



The impact of caring on the health & wellbeing of Surrey parent carers: research report

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Introduction

Family Voice Surrey won funding from the Department for Education to carry out research into the current health and wellbeing of parent carers in Surrey. The research aims to develop a better understanding of the impact caring has on parent carers' health and wellbeing, and highlight any areas of concern and/or gaps in service provision.

This report outlines the findings and provides recommendations for the Joint Surrey Carers Commissioning Group and others.

At the heart of this report is a group of parents and grandparents, all of whom are unpaid carers for their special needs child or children. While some may fare better than others, the report shows that very few are thriving. The impact of caring on their lives - and the need for greater support from services - is summed up in this quote from one respondent:

“I no longer enjoy my life. I used to look forward to the future, plan things, hope and expect things to be better, have hobbies, friends etc. Now I know what my future is - full time carer with no life of my own - and I'm not getting any younger or richer. Life can only get harder, plus I must face the fact that I can't live my daughter's lifetime so what will become of her, this beautiful, so vulnerable girl I love with all my heart, when I'm gone? I [experience] an all-encompassing feeling of hopelessness, and sadness, which goes beyond depression. There is no colour in my life anymore, no hope, just an inevitability of an increasing struggle to cope.”

Background

Family Voice Surrey is Surrey's official parent carer forum for families with children with additional needs and/or disabilities. We promote and facilitate parent participation in decision-making at local authority level, aiming to work with families and commissioners to develop and deliver services co-produced with them.

A Family Voice Surrey satisfaction survey in 2015, followed by a survey related to the recommissioning of Surrey's Short Breaks service in 2016, both indicated that caring was having a significant impact on the health and wellbeing of parent carers and their families. It was felt that this area would benefit from further research - not least because Family Voice Surrey is keen to address potential barriers to parent participation.

This research aims to build on the research published in February 2012 by NHS Surrey in partnership with Action for Carers and Surrey County Council looking at adult carers health & wellbeing in Surrey¹.

Definitions

A **'parent carer'**: parents or carers of children and young people with a special educational need and/or disability. Some carers do not call themselves carers but see themselves as mother or father, grandparent, aunt or uncle etc.

'Health': The World Health Organisation defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"².

Mental health is defined as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.

'Wellbeing': defined in the Care Act³, its definition is very broad and includes social and economic wellbeing, personal dignity, control over your day to day life, participation in education, work or social activities, relationships with other people, having suitable accommodation and protection from abuse and neglect.

Methodology

¹ Surrey Adult Carers Health Survey 2011: <http://carersworldradio.ihoststudio.com/useful/healthsurvey.pdf>

² <http://www.who.int/suggestions/faq/en/>

³ Care Act statutory guidance, Chapter 1: <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#chapter-1>

Initially desktop research was carried out, which included a review of information available through:

- NHS Surrey's Adult Carers Health Survey 2011
- Joint Strategic Needs Assessment January 2017⁴
- Joint Strategic Needs Assessment: Wellbeing and Adult Mental Health, December 2016⁵
- FVS satisfaction survey 2015 and Short Breaks recommissioning survey 2016

This was followed by an online survey, which ran for three weeks from 27 February - 20 March. The survey was sent to Family Voice Surrey's 1350 members, posted on social media, and circulated via partners (including Carers Support organisations, the Surrey branch of the NAS and other Surrey-based providers). Paper-copy surveys were also made available at FVS events run during the period.

In total, 236 surveys were completed.

In addition, we carried out six telephone interviews with some of the respondents, and held a focus group with 12 respondents. Parent carers have shaped the recommendations we make at the end of this report.

Summary

Key survey findings:

- 68% were caring for 50+ hours a week.
- <1% of carers said caring had had no impact on their physical or mental health.
- 68% had registered as a carer with their GP (2011 survey: 55% were registered).
- 33% had had a carer's assessment (2011 survey: approx. 50%). Of those, 48% were asked about their own health needs during the assessment.
- 40% were also caring for someone else: most commonly either one or more elderly parents, and/or a spouse. This is in addition to any other children in the family.
- 16% said they never had time for leisure activities
- 66% said they reduced their working hours or gave up work when they became a carer
- 74% said caring had had a negative impact on their relationship with their spouse, and 61% said it had a negative impact on their relationship with their other children

Health & wellbeing of parent carers: research findings

⁴ <http://www.surreyi.gov.uk/ViewPage1.aspx?C=resource&ResourceID=1758>

⁵ <http://www.surreyi.gov.uk/ViewPage1.aspx?C=Resource&ResourceID=1740>

1. Demographics

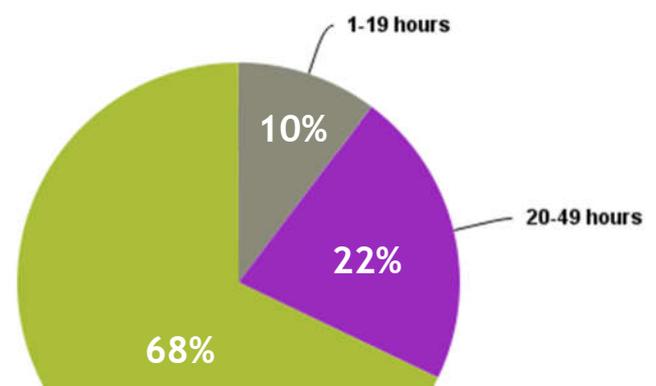
Gender:	
Women	93.5%
Men	6.5%

Age:	
18-34	6%
35-64	90%
65-79	4%

Marital status:	
Single	6%
Married/Civil partnership/In a relationship	83.5%
Separated/divorced	10%
Widowed/Surviving partner	0.5%

Ethnicity	Our Survey	2011 Census Surrey
White British	86.5%	83.5%
White other/White Irish	8%	6.8%
Asian/Indian/Pakistani/other	3%	9.7%

Number of hours spent caring/week:



We asked carers to estimate how many hours they spent caring each week, using the same parameters used in the 2011 carers health survey. 68% said they were caring for over 50+ hours/week (compared to 60% in the 2011 survey).

We asked people to estimate how much of this time was spent on admin (phone calls, paperwork, meetings).

Estimates varied considerably - anywhere between 1-20 hours/week most commonly cited, with 2-3 hours and 5 hours most commonly cited.

“I spend around 40% of my time on paperwork, on top of looking after my life-limited daughter & my husband who died 4 weeks ago. No one realises that some of us carers support more than one person.”

Who are they caring for?

40% of carers said they were also caring for someone else. Most commonly this was either one or more elderly parents, and/or a spouse. This is in addition to any other children in the family.

The type of illness or disability of their child included:

- ADHD
- ASD
- Cerebral palsy
- Down’s syndrome
- Dyslexia
- Dyspraxia
- Epilepsy
- Fragile X syndrome
- Genetic disorders
- Heart conditions
- Learning disabilities
- Life-limiting conditions
- Mental health conditions including anorexia
- Spina bifida
- Visual and hearing impairments

How long had people been caring?

Number of years caring	% respondents with no Carers Assessment
0-5 years	26%
6-10 years	35%
11-20 years	35%
21+ years	4%

2. Impact on physical and mental health

Respondents rated their health as follows:

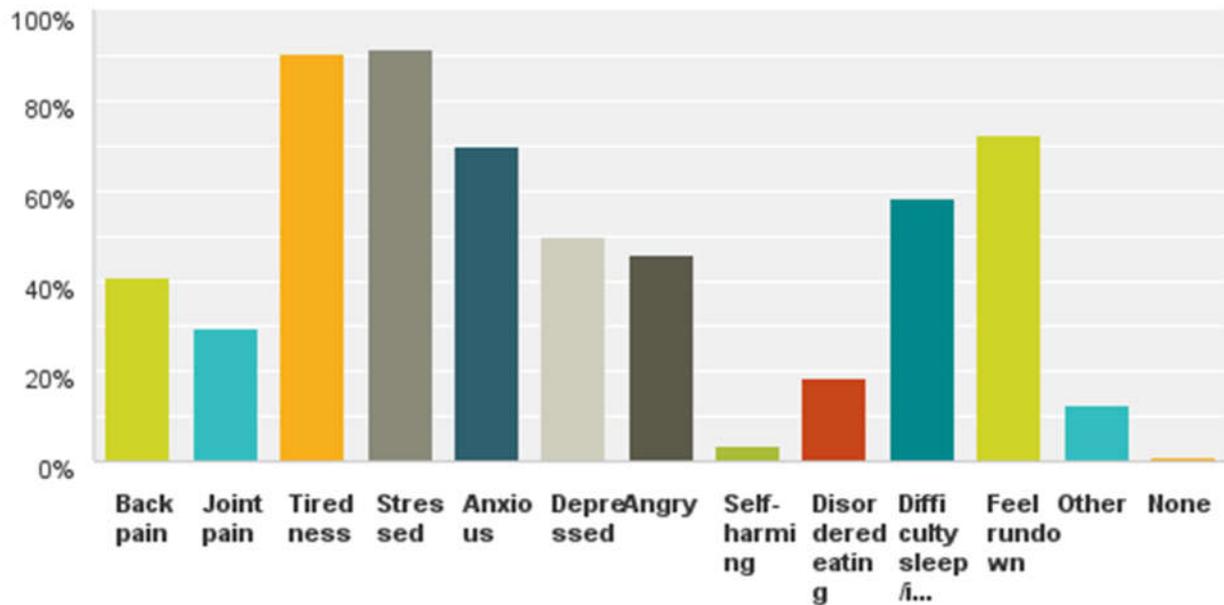
	Physical health	Mental health
Very good	5%	4%
Good	31.3%	25%
Fair	48%	46%
Bad	14.3%	21%
Very bad	1.3%	4%

1 in 5 said they had a pre-existing health condition before they began caring, with over half of these saying their caring role had made managing their own condition more difficult. Comments included:

“I have had occasions where I should have been admitted to hospital but, because of my role as a carer I felt it impossible to do.”

“I have had problems with my back in the past - now, because of my caring role, I daren't seek help for my back during periods when it is bad just in case it is made worse and I am completely incapacitated.”

Respondents reported the following impact caring had had on their health:



More than 90% of respondents cited experiencing **tiredness and stress**. Added to this, some people described developing stress-related conditions including IBS, fibromyalgia, thyroid disorders and high blood pressure.

Around 70% also reported feeling **run down and anxious**, and 58% suffered with **sleep issues**

50% described being **depressed** and 45% being **angry**. Respondents described feelings of sadness, jealousy, demotivation and being overwhelmed. Others described how this had impacted on their lifestyle choices (such as eating or drinking) - in fact 18.5% of respondents identified **disordered eating** as a further impact.

An alarming 3.5% **described self-harming**, with a small number describing suicide attempts. All were female. Single/divorced/widowed parent carers were more likely to report self-harming.

Physically, 41% experienced **back pain**, and 30% **joint pain**.

Only two respondents said their caring role had had no impact on their health.

Injuries

Over one third (38%) of respondents said they had been injured while caring. Most commonly this was either back/joint injuries as a result of lifting or falls, or injuries caused by hitting, biting etc. from an anxious child. Some respondents also described emotional injury.

Case study: Gill*'s story

Gill cares for her 4 year old son who has a speech and language disability, hypertonia and global developmental delay, requiring support with all emotional and physical care needs. He started school in Sept 2016 but left after 4 days as it was the wrong placement and he was so scared. This resulted in a post-traumatic stress disorder diagnosis.

Gill and her husband looked for an alternative school placement - they ended up taking Surrey to tribunal to secure it. Surrey conceded shortly before the tribunal date. Gill and her husband privately funded a carer for 3 hours a day whilst Gill worked on the tribunal. Gill also reduced her hours of work from 3 days to 1 day a week. Gill says this has financially crippled the family and they had to re-mortgage their house.

“Caring has changed my life completely. I’ve had to reduce my work which I would have preferred not to. I’m awake at night with my son and am therefore tired from lack of sleep and the attention my son requires when he is at home. My son is getting bigger and heavier and he requires lots of lifting. I have a damaged wrist and a bad back; the moving and handling team couldn’t help.”

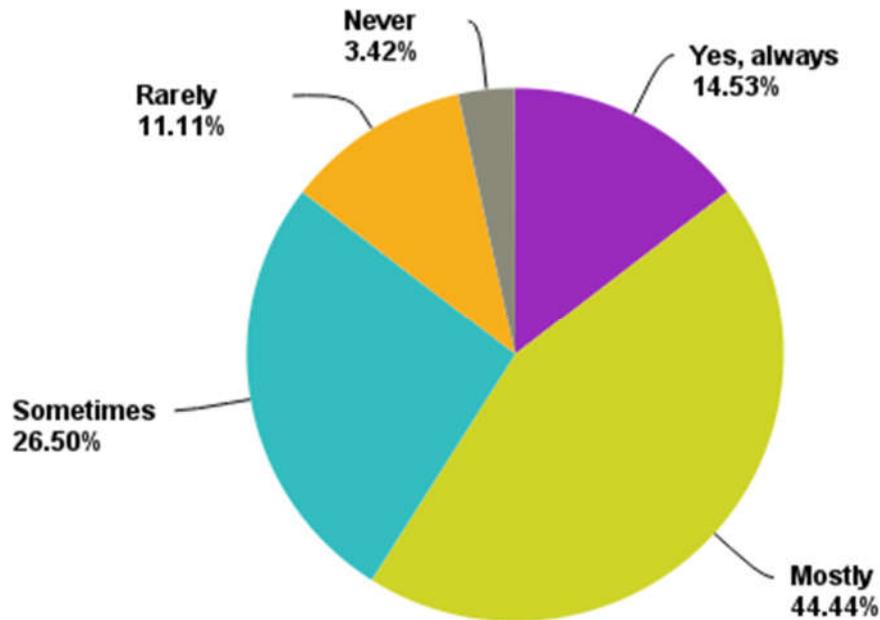
The situation has had a massive effect on her marriage, and Gill’s husband is very stressed about the £20,000 costs incurred for the tribunal.

“This all had a domino effect but I felt like I couldn’t breathe with the constant never getting a break, it was too much. My caring role was unbearable with long hours caring, another small baby to look after and a job. I called the Children with Disabilities team for an assessment and we were turned down twice. I became more and more ill and this resulted in my suicide attempt. At this point, we got a social worker and Social Services funded the 10 hours of social care. But things only changed for me once we knew my son had got a school placement.”

**Name has been changed*

Looking after yourself and lifestyle choices

Parent carers reported finding it harder to keep health appointments and make positive lifestyle choices, due to their caring role. Almost 15% of respondents said they rarely or never kept routine appointments, such as dentist or opticians:



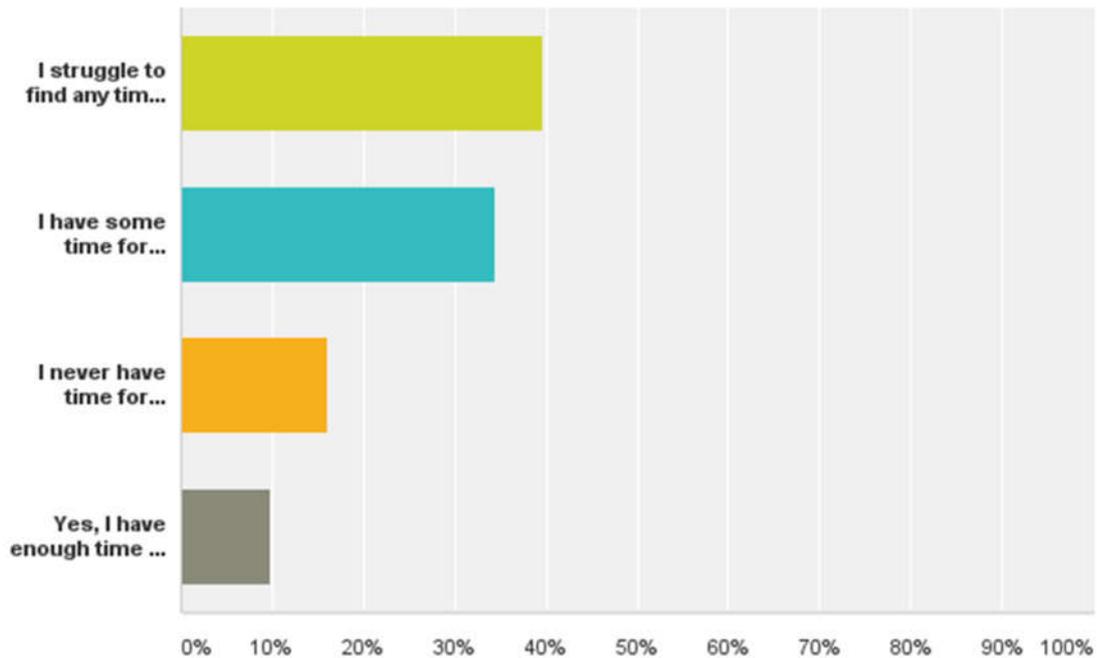
Respondents were also asked to rate the impact caring had on their lifestyle choices:

	No impact	Positive impact	Negative impact
Physical exercise	15%	12%	73%
Eating habits	32%	6%	62%
Sleep	9.5%	>1%	89.5%
Smoking	86.5%	3%	10.5%
Alcohol	72%	4.5%	23.5%
Caffeine	67%	2%	31%
Drugs (prescription/over the counter/other)	64%	5%	31%

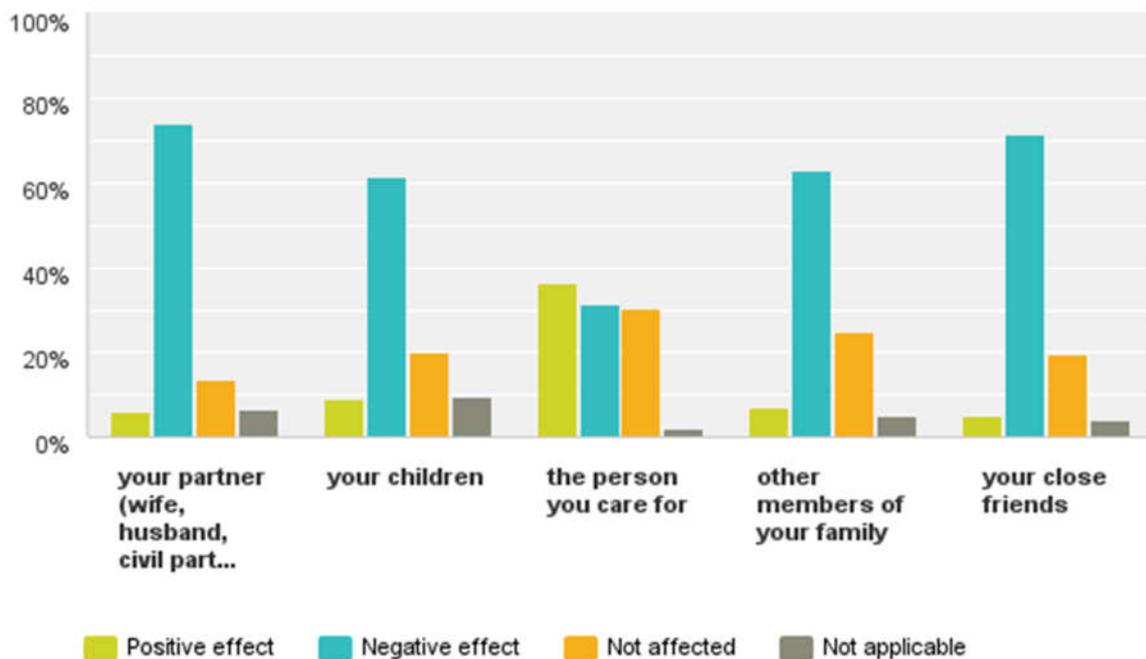
3. Impact on social and emotional wellbeing

Without a doubt, parent carers struggle to find time for activities that benefit them. When we asked about time - for yourself, for friends and family, and for leisure activities - **less than 10%** said they had enough time.

16% said they never had time for leisure activities, and **40%** said they struggle to find any time.



Parent carers told us overwhelming that caring had a negative impact on their relationships with the people closest to them:



Case study: Janet**'s story

Janet has an 8-year-old son who has a rare syndrome. He has physical needs, is globally delayed and a cognitive age of a two-year-old. He started walking when he was four and a half and is very large due to his syndrome causing issues with growth.

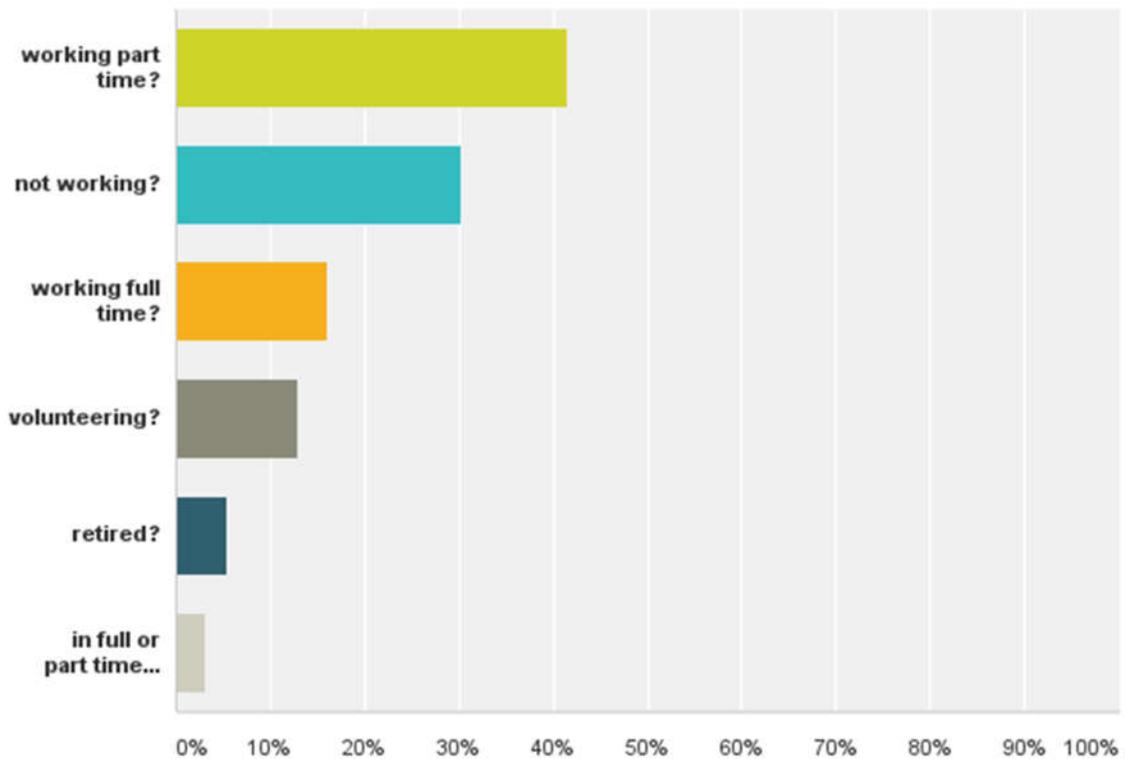
Janet and her husband are unable to share a bed together. They used to have a baby video monitor for their son at night as he sleeps downstairs. He would wake up around 2am but by the time one of the parents got to him, he was in a state and then unable to get to sleep. Janet's husband now sleeps on a sofa in the dining room which is outside their son's room, so as to settle him quickly. Their 6-year-old daughter sleeps in bed with Janet as she has nightmares due to being hit by her brother.

Janet says the sleeping arrangement having a big impact on the relationship between her and her husband, with no time together, even to have a conversation. Janet and her husband have four other children from previous relationships.

**Name has been changed*

4. Impact on economic wellbeing

Respondents were asked about their current employment status.



66% of respondents said they had reduced their working hours or stopped working altogether when they became a carer. Of these:

41% reduced hours when they became a carer

59% gave up work altogether

57% of male respondents worked full time

“I work part time but with so many appointments I still struggle to keep up as I can’t always change them to the days when I am off.”

“I used to work as a journalist on The Times, Financial Times and for international media, and authored two books. But in the end I couldn’t keep going alongside caring for my daughter and fighting the legal battles for her health and education, so I had to stop working.”

“I run my own business on my own. The business is struggling because I have to keep closing to attend meetings, go to appointments. It is becoming a vicious circle and means I am behind with overheads which results in more stress and health issues.”

“I have to give my job up in four months to look after my son when he leaves school as I can’t leave him on his own.”

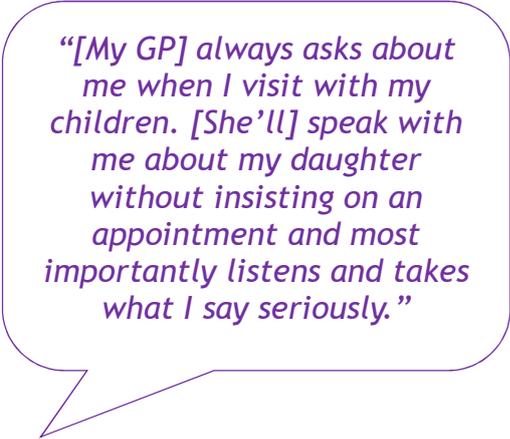
5. Support from GPs

It was clear from the survey comments, and from the in-depth interviews we carried out afterwards, that GP support could make the difference between coping and struggling.

Just over two thirds (68%) had registered as a carer with their GP. For dads this reduced to 28.5%. However, as an overall figure, this is an improvement on the 2011 findings, where 55% of carers reported having registered with their GPs.

Experiences of GPs were variable. GPs supported parent carers by:

- Offering flexible appointments (eg: home visits, a separate waiting area, longer appointments)
- Text messaging service
- Taking time to listen
- Offering counselling and other health checks
- Offering GP carers breaks grants
- Offering support in other areas, eg: obtaining a blue badge



“[My GP] always asks about me when I visit with my children. [She’ll] speak with me about my daughter without insisting on an appointment and most importantly listens and takes what I say seriously.”

When this wasn’t available, it made accessing GP appointments - either for themselves, or for their family - much harder. For example:

“They let us wait in a separate room at the GP if I ask. This separate waiting area is the GP surgery’s kitchen where the photo copier is and we were definitely ‘in the way’ of the operations of the surgery and got a lot of comment.”

“Very difficult to see my doctor to fit in with caring responsibilities. Even though I am registered as a carer there is no flexibility given by my surgery when I phone to book an appointment at a time when I can see the doctor without the person I care for.”

6. Carers assessments

“Social services didn't offer anything to me. I was always told the service was for the child only - they are CHILD social services, as they kept reminding me. It was just that I had to have almost broken down before they gave her any services. Your question has confused me a bit, I must say. I don't think in Surrey that Children's Social Services remit covers carers' health and wellbeing.”

Only **one third (33%)** of respondents had had a carer's assessment (for fathers, this was even lower, at 15%). Of those, less than half (48%) were asked about their own health needs during the assessment. This was a disappointing - and worrying - result when compared to the 2011 survey, where 50% of carers had had a carers assessment.

There was no obvious reason for this result. The respondents who answered 'no' had the same profile in terms of hours of caring, impact on relationships, and time for activities as those who answered yes. Fewer had registered with their GP as a carer.

When carers had had an assessment, quite often there was little or no follow up, or nothing was put in place. One respondent commented: *“The assessment was so long ago! Nothing came of it... just another waste of my time.”*

Case study: Judy*'s story

Judy has a 16-year-old son who has Downs Syndrome. He goes to a special school and requires help with most things. He is unable to go out without 1:1 support.

The Children with Disabilities team was involved in 2016 but they informed Judy that they could not do anything for her son as there were no services for him. The social worker did not meet her son, she only saw him as he poked his head through the door. The family was not offered direct payments and therefore no personal assistant to support her son.

Her son has no social worker, the family has no respite and Judy has had no carers assessment. She has also been unable to get social care input for the EHCP process. She spent an hour on the phone being transferred from one department to another.

**Name has been changed*

7. Services that would make a difference to parent carers' health and wellbeing

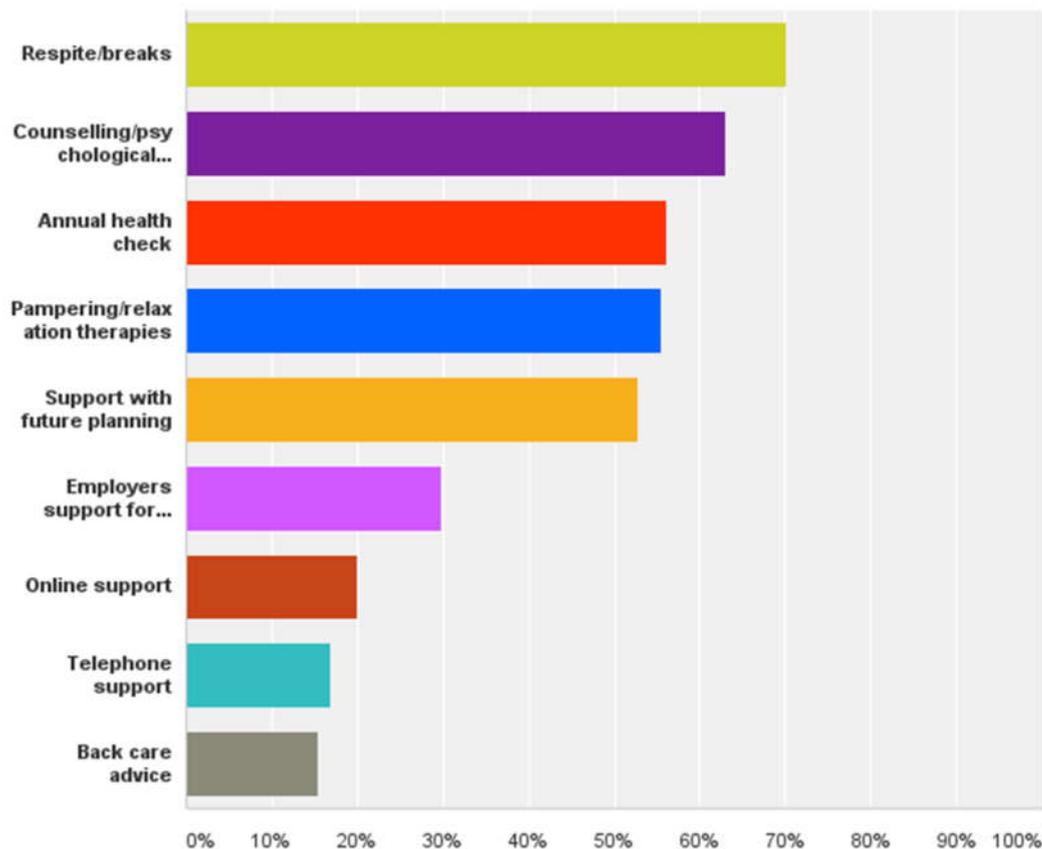
A significant number of respondents benefited from the support of their local Carers Support group. This support came across very strongly as being central to carers accessing the information they need.

Other areas of support included:

- GP carers breaks grants
- Counselling
- Support groups, including online support groups
- Statutory services such as Short Breaks and CAMHS

Many respondents had not used any support services, not knowing what was available to them or where to find that information.

In the 2011 Surrey NHS survey, Surrey carers identified a number of support services that they felt would help support and improve their health and wellbeing. Using this list, we asked respondents to tick 3 - 5 of the services that they thought would help the most.



They were also given the opportunity to make additional comments or to suggest other forms of support.

Respondents also suggested (in order of priority):

- Support worker who'd provide information, advice and help with filling in forms
- More meeting places/groups for parent carers to go with their children
- Free courses/e-learning/exercise classes
- Mentoring/buddying/sitter/befriending service (for children and for the family)

- Free legal advice
- Respite (running alongside activities aimed at carers)
- Recognition by professionals of what's involved in caring for a child with additional needs. Minimise unnecessary meetings, appointments, and give information that is accurate.
- Advocacy

Part of the grant funding Family Voice Surrey received for this project was for improved signposting for parent carers. Links to parent-recommended organisations are now up on the Family Voice Surrey website (click [here](#)) and a guide has also been published in leaflet form for parent carers, listing the key organisations parent carers might refer to, and sent to all GP surgeries in Surrey.

8. Recommendations

In conjunction with a group of parents who responded to the original survey, Family Voice Surrey has used these findings to inform five recommendations for change that we would like to make to local health and social care services:

1. A consistent approach to carers by GP and other healthcare services

Parent carers told us that their GP could make the difference between being able to cope or struggling. Effective GP support included flexible, longer appointments, an understanding of what a carer might be dealing with, and a degree of knowledge about where they might go for further help.

Next Steps?

- We would like to see more GPs and other healthcare providers (eg dentists, mental health services) offering flexible appointments, such as:
 - Telephone/email consultations
 - Home visits
 - Longer appointments, where possible.
 - Understanding if appointments have to be cancelled at short noticeDo GPs and other healthcare providers have any guidelines set around how to support carers? If not, could these be developed?
- A carer and/or SEND champion in GP practices, who would promote understanding and encourage the practice as a whole to respond to issues - not just prescribe pills - and increase awareness of sources of support.
- Improved service for parent carers who might face additional difficulties attending appointments with children. If possible, provide separate waiting areas in surgeries, or a text/call service to contact parents once the doctor/dentist is free to allow parents to wait with their children somewhere else outside of the surgery. Could certain appointments (eg: smear tests, counselling) be offered with additional respite if childcare is an issue?
- More GP surgeries offering online/email prescription renewal service
- A same-day emergency appointment system that doesn't require calling up during the school run!

2. A consistent approach to child and carer assessments

Respondents described how they found it difficult to access help such as Short Breaks, and were often told they would not be eligible for additional support. This then had an impact on their health and wellbeing.

In addition, some respondents were refused Carers Assessments when requested; if they were carried out, there was a lack of follow up. Again, this had a knock-on effect on carers' ability to cope, with examples of people reaching crisis point before any provision was put in place. We received a strong message that families feel sure that early intervention would cost less in the long run.

Next Steps?

We would like to see:

- A review of the eligibility criteria for support via the Children with Disabilities team and of assessment procedure for access to specialist Short Breaks
- Clearer information about the range of support and intervention available from Social Care

- Carers Assessments consistently carried out, when requested.
- A more proactive approach to offering carers assessments, driven by greater awareness of the needs of parent carers.
- Improved access to respite/short breaks, including activities for young people that run alongside activities for parent carers.

3. Counselling

The survey highlighted that carers feel under a lot of strain, and that this in turn puts a strain on relationships. Carers said they needed someone to help their families work together as a team.

Next Steps?

While counselling is offered through surgeries, we would like a wider range of counselling and therapies to be offered to SEND families - including young carers - which would ideally include:

- Relationship counselling/family therapy
- Group counselling/peer support with other parent carers - especially at the point of diagnosis. Could this be facilitated through GP surgeries and Community CAMHS clinics?
- Longer term talking therapies: for some, the standard 6-12 sessions was not enough.

4. Improved financial and practical support, especially for single parent carers

Caring puts a financial strain on families, but trying to find information around financial support can be difficult. In addition, the admin involved in caring for a child with SEND can be onerous, and just adds extra pressure. As finances were often constrained, paying for respite/going out/looking after your health became more costly and less of a priority.

Next Steps?

- Improved signposting to services which offer financial and practical support by GPs and paediatricians in particular (as these are the people parent carers first come into contact with)
- More free stuff! Carers asked for lower cost/free gym membership or swimming sessions, and free courses to help with retraining/returning to work.

5. Increased awareness of GP Carers Breaks

We understand GP Carers Breaks are offered based on clinical need, which makes evaluating how these are applied via this survey tricky. However, there did appear to be some inconsistency around awareness of GP Carers Breaks, with many respondents commenting that they had had to tell their GP about these. There also appeared to be some inconsistency with who was deemed eligible - for example, very few of the carers who said they had self-harmed mentioned receiving this.

Next Steps?

- Raise awareness of these with GPs
- Review how these are being applied.

Thanks and contact

We would like to thank all the parents and carers who took part in this research.

Thank you, too, to Debbie Hustings, NHS Partnership Manager for Carers, who supported this project, and the Department for Education, which funded it.

If you would like to discuss this report, please email contact@familyvoicesurrey.org

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