concerns for young carers.

YMCA counselling service

The Guildford39, Redhill and Reigate40, Woking41 branch of the YMCA all provide counselling services. 2 are available free the Guildford branch requires a donation based on ability to pay. The Redhill and Reigate is restricted to 14-24 year olds and Woking service is open to 16 – 25 year olds.

Relate Counselling service

Relate Mid Surrey in Reigate have receive funding from Surrey County Council Local Committee for Reigate & Banstead towards counselling for young people, especially for teenagers caring for an adult with physical or mental health problems at home.

Counselling at Relate Mid Surrey is confidential. It can benefit those young people who are caring for others in their family, giving them a voice to improve their own mental health and

38 http://www.iapt.nhs.uk/cyp-iapt/cyp-iapts-project--launch-of-offer-for-201314/
39 http://www.guildfordymca.org.uk/counselling.htm
41 http://www.wokingymca.org.uk/y_talk_counselling.htm
in turn helping with their self-esteem to withstand bullying. This will encourage them to talk to friends and teachers about the impact that being a carer can have on their lives.

**NE Hampshire CCG – Appropriate use of Accident and Emergency services for mental health patients.**

North East Hampshire and Farnham Clinical Commissioning Group has commissioned Uscreates, a social research agency, to help improve the experience and outcomes for mentally ill patients who are frequent attendees at A&E. The research seeks to understand the patient’s needs, experiences and perspectives, and identify what factors may drive them to crisis point and episodes of self-harm leading to A&E attendance. This research is ongoing but may help to inform commissioners on issues which relate to young carers self harming and other at risk behaviours.

Key insights for total population include the following:

1. There is no local 24/7 service to help avert a crisis
2. There is a lack of trust in some existing services
3. There is a lack of clear understanding of what some existing services offer
4. Self-management support tends towards coping rather than prevention

Crisis triggers:

1. Crisis moments can be triggered by feelings of isolation, loneliness and rejection
2. Service users say triggers can be reduced through physical company, compassion and conversation

Further reading into this research is available in the appendices.

**BBC in partnership with Carers UK report- Doctors should screen carers for depression (11th May 2013)***

The Royal College of General Practitioners (RCGP) estimates one in every 20 patients registered with a GP practice is providing unpaid care. About 40% of carers are thought to be at risk of depression or stress because of their caring role.

The Charity Carers UK says GPs have a vital role to play in supporting carers. The RCGP says more should be done to improve the support and services offered to carers. It says the "screening" process for depression should involve "a small number of general, non-invasive, questions about mood and mental wellbeing". The RCGP has also drawn up a list for clinical commissioning groups - groups of GPs that plan local care - of measures to ensure carers' needs are taken into account:

- Improve GP access by allocating routine appointments and vaccinations at convenient times for carers
- Appoint a carers' "champion" in all GP surgeries

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• Maintain a carers' register within the GP practice
• Carry out audits to measure improvements in carer support

Dr Clare Gerada, chairwoman of the Royal College of GPs, said carers often found it hard to admit they were struggling. “Carers often neglect their own healthcare needs and in many cases it is only a matter of time before they themselves become ill. GPs can play a crucial role in identifying potential problems in the early stages and 'screening' for depression is something that many GPs are doing already. Commissioners need to invest in supporting carers as a critical asset.”

The Royal College of General Practitioners have confirmed that young carers were included as part of this survey and that new guidance is being developed and will be made available on their website soon.

Quotes from young carers:

“Be nice if someone asked how we were.”
“ Asking for help was humiliating.”
“You have to keep explaining and explaining and no one understands.”
“I need time to talk and relax.”
“Everyone thinks caring is just physical but it’s emotional too. I started caring for my sister with Downs Syndrome at the age of 2. I had to grow up fast and hated being a teenager. I skipped those years. I feel really old. I have no friends of my age as I can’t relate to them or them to me. I’ve always been worried throughout my whole life and know nothing else.’

Caring for someone with a drug or alcohol problem

These young carers are particularly vulnerable as they are often not identified due to stigma and parental concerns that their children will be taken away from them so do not get the chance to access support services. Young carers have described the emotional impact of caring for parents where there is a drug/alcohol problem. A theme that runs through all the national research is anger.

Case Study – Carers Trust/Children’s Society

Tanya has an alcoholic mother and also cares for a younger brother with autism. She describes how she takes the role of mother when her own mum is drunk. She has to make sure her mother is safe and then clear up after her. She does all the housework. She describes feeling overwhelming anger and rebellion. She says:
“I argue with my mother all the time but I worry about her. When social services come they see the house is clean so assume mums ok”
“I don’t know why I bother”

emotional support both during the person’s life and after bereavement. Carers already have the right to have their own needs assessed and reviewed and to have a carer’s care plan. The Macmillan Cancer Trust estimates that there are 1.1 million carers of people with cancer of which 95% have not received a carers’ assessment. This will impact on children in the family and young carers are less likely to be considered as carers and they are therefore less likely to have their needs assessed. Further reading available in the appendices.

Although not raised in this survey EOL care planning must take into account the needs of any young carer. Children are the highest age group to die in hospital. For young carers who are involved in caring for a sibling it is important they can access support to maintain their education whilst their sibling receives treatment and emotional support. Young carers refer time and time again to the fact that they are largely ignored within a hospital setting.

The National EOL strategy focuses on services for adults. A separate review of children’s palliative care services was undertaken by Professor Sir Alan Craft and Sue Killen and was published in May 2007. The review drew attention to the challenges facing palliative and end of life care services for children and set out a number of recommendations for government, as well as for the development of services at a local level. The recommendations were endorsed by the government and a first ever national strategy for children’s palliative care ‘Better Care, Better Lives’ was published in February 2008. It is important to note that there are a wide variety of childhood conditions causing death before adulthood, many of which are rare. The time span of children’s illnesses may also be different from adults, meaning that palliative care extends over many years. Moreover, children continue to develop physically, emotionally and cognitively, and this affects both their medical and social needs, as well as their understanding of disease and death. Above all, a child’s death remains emotionally difficult, unnatural and unexpected for families and siblings who may have taken on a caring role.

The role of hospices as providers of bereavement services is essential to young carers. The Princess Alice Hospice in Esher operates a family and children’s bereavement service.

Currently young carers’ services refer young carers to Winstons Wish. Winston's Wish is the leading childhood bereavement charity and the largest provider of services to bereaved children, young people and their families in the UK.

Assessment of needs

Young carers perform their caring roles because of unmet care needs, but no care package should rely on the inappropriate caring role of a child. Adult Social Care Services Department have a duty to assess the care needs of the family member under the NHS and Community Care Act 1990. GPs are an essential part of this referral process.

Young carers are eligible for assessment under carers’ legislation and the Children Act 1989 as children ‘in need’. However, only a minority of young carers are receiving a formal assessment. ‘Those caring for someone with drug/alcohol problems are more likely to receive an assessment under the Children Act.’

Like adults, young carers are entitled to referral for a carer’s assessment. GPs and other health practitioners can refer the young carer to Surrey’s Children’s Services for an assessment under the Common Assessment Framework. A young carer assessment should

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45 [http://www.guardian.co.uk/society/2013/jun/26/carers-cancer-patients-support](http://www.guardian.co.uk/society/2013/jun/26/carers-cancer-patients-support)
46 Hansard Report 20th June 2013 - Barbara Keeley (Worsley and Eccles South) (Lab)
47 Palliative Care Services for Children and Young People in England. Craft/Killen, 2007
automatically trigger a community care assessment or review of the person being cared for. Some young carers and their families are reluctant to admit the child’s role as a carer and are fearful of seeking help from social services.

Some young carers may be caring inappropriately or coming to significant harm as a result of their caring duties, some may be in danger or being neglected as a result of a family member’s illness in these case GPs have a duty under the 1989 Children’s Act, to refer to the Children’s Services for an assessment if they feel that a child is ‘in need’ or ‘at risk’, with or without the consent of the parent(s). GPs can seek assistance in the decision making by contacting the local children’s safeguarding lead for advice.

One of the major stresses that young carers identify in the survey was whilst they may be the person who spends most time looking after someone in their family, they are also often the person who knows least about the ‘cared for’ person’s health condition. Health professionals working with adults who have children should try to encourage them to explain their health condition. Alternatively, professionals could do this on behalf of the adult if the adult does not feel comfortable to do so. If this is not possible, there is no data protection barrier to giving a child or young person general information about the relevant health condition. This applies to both primary and acute settings. Young carers reported that they are frequently ignored and ‘talked over’ when health professionals are involved particularly where this occurred within A&E Departments.

Case Study – Carers Trust/Children’s Society
A young carer who was caring for her disabled brother but also had a disabled mother says:
“I needed training. I’ve been wiping my brother’s bum since I was 8. If I don’t he’ll just poo his pants again. No one helped me or showed me how I could help him to learn how to wipe his own bum”

Case Study – Carers Trust/Children’s Society
Another female young carer whose mother’s first language was not English was asked by a hospital doctor to translate to her mother that she had a life threatening illness

Case Study – Hospital Experience
Another young carer describes her experience and treatment whilst her brother was receiving treatment on a hospital ward
“Everyone spoke to my dad but they just ignore you like you are nothing. One doctor just pushed me out the way.”

“Talk about us as a family, nobody lives in isolation”

“The surgery took for granted my son would care for me and bring me in for appointments”

Importance of Identifying Young Carers

Young people should not be expected to carry the same caring responsibilities as an adult so their identification is the first step in enabling them to have the same life opportunities as other young people. GPs and their staff have a pivotal role in identifying young carers. In
Surrey there are 3 GP Carer Awareness advisors who support primary care practitioners in identifying young carers. Under the old Quality Outcomes Framework (QOF) management standard 9, GPs were offered financial incentives to register carers. This standard has now been made redundant and there is less incentive for GPs to register carers. The number of children registered as young carers with their GPs has never been identified.

Statistically Surrey is only supporting roughly 10% of its young carers. The reason such a small proportion of young carers are supported is because relatively low numbers of young carers are identified and referred on to the Young Carers Projects from Adult Social Care, Children’s Services and Health Services. The Interagency Strategy for Young Carers in Surrey identified a number of reasons why so few young carers are identified. These are:

- Lack of awareness by a professional in contact with a child and/or their family
- Poor information systems collating data about young carers
- Young carers and their families’ reluctance to be identified
- Children / young people not seeing themselves as a young carer

Additionally young carers report:

- A lack of awareness by professionals of what services are available.

A report from OFSTED on multi-agency support for Young Carers notes the importance of personal, social, health and economic education (PSHE) in increasing the identification and well-being of young carers. Another report from OFSTED ‘Not yet good enough: personal, social, health and economic education in schools’ May 2013 describes the current state of PSHE in England. Also from Children’s Society Young Carers report ‘Hidden from View’, pages 12-13 Research by the Audit Commission in 2010 found that young adult carers between the ages of 16 and 18 had a much greater chance of being not in education, employment and training (NEET). Of these, 75% had been NEET at least once (compared with 25% of all young people) and 42% had been NEET for six months or more (compared with 10% of all young people). Further reading in the appendices.

**Surrey Healthy Schools**

The Surrey Healthy Schools team (who sit within Babcock 4S – Surrey School Support Service) is the local team that deliver the Healthy Schools programme set up by the Dept of Health and Dept of Children Schools & Families (the ‘blue plaque’ scheme), and they train teachers on PSHE. They have developed a Guide for Schools supporting young carers. This is available in the appendices.

Action for Carers (Surrey) GP Carers Awareness Service has encouraged surgeries to identify young carers, and referrals are now being made by surgeries to Surrey Young Carers. For example Wayside Surgery in Horley did not register siblings of disabled children as young carers since the mother is registered as the main carer. However after a particular family came to the attention of the senior GP Carers Awareness advisor she talked to the Practice Manager there, Rebecca Preston, about the impact on children of having a disabled child in the family and she agreed that she would start to code siblings in such a situation as young carers. She confirmed to Ruth Martin that “we are marking siblings as young carers.... we know to do that now.”
Quote from young carer

“After meeting with my GP it left me wanting to beg for help”

However with the retirement of the Quality and Outcomes Framework (QOF) Management Standard 9 which relates to individual practices maintaining carers register in 2014 it remains unclear if practice managers will continue to collect data on carers registered much less young carers.

**GP Carers Awareness Advice Service – Action for Carers (Surrey)**

Since the inception of the Surrey wide GP Carers Awareness Service in 2011 significant progress has been made in the number of carers now registered with their GP although data concerning young carers registered is not available.

<table>
<thead>
<tr>
<th>Date</th>
<th>Total number of registered carers at Surrey Surgeries</th>
<th>Number of Carers in Surrey</th>
<th>% of Carers based on Surrey Carers population</th>
<th>% of total Surrey population registered as Carers – 2011 census 1,132,390 (2011Census)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>January 2011</td>
<td>6,247</td>
<td>106,700 + 12,000 (Young Carers) Total -118,700</td>
<td>5.3%</td>
<td>0.5</td>
</tr>
<tr>
<td>January 2012</td>
<td>10,537</td>
<td>106,700 + 12,000 (Young Carers) Total -118,700</td>
<td>8.9%</td>
<td>0.9</td>
</tr>
<tr>
<td>January 2013</td>
<td><strong>13,564</strong></td>
<td>108,433 + 14,030 (Young Carers) Total – 122,463</td>
<td>11%</td>
<td>1.2%</td>
</tr>
</tbody>
</table>

*Carers Trust estimate that at any one time a practice list will be made up of 10% carers.

** Represents 127:131 Surgeries

For the purposes of this report we have researched the impact that “caring” can have on the health of children yet it is equally important to recognise the impact on children who do not undertake a caring role. Many parents try hard to shield their children from the responsibilities of a caring role. It’s important not to lose sight of this when we focus on children who have a recognised caring role. Health and Social care professionals need to assess the needs of all children in the family irrespective of whether they have been identified as young carers. These children are just as vulnerable and can develop emotional issues; anger; are worried etc without ever having access to care or support.

Research by Macmillan has found that while over 70% of carers came into contact with GPs, doctors and nursing staff, only 11% of all carers reported that they had been identified as a carer by a health professional.50

**Taking a break**

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50 Hansard Report 20th June – Paul Burstow
Taking a break from caring and having the opportunity to take time out is the top priority for young carers.

Support for young carers is a priority for both the County Council and the NHS in Surrey. The Carers and Disabled Children's Act, now ensures that local authorities can now offer Carers’ Direct Payments to help cover the cost of taking a break. This is available to young carers over the ages of 16 years who provide regular and substantive care and have received a carers’ assessment.

Surrey County Council also provides funding to Surrey Young Carers (SYC) Services to provide breaks for young carers called ‘Early Intervention Payments’. SYC act as trusted assessors. Up to £500 is available in any one financial year per young carer. From March 2012 –Feb 2013 (11 months) 132, young carers direct payments were made. The money was spent on a variety of services or equipment including: e.g. Merlin Pass, Drum lessons, I Pad, Holiday, Horse riding lessons, after school club, swimming lessons and football club.

Additionally Surrey Young Carers host a ‘Facility Peer Network’ which allows young carers to be in touch with other young carers through activities, groups and social media. An example of this would be their 16+ meals project. This takes place bi monthly and provides an opportunity for young carers to come out and have an evening away from home whilst meeting other young carers. It provides an opportunity for information to be exchanged such as at a recent event ‘stress bags’ were distributed with information about coping techniques during exam season. Currently 50 young carers benefit from this popular service.

In 2011 NHS Surrey provided an additional £1.9 million a year new investment in breaks services all of which are open to young carers. This has included:

- Breaks agreed by GP surgeries 2,440 payments at a cost of £1.3Million pa.
- Additional funding for home based breaks services - £300,000 pa.
- Breaks in end of life care - £300,000 pa.

Surrey operates a GP Carers Breaks service, where GPs are able to refer patients who are registered as carers at their practice for a GP Carers Break payment. The Service is administered by Surrey Independent Living Council (SILC). Carers including young carers who meet the eligibility criteria can receive a contribution of up to £500 per household in any one financial year.

During 2012-13 Surrey Independent Living Council (SILC) who host the Surrey GP Carers Break Service reported that 7 Young carers received a referral. This represents 0.5% of the total of referrals made.

During 2012-13 no young carers were referred to End of Life Carers Support.

Surrey County Council provides additional break services to young carers.
Safeguarding

Safeguarding can be challenging when working across both adult and children’s services. Services need to work together to identify and support families to prevent inappropriate caring roles and Young carers should receive an assessment of their needs. This can be achieved by using ‘Whole family’ assessments such as Common Assessment Framework\(^{51}\) (CAF). Where health is concerned emergency/hospital admission and discharge plans for parents need to reflect the needs of any young carers.

**Revised safeguarding statutory guidance – ‘Working Together to Safeguard Children’\(^{52}\).**

Following formal consultation the Department of Education have published the revised statutory guidance *Working Together to Safeguard Children (2013)* which will come into effect from 15 April 2013. The guidance clarifies the core legal requirements on individuals and organisations to keep children safe. The framework has been revised and the previous specific section on young carers has now been removed.

**Surrey Young Carers Services – Action for Carers (Surrey)**

Action for Carers (Surrey) is the only provider commissioned to provide young carers’ services. Surrey Young Carers has been supporting young carers across Surrey since 1996. They can offer free impartial information and support to young carers. Their aim is to promote the needs of young carers in all child care and adult settings. They are funded by Surrey County Council and currently support just under 1000 young carers.

Information about Surrey Young Carers services and what they offer can be found on the following link:


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\(^{52}\) [https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DFE-00030-2013](https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DFE-00030-2013)
Referral rates from GP is 6%
Referral rates from other health professionals is 6%

**2012 -13**
GPs made 14 referrals
Other health professionals made 19 referrals (Total referral flow for year 313)
5. Methodology

NHS Surrey in partnership with Surrey Young Carers launched a consultation to research the impact that caring has on young carers’ health. The consultation was formally launched at the Young Carers Forum on the 24th July 2012 and closed 31st December 2012.

An online survey was co designed with partners including young carers and colleagues working in Public Health. This was available on the following link: http://www.surveymonkey.com/s/NVJJBNG

The survey was designed to be age appropriate. All answers provided were anonymous and confidential. Young carers were reassured that they would not be identified by their responses either by name or personal details.

It was felt important to capture the views of young adult carers therefore the age range was extended to include post 18 years. Note the response rate for this age group was small.

Support was made available from Surrey Young Carers and parental consent was required for those under the age of 16 years.

Consideration to the profile of the young carers who completed the survey is important as this largely reflects those who already have had access to young carers’ services. It is important to bear in mind that caring (which often includes multiple caring) is one responsibility among many—the others being educational, training, work commitments as well as other family responsibilities. Furthermore there is an impact on young carers who do not live with the person(s) they care for or who provide remote caring which can carry different stresses and anxieties. This is particularly relevant where a young carers’ parent’s relationship has broken down or if they have left home to attend higher education opportunities.

Any future survey by health on young carers may benefit from taking the approach used by the Action for Carers (Surrey) Young Carers Service Survey 2012 who found:

- The high proportion of respondents who preferred to receive a survey in the post was an unexpected result, possibly due to young people not receiving much surface mail and so attaching a greater importance to mail received this way
- Simple texting surveys also prove popular for young carers.

In this survey we were unable to offer an incentive to young carers to take part as it was essential, given the nature of some of the questions, to protect their identity and encourage disclosure. A less specific piece of work may capture a larger audience especially if an incentive was provided.
Evidentially the higher level of response in the GU and KT areas was because activity days were held there and the survey was promoted more extensively these areas.

To identify postcode areas click on this link: http://www.royalmail.com/personal/help-and-support/postcode-finder
Boys maybe reluctant to admit they are carers due to stereotyping. Findings are reflective of adult carers health survey 2011 gender break down. Research confirms that girls are more likely to be involved in all aspects of caring particularly in relation to domestic chores and intimate care.53

This report did not research the health needs of young adult carers.

53 http://saulbecker.co.uk/v1/downloads/young_carers/statistical%20profiles%20of%20young%20carers%202003.pdf
This is a good result with 14% of the responses coming from BME young carers. Surrey has an estimated BME population of approx 5%.

The result reflects that the majority of responders were school aged young carers.
Please tell us how you feel caring has affected your health. You may tick as many boxes that apply to you.

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Back Pain</td>
<td>5.8%</td>
<td>3</td>
</tr>
<tr>
<td>Tiredness</td>
<td>61.5%</td>
<td>32</td>
</tr>
<tr>
<td>Stressed</td>
<td>65.4%</td>
<td>34</td>
</tr>
<tr>
<td>Anxious</td>
<td>28.8%</td>
<td>15</td>
</tr>
<tr>
<td>Depression</td>
<td>28.8%</td>
<td>15</td>
</tr>
<tr>
<td>Self Harming</td>
<td>19.2%</td>
<td>10</td>
</tr>
<tr>
<td>Eating Disorders</td>
<td>9.6%</td>
<td>5</td>
</tr>
<tr>
<td>Anger</td>
<td>50.0%</td>
<td>26</td>
</tr>
<tr>
<td>Joint Pain</td>
<td>7.7%</td>
<td>4</td>
</tr>
<tr>
<td>Relationship Problems</td>
<td>17.3%</td>
<td>9</td>
</tr>
<tr>
<td>Lack of Sleep</td>
<td>38.5%</td>
<td>20</td>
</tr>
<tr>
<td>Feel Rundown</td>
<td>34.6%</td>
<td>18</td>
</tr>
<tr>
<td>Other</td>
<td>5.8%</td>
<td>3</td>
</tr>
<tr>
<td>None</td>
<td>9.6%</td>
<td>5</td>
</tr>
</tbody>
</table>

answered question 52

Quote: Russell Minns – Apprentice Young Carers Service
“This is a frightening picture of young carers’ health but particularly their mental health. This doesn’t surprise me as it’s what I expected with my work with young carers”

Further comparisons can be made against the national picture evidenced in the Report of the children and young person’s mental health outcomes forum (Published 15th May 2013). A&E attendances by young people who have self-harmed (estimated): 25,000 (0.1%)”
(British Medical Journal, 2002)"
This evidences the negative impact on the emotional well being and resilience of young carers. It may also evidence low self esteem.

Nationally over 39% of young carers had not informed their teacher or any member of staff that they were a young carer.\textsuperscript{54} 
27% of young carers (aged 11–15) miss school or experience educational difficulties (40% where children care for a relative with drug or alcohol problems)\textsuperscript{55}

\begin{itemize}
\item Characteristics of bullying victims in schools DFE 2010.
\item Dearden, C, Becker, S (2004), 'Young Carers in the UK: the 2004 Report'. Carers UK and The Children’s Society.
\end{itemize}
Source Surrey Young Carers Survey 2012

The aim of the questionnaire was to get the views of the young carers about how the Surrey Young carers (SYC) service is run and what they would like in the future with SYC in terms of service improvements’. Approximately 700/800 surveys were mailed out and received 265 responses.

What issues would you like to know more about?

![Bar graph showing the popularity of issues]

From this question; the most popular answer is opportunities for the future. Although Bullying, Coping Methods and Medical Conditions highlights an information gap for young carers.

Nationally: 68% of young carers are bullied in schools and having a caring responsibility is one of the main characteristics of young people aged between 14 and 16 who have been bullied.\(^5^6\)

Being a young carer can seriously affect a pupil’s attendance, achievement and attainment at school, and many young carers report that they have dropped out of school in the past.\(^5^7\) Often however, schools are unaware that caring responsibilities are the root cause.


\(^5^7\) www.carers.org/professionals.
Public Health Questions relating to possible ‘At Risk’ Behaviours

These results may hide actual behaviours due to responders being concerned that they would be identified.
How many people in the UK have an eating disorder?

There is a lack of data detailing how many people in the UK suffer from an eating disorder. Although the Department of Health provides hospital episode statistics, these only include those affected by eating disorders who are in inpatient NHS treatment. These figures therefore leave out all those who have not come forward, have not been diagnosed, are receiving private treatment, or are being treated as an outpatient or in the community.

The most accurate figures available come from the National Institute of Health and Clinical Excellence. These suggest that 1.6 million people in the UK are affected by an eating disorder, of which around 11% are male. However, more recent research from the NHS information centre showed that up to 6.4% of adults displayed signs of an eating disorder (Adult Psychiatric Morbidity Survey, 2007). This survey also showed that a quarter of those showing signs of an eating disorder were male, a figure much higher than previous studies had suggested.

It is estimated that of those with eating disorders:

- 10% of sufferers are anorexic,
- 40% are bulimic, and
- the rest fall into the Eating Disorders Not Otherwise Specified (EDNOS) category, including those with binge eating disorder.

The hospital episode statistics do give an indication of regional figures, and differences between sexes and age-ranges, but as explained above these statistics only describe a small part of the problem.

At what age do people develop eating disorders?

Although many eating disorders develop during adolescence, it is not at all unusual for people to develop eating disorders earlier or later in life. In fact there are many cases of anorexia nervosa in children as young as 6, and some research reports cases developing in women in their 70’s. What is known is that outside of the stereotypical age bracket, people are less likely to be appropriately diagnosed due to a lack of understanding and awareness.

of eating disorders in these age groups. The link between Eating Disorders and Young Carers needs to be discussed.

Guidance around levels of physical activity for Children is published by NICE in the Public Health framework 17. Measuring physical activity in children is extremely difficult and therefore understanding the results above difficult to interpret within national context. There is no national data set for children’s activity levels although some research is available from the health survey for England in 2008. The ‘taking part’ survey also provides some data but it is not present and therefore not in line with the recommendation of 60 minutes per day. What we do know is that the number of children doing enough physical activity to maintain their own health is likely to be far higher than estimated especially when comparisons are drawn with rising obesity levels.

Government guidance states to maintain good health and stave off obesity and other serious illness in later life, it is recommended that children engage in at least 60 minutes of moderate to vigorous physical activity every day, such as brisk walking, running, and sports. There appears to be a general consensus in all recent research within the UK that the Early Years is one of the critical time periods in the establishment of sedentary and physical activity behaviours.

Further information can be accessed on the following link:
http://www.nhs.uk/Livewell/fitness/Pages/physical-activity-guidelines-for-young-people.aspx

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59 http://www.nice.org.uk/PH17
A young carer wrote

‘Young carers feel responsible all the time and have to be around all the time. We’re too tired to do any sports or other activities. I have to be there at all meal times’

This result clearly evidences that young carers most value taking a break albeit through a variety of different methods. Significantly the ability to access emotional support through peer support, counselling services or simply talking to someone runs a high second. These results reflect similarly to the findings of the adult carers health survey 2011 although unlike the adult survey young carers did not see carers health checks as a priority which may indicate that this is of low concern to them.

What would make a difference?

<table>
<thead>
<tr>
<th>What do you think would improve your health as a Carer?</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>A break from caring</td>
<td>47.8%</td>
<td>22</td>
</tr>
<tr>
<td>talking to someone</td>
<td>41.3%</td>
<td>19</td>
</tr>
<tr>
<td>meeting with other young carers</td>
<td>56.5%</td>
<td>26</td>
</tr>
<tr>
<td>more time for social / sports / activities</td>
<td>47.8%</td>
<td>22</td>
</tr>
<tr>
<td>help getting around (eg bus pass etc)</td>
<td>21.7%</td>
<td>10</td>
</tr>
<tr>
<td>organised group holidays</td>
<td>32.6%</td>
<td>15</td>
</tr>
<tr>
<td>activity days during school holiday time</td>
<td>47.8%</td>
<td>22</td>
</tr>
<tr>
<td>time to talk to your doctor or school nurse</td>
<td>10.9%</td>
<td>5</td>
</tr>
</tbody>
</table>

What do you think would improve your health as a Carer?
support and information on the person you care for condition
counselling

<table>
<thead>
<tr>
<th></th>
<th>%</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>support and information on the person you care for condition</td>
<td>30.4%</td>
<td>14</td>
</tr>
<tr>
<td>counselling</td>
<td>26.1%</td>
<td>12</td>
</tr>
</tbody>
</table>

answered question 46

Have you told your doctor you are a Young Carer?

“This may be due in part to the fact that normally the young carer is in the shadow of the person they care for. The young carer doesn’t recognise themselves as a priority.”
Geoff Parks Deputy Manager Young Carers Service

If you have not told your doctor you are a young carer would you be willing to do so

This is an encouraging result as the findings indicate that young carers would be willing to identify themselves to their GP but this must be matched by a positive outcome.
With nearly 25% reporting that they find it difficult to balance their caring role with accessing their GP services. This may reflect a lack of opportunity for flexible appointment times.

The traditional role of school nurses has changed and many young carers will not have had access to their services unless they have complex family circumstances. The new government imitative to get school nurses to act as young carers champions may improve awareness.
This question was included to recognise the fact that there will be some young carers already in employment. Although response rate from the age group was small this does indicate that young carers do not feel confident about disclosing their caring role to employers.

These findings reflect the referral rates to Surrey Young Carers service by GPs and other health professionals.
The above result is for daily number of hours spent on caring and must be read in context that most of the young carers who responded were of school age.
National data: 50% of young carers care for ten hours or fewer per week; one third for 11–20 hours per week; and 16% for over 20 hours per week. 2% care for more than 50 hours each week.\textsuperscript{60}

\textsuperscript{60} Dearden, C, Becker, S (2004), 'Young Carers in the UK: the 2004 Report'. Carers UK and The Children's Society.
Have you had an injury as a result of your caring tasks e.g. back, neck, shoulder, joints etc?

Did you have to seek medical help because of this injury, e.g. by seeing your doctor or going to hospital?
National data sets on the number of GP appointments for children is not available.

This evidences the emotional ‘wear and tear’ caring can have.
Think about what you do for the person in a day, look at the tasks listed below and tick the boxes that apply to you.

![Bar chart showing various tasks]

The above graph is reflective of the Carers Trust data that reports that 82% is about providing emotional support.

Part B
About the ‘cared for’ person
In 1997 a national survey provided the following data: 60% physical health problem or disability, 29% mental health, 6% learning difficulty, 4% sensory impairment.\textsuperscript{61}

National Data: 22% of young people under 16 in the UK (2.6 million) live with a hazardous drinker.\textsuperscript{62}

In the UK, 335,000 children live with a drug dependent parent.\textsuperscript{63}

\textsuperscript{61} http://saulbecker.co.uk/v1/downloads/young_carers/statistical%20profiles%20of%20young%20carers%202003.pdf


\textsuperscript{63} New estimates of the number of children living with substance misusing parents: results from UK national household surveys, National Addiction Centre and Criminal Justice Research Centre, BMC Public Health 2009, 9:377, 8 October 2009.
The findings are representative of the fact that in the main young carers are caring for a parent or a sibling which reflect national data.

During the development of the survey this issue was raised by young carers whose parents had separated. One young carer lived with her mother but still cared for her father at distance.
This result reflects the ages of the 2 client groups that young carers are most likely to care for.
i.e Parents’ or siblings
7. Young Carers Health and Wellbeing

There is very little known about the health effects of caring on young carers however, they commonly report:

- Feeling worried, anxious or stressed about caring responsibilities and the person they care for.
- Physical injuries (e.g. back strain or muscular injuries) as a result of caring duties.
- Missing healthcare appointments with doctors or dentists.
- Poor diet because of financial constraints on the family food budget, or because they have responsibility for preparing meals but lack basic cooking skills.
- Behaviour problems, particularly self-harm\(^{64}\).

Being a young carer can often have a severe, significant and long-lasting impact on a young person’s health and wellbeing. Tiredness, poor diet, interrupted sleep, back injury, stress and trauma are just some of the physical and mental health impacts young carers experience and these, if left untreated, can continue on into adulthood. Health Services therefore need to consider how they will support young carers with regards to their physical and mental health and wellbeing.

There may be conflict between the needs of the young carer and those of the person being cared for. This may lead to feelings of guilt, anger, isolation (no-one else understands their experiences), or being trapped. Young carers are also more likely to suffer traumatic life events such as death of a parent or sibling.

Young carers may have difficulties playing or socialising with other children, and joining in with sporting and leisure activities as a result of lack of time due to caring responsibilities and/or lack of parental support. For this reason, young carers often have restricted peer networks. They may also find that they are mature beyond their years and have little in common with same-age peers. These factors may contribute to the relatively high levels of bullying that young carers report\(^{65}\). Many continue to have emotional problems into adulthood and may have ongoing difficulties establishing relationships.

For just over one in five young carers (22%), caring has a negative impact on education. Educational difficulties are more common in the 11-15 year old age group\(^{66}\) and include:

- Increased absences and/or lateness.
- Failure to submit homework or coursework, or poor quality work.
- Tiredness, poor concentration and/or lack of attention.
- Under-attainment which may restrict higher education options, and job prospects long-term.

For commissioners of Young Carers Services there needs to be an understanding of the needs of young carers and their families so that they can plan what services are required for young carers and families and know what they look like. In Surrey this is lead by the Multi-Agency Young Carers Strategy Group who agree approaches and actions, funding and measure outcomes based on the strategy and action plan.

The National Carers Strategy is clear: Carers Strategy (Refresh) 2010

Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive and to enjoy positive childhoods.

Practitioners in universal/frontline services to have the skills and understanding to lend effective support

- Young carers in all areas to have access to face to face, targeted support they need
- Joined up, whole family support to be provided, so that young people are better protected from inappropriate caring

Key National Statistics:

- 2001 census: 175,000 young carers in the UK. This has increased by a further 19% for 2011 census.67
- 2010: BBC found 8% of pupils in secondary schools to be young carers = 700,000 young carers in the UK
- Most young carers look after their mother. About 15% look after their father
- Just under a third care for a brother or sister; many who care for parents also take on child care
- Half of all young carers look after someone with a physical illness
- 29% look after someone with mental ill health
- Often, there is more than one condition present e.g. depression and alcohol misuse.
- One in ten young carers care for more than one person.

Commissioners need to understand local needs, resources and priorities in order to agree on desired outcomes. Furthermore an Equality impact assessment (EIA) will help tackle inequalities faced by distinct groups of young carers especially:

- Young carers caring for someone with mental ill health/substance misuse/ HIV/AIDS
- Young carers from BME communities
- Young adult carers (aged 18-25)
- Young carers from Lesbian, Gay, Bisexual or Transgender families
- Rural young carers
- Young carers with disabilities

67 http://www.ons.gov.uk/ons/dcp171778_310514.pdf (page 18)
For the purpose of this report it has not been possible to calculate the cost benefit of investment into young carers services however some specific work on value for money has been carried out, such as on the interventions in the Young Carers Pathfinder Programme (2007), where conservative assessments of the return on investment indicated that for every £1 spent, there was a saving of was £1.89.68 Previous research commissioned by The (former) Princess Royal Trust for Carers and Crossroads Care highlighted that for every £1 invested in a young carers service (specifically, targeting interventions on young carers affected by parental substance misuse and parental mental ill health), the saving to the Exchequer and wider society as a whole is £6.72.69

With regards to health the GPs role is previously described is central but beyond that:

- Health visitors can play a key role in providing families with information and identifying individual children and families in need of help. They are uniquely placed to provide support at an early stage before a caring role impacts on a young carer’s health and wellbeing.

- School nurses are also well placed to play a pivotal role. By ensuring that young carers are identified early and receive timely, age-appropriate information, by spotting and addressing any emerging health needs and by ensuring that young carers are accessing appropriate health services and other support. School nurses can help reduce the negative impact on the health and wellbeing of young carers.

- Hospital staff including those based on the wards, A&E and those who conduct admission/discharge play a vital role in identifying, recognising and supporting young carers.

**Surrey Carers Care Pathway**

The Surrey Carers Care Pathway provides a whole systems approach with a focus on the family for health professionals to identify, recognise and support carers and young carers. Surrey follows a model of ‘whole systems approach’ to health and social care, which brings together practitioners from a wide range of different statutory and voluntary agencies to work together. This coordinated partnership approach helps build on family strengths and brings about sustainable change in identified areas of concern. The focus is on working with the family in a holistic way using a whole family approach.

**Public Health**

Surrey County Councils has now taken over the responsibility for the health and wellbeing of Surrey residents for the first time since the 1970s. Preventative health is emerging as the focal point of the government's health reforms with democratic accountability an essential component. Effective from 1st April 2013, all local authorities have become formally responsible for public health, which includes everything from substance misuse to obesity and immunisation but also young carers.


Surrey County Council, through its health and wellbeing boards (HWBs), works with the 6 Surrey based clinical commissioning groups (CCGs) made up of local GPs who buy in health services for the area. Through a consultation process that started in 2012 the council has now published its first ‘Health and Well Being’ Strategy of which carers form a golden thread throughout all the priority areas.

Surrey has a ring fenced Public Health budget to deliver on the Public Health outcomes framework. The findings of this report will help inform Public Health and focus them on what they need to deliver in relation to young carers specifically the findings relating to eating disorders and other at risk behaviours.

In this report we have evidenced that some young carers are vulnerable to certain ‘at risk’ behaviours. It is the role of Public Health to support these young carers throughout all their work programmes. Public health will need to ensure that those who come into contact with young carers have the skills and knowledge to support the young carer and where appropriate refer them to those services best able to meet their needs.

High stress levels, together with social exclusion and financial problems may leave young carers vulnerable to depression and anxiety. Harmful coping mechanisms such as self-harm in young carers, alcohol misuse or smoking may exacerbate health problems. Of particular interest was the fact that 35% of the young carers surveyed reported they experienced the symptoms’ of an eating disorder (albeit that only 9.6 % felt this was caused by their caring role).

A national dedicated website for young people provides online support and includes a carers’ forum. Further information can be found on the following link: http://www.b-eat.co.uk/

Also worth noting that approx 50% of the respondents took part in less than 1 hour a week of any physical activity which falls well below the government target of 1 hour a day for this age group.

**Healthy Lives and Healthy People 2010** states:

A total of 1 in 10 people are carers, and analysis of the 2001 census data shows that 1 in 5 carers providing over 50 hours of care a week say they are in poor health, compared with 1 in 9 non-carers.

Carers also play a vital role in supporting people to stay at home. The Department of Health carers’ strategy sets out how we will support carers to recognise the value of their contribution, involve them in how care is delivered, support their mental and physical health and enable them to have a work, family and community life. As part of this, the Government is making an additional £400 million available through the NHS over the next four years to support carers’ breaks.

**Prevention through Partnership**

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70 P46 RCGP Commissioning for Carers Guide 2013
Hosted by the Children’s Society this government funded programme works nationally to promote multi-agency joined up working to support families affected by parental mental ill health and/or parental substance misuse to prevent children taking on inappropriate caring roles. Resources and tool kits are available to professionals online at the following address: http://www.youngcarer.com/resources/ptp
They include ‘Whole Family in a Bag,’ Participation Kits, School Tool kits and Train the trainer.

8. Future commissioning intentions

Recommendations:

The majority of young carers in Surrey are not being identified by services and therefore may not be receiving the support they need. In order to remedy this, the barriers that are preventing identification of young carers need to be addressed.

GPs and other health practitioners, who are likely to come into contact with young carers and need to be aware of the issues, are able to identify them and address them in a sensitive manner. These professionals must also be aware of the support available to young carers and refer them on to the appropriate services. GPs are often the first people who families speak to when they are dealing with ill health and disability. GPs have a key role to play in identifying and registering young carers, monitoring their health and signposting them to advice, information and support, including ensuring they know they are entitled to a carer’s assessment. There is a joint working protocol between social care services and health. Good practice around referral of young carers to appropriate agencies needs to be embedded through the implementation of the Surrey Carers Care Pathway. The GP Carers Awareness Advisers roles hosted by Action for Carers in Surrey are working with GPs to raise awareness of young carers and their needs.

Young carers and their families also need to be made aware of their rights and of the support that is available to them. This is already being addressed through Healthy Schools Programme and PHSE provision.

If a greater proportion of young carers are identified and supported, the capacity of support currently offered may need to be extended. The needs of young carers should be considered and supported when commissioning support using the funding released by the government for short breaks.

A new multi Agency Young Carers Strategy for 2011 –14 should address these issues.

The following recommendations are made and should be reflected in the refreshed Action Plan.
Recommendations

The recommendations are based on government; local policy; strategy and best practice guidance

**Commissioning guidance for CCGs on working with local communities was published by Royal College of General Practitioners’ (RCGP) April 2013.**

‘Working with Communities, Developing Communities’ has been produced by the RCGP Centre for Commissioning, set up in 2010 to support GPs with the commissioning and delivery of healthcare and service. The guide puts forward both a financial case and health case as to why investing resources in Community Development is beneficial for local populations, primary care practitioners and CCGs.

This guidance may be useful to help inform CCG commissioning intentions.

Further to the above guidance the RCGP Commissioning for Carers Guide 2013 states:

Inappropriate caring roles or long hours of caring are likely to have a detrimental impact on young carers’ lives and life chances, including their health and educational achievement. Commissioners have a statutory duty to support them to achieve their potential and to have the same opportunities that other young people enjoy.

The primary message from young carers has consistently been the need for more support for the person they care for. Young carers have also stated the value of the direct support they receive from the Surrey young carers’ service. They value the social and support activities provided and the opportunity these offer to get a break and mix with other young carers

The National Young Carers Coalition (NYCC) identified five key priorities submitted by its member networks. The majority of services represented by the NYCC supported the following priorities:

- Early identification and prevention of young carers.
- Adoption of the ADCS/ADASS Memorandum of Understanding.
- Outreach to hidden young carers.
- Awareness-raising.
- Support for young adult carers.

Although not specifically identified as an area of need in this report dedicated support services and extra support should be available for those young carers with the most intensive caring roles and those caring for someone with stigmatised conditions such as mental ill health, substance misuse issues or HIV.

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72 P46 RCGP Commissioning for Carers Guide 2013

73 Association of Directors of Adult Social Services (ADASS) and Association of Directors of Children’s Services (ADCS) (2009), ‘Working Together To Support Young Carers – A Model Local Memorandum of Understanding between Statutory Directors for Children’s Services and Adult Social Services’. ADASS and ADCS.
Further consideration should be given to how to provide support to young carers of people receiving a home dialysis service.

It is important for health professionals to receive training and information on the needs of young carers in order to help them:

- Identify young carers.
- Make appropriate referrals to other agencies.
- Understand potential issues that young carers may face when, for example, family members are discharged from hospital.
- Provide age-appropriate information to young carers about their parent’s or sibling’s condition.

**Priority Areas and Monitoring Plan**

The recommendations made in this report should be referenced in the Inter Agency Surrey Young Carers Strategy 2011-14. The Surrey Multi Agency Young Carers Strategy Group will be responsible for implementing and monitoring the action plan.

**Transfer of NHS Carers Services**

A dialogue between Guildford and Waverley, East Surrey and Surrey Downs CCG based CCGs is progressing and will hopefully lead to a Carers Service Level Agreement with the appointment of a CCG lead for carers in this area.

<table>
<thead>
<tr>
<th>Priority Area</th>
<th>Organisation Lead</th>
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<tbody>
<tr>
<td><strong>Carers Breaks</strong></td>
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<tr>
<td>1. Promote GP Carers Breaks for young carers</td>
<td>CCGs</td>
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<td>2. Surrey Young Carers – Early Intervention Payments</td>
<td>Young Carers Service</td>
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<td>School Nurses</td>
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<td>Health Visitors</td>
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<td><strong>Health and Well Being</strong></td>
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<tr>
<td>2. Promote and raise awareness of young carers and the support they need through all NHS services. Identify, recognise and offer support to young 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 BME and LBGT.</td>
<td>CCGs and all NHS providers</td>
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<tr>
<td>3. Engagement leads need to invest special attention in engaging</td>
<td>All</td>
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<td><strong>young carers and those from a range of ethnic and religious backgrounds where caring may or may not be a more integrated part of everyday family life.</strong></td>
<td>NHS Providers</td>
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<td>4. In line with Government and SCC policy, NHS providers to adopt a ‘family centred approach’ to supporting carers.</td>
<td>SCC</td>
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<td>5. Local authority or school registers of young carers</td>
<td>Boroughs and Districts</td>
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<td>6. Encourage borough and district councils to provide young carer concessions to sport and leisure</td>
<td>All partners</td>
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<tr>
<td>7. Ensure Young Carers issues are identified and supported within the future plans of Health and Wellbeing boards.</td>
<td>Providers</td>
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<td>8. Implement the new policy of School Nurses becoming young carers champions</td>
<td>Acute Hospitals and Education</td>
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<td>9. Encourage take up of Education support in hospital setting for young carers.</td>
<td>All</td>
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<tr>
<td>11. Further research is required into the health needs of young adult carers.</td>
<td>National</td>
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<td>12. Further research and longitudinal studies would allow for a more precise picture on the long term impact that caring can have on young carers health.</td>
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<th><strong>Emotional Support</strong></th>
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<tr>
<td>1. Map existing counselling services available in Surrey. Review the provision of counselling services within Surrey and access to CYC IAPT programme, bereavement services, Relate Teen counselling, First Steps service for young carers.</td>
<td>CCGs</td>
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<tr>
<td>2. Promote peer mentoring for young carers</td>
<td>Young carers service Partners</td>
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<td>3. Raise awareness of existing counselling services and update carers websites including professionals pages with details</td>
<td>Church and other faith groups.</td>
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<tr>
<td>4. Work alongside Guildford Dioceses community and engagement service to promote support through their services, including their multi faith group.</td>
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<tr>
<th><strong>Training</strong></th>
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<tbody>
<tr>
<td>1. All frontline staff in NHS services, health are trained to be aware of the signs that someone is a young carer and what support they can provide in their role.</td>
<td>All</td>
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<tr>
<td>2. Promote the Royal College of General Practitioners guidance on carer friendly services within general practice and primary care settings.</td>
<td>CCGs and Action for Carers (Surrey)</td>
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<tr>
<td>3. All Clinical commissioning groups (CCG’s) to raise the level of young carer awareness and their health needs by circulating this report.</td>
<td>CCGs</td>
</tr>
<tr>
<td>4. Work in partnership with other NHS community providers to improve young carer awareness i.e. Health Visitors, dentistry, pharmacy etc.</td>
<td>NHS providers</td>
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<td>5. If patients are reliant upon a young carer this needs to be recorded on their medical notes.</td>
<td>CCGs and other networks</td>
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<td>6. Work with disease specific and condition related organisations to improve on the age appropriate provision of information</td>
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<td>7.</td>
<td>Promote e learning on young carers’ awareness to all health staff including school nurses and health visitors. Run a promotion during annual Carers Week</td>
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<td>8.</td>
<td>Report back to CCGs and NHS providers on annual take up of ‘Because Carers Count’ Training</td>
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<td>9.</td>
<td>Increasing teachers’ awareness / understanding of the additional stressors that young carers invariably experience using e learning</td>
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<td>10.</td>
<td>Promoting young carer content in PSHE programmes in key stage 2 and 3</td>
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<td>11.</td>
<td>Improving liaison between school pastoral staff / CPLOs and the Adult Social Care and (Adult) Community Mental Health teams</td>
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### Carers ‘Care’ Pathway – Identifying, Recognising and Supporting Young Carers

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<tr>
<td>1.</td>
<td>Young Carers’ Assessments: Using the Surrey Carers Care Pathway Health professionals can help by identifying young carers, making referrals to social services (both Adult and Children’s) and/ or by providing young carers with information and sign posting.</td>
<td>SCC and NHS GP Carers Awareness service</td>
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<tr>
<td>2.</td>
<td>Continue to promote GP Young carers awareness and GP Y/C registration. Promote Y/C friendly practice such as flexible appointments.</td>
<td>All CCGs</td>
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<td>3.</td>
<td>Ensure young carers’ needs are reflected in all future development around patient care pathways. All pathways need to reflect the government’s commitment to a family centred approach and therefore include children who may have young carer responsibilities.</td>
<td>NHS providers</td>
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<td>4.</td>
<td>Work in partnership with NHS providers to improve young carers’ experience of Hospital Discharge. Ensure young carers are identified as part of any admission and support offered.</td>
<td>NHS providers</td>
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<tr>
<td>5.</td>
<td>Promote and display the Young Carers Hospital poster</td>
<td>Surrey Downs CCG</td>
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<td>6.</td>
<td>Display Young Carers information within primary and hospital settings</td>
<td>CCG and NHS providers</td>
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<tr>
<td>7.</td>
<td>Ensure NHS funded health care assessments adopt and implement the Surrey Carers Care Pathway.</td>
<td>All</td>
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<td>8.</td>
<td>Where Intermediate Care applies, a more joined up approach to service delivery is required. Review referral protocols where NHS 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.</td>
<td>All</td>
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<td>9.</td>
<td>Ensure that other Surrey wide strategies including Dementia and Mental Health reflect young carers’ needs.</td>
<td>All</td>
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<td>10.</td>
<td>Ensure EOL care pathways include identification and support for young carers.</td>
<td>Public Health</td>
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<td>11.</td>
<td>Raise awareness of Young Carers Services and referral on through Drug and Alcohol team</td>
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</tbody>
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9. Appendices and further information

NHS Direct Young Carers - [http://www.nhs.uk/CarersDirect/young/Pages/Youngcarershome.aspx](http://www.nhs.uk/CarersDirect/young/Pages/Youngcarershome.aspx)

Childrens’ Society - [http://www.childrenssociety.org.uk/about-us](http://www.childrenssociety.org.uk/about-us)

Carers Trust Professionals pages - [http://professionals.carers.org/young-carers/](http://professionals.carers.org/young-carers/)


Professor Saul Becker Nottingham University List of Publications and Further reading – [http://www.saulbecker.co.uk/all_publications.pdf](http://www.saulbecker.co.uk/all_publications.pdf)

TaMHS May 2013 Update

The Children’s Society Survey 2011

Ofsted Report

Young Carers and NEET report

Healthy Schools Young Carers Guide

British Heart Foundation National Centre – Fact Sheet on Physical activity levels of children between the ages of 2 -15 years

North East Hampshire - Improving outcomes for patients with mental illness Co-design workshop May 2013

Norman Lamb Letter to Carers Trust re Young Carers and the Care Bill

Macmillian Cancer Trust – Facts and Figures

Definition of Short Break:

There is not a national definition for what a short break actually is. In Surrey the ‘Carers Review’ task group agreed the following wording; this would apply also to young carers:

*A short break is to enable carers to have time to themselves outside of their caring arrangements, and refers to any period of time which enables a carer to meet their own expressed needs. The nature of the break will depend upon the outcomes the carer wants to achieve, the circumstances of*
the caring role, and the needs of the person they are caring for: the break should be a positive experience for both. Short breaks come in many forms, from ‘open to all’ inclusive activity provided by the voluntary sector and in day centres, to specialist provision providing residential care. A short break could therefore be for a few hours or for longer, and could mean a short stay in residential or other accommodation, services from a care worker at the cared-for person’s home, or support with leisure or other activities.