
Parent Carer Health

The impact of the caring role



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Introduction

Background:

In the Summer of 2017, one of our Directors (a parent carer) suffered from ill health but never mentioned this on social media. However, in September, she decided to let people know, as a way of explaining why she was limiting the work she was taking on.

She was amazed how many other parent carers came back and said Me too.

The majority of these parents had not shared this publicly so we started to wonder how many other parent carers were out there, suffering in silence, without support.

The Questionnaire:

We launched a quick questionnaire asking parent carers about the impact their role had on their health.

We asked parents a number of questions, all based on their health and the support they had asked for, received or, as we found, they didn't even know existed.

Response:

1,087 people responded to the questionnaire.

- 1,081 were parent carers
- The remaining 6 were either siblings or grandparent carers.

Future Work

We also asked parents if they wish to be updated on future work or involved in any future projects.

Q1 -Ill health related to role?

Have you (and/or your partner) experienced ill health in the last five years - which you believe to be related to being a parent carer?

Responses:

1086 people responded

- **962 (88.5%) said yes**
- 65 (6%) said no
- 59 (5.4%) said other

Those who commented described the following (with Anxiety, Depression and Tired used the most frequently).

Anxiety

Back Ache

Depression

Emotional Exhaustion

Mood Swings

Stress

Tired all the time

- *Anxiety and depression caused by fighting the system constantly as well as having to care for 3 children*

Emotional exhaustion from the pressure to be doing all the right things for my child and worrying I am not a good parent.

-- *Always tired, at times unable to attend own appointments (docs/dentist) due to caring commitments so sooner or later health will always be affected*

Those who commented 'other' were either not sure if related but thought it possibly was. This means that 93.9% either were certain or thought their ill health in the past five years was related to their parent carer role.

Q2 - Ill Health due to Stress?

Do you believe your ill health is stress-related, or made worse by being stressed?

We could see that many people believe their role as parent carer was in part responsible for their ill health, so we wanted to see how much of this they believed was due to the stress of being a parent carer?

Responses:

1079 responded

- *Yes - the two are inextricably linked*

● **1008 (93.4%) said yes**

● 42 (3.9%) said no

● 29 (2.7%) said other

An interesting question may have been What causes you more stress - your child's health or the fight to access suitable services? Whilst our child's health is obviously the most IMPORTANT I think a lot of parent carers would say the fight for suitable services would be the most stressful of the two.

My child's worries are ongoing & never-ending apparently & not having any guidance as to how to help or cope doesn't help.

it isn't the care itself but the system that made me stressed

Q3 - Impact on Recovery

Do you think being a parent carer may not be directly responsible for your ill health but is having an impact on your ability to recover?

Responses

Prevention is better than cure...unless you're a carer then there's no time for prevention!

1064 responded

- **748 (70.3%) said yes**
- 233 (12.9%) said no
- 83 (7.8%) said other

Not being able to get to appointments in a timely manner due to caring responsibilities means that illnesses are not treated in time or go untreated altogether. Not being able to rest and recover but having to carry on through the illness.

I believe it is absolutely the reason, I was a different person in every way prior to becoming a parent carer. I hate my life there is no joy in it only struggles

Even my GP looks embarrassed when he tells me I just need to rest

Q4 - Told others about health

Have you told anyone about your ill health?

Responses

1078 responded

- 295 (27.3%) had told family and/or friends
- **610 (56.6%) had told a practitioner**
- 173 (16.1%) had not told anyone

My situation isn't going to change any time soon - I need to just get on with it.

Q5 - Offered Useful Support?

If yes, did they offer any support?

Responses

955 responded

- 247 (25.9%) said "yes – they were great"
- **476 (49.8%) said "yes – but it was not the support I needed"**
- 232 (24.3%) said "no"

Said 'it's stress madam. Find ways to de-stress'

It doesn't look like anything is wrong!

Q6 - What stops you asking

If not, what stops you from confiding in people about your ill health?

Responses

324 people responded

Thinking it's just me...everyone else manages (& that's what people will think)

There were a few common theme as to why people don't confide about their ill health.

Being judged

Don't have time

Because I see people managing and coping with much worse. Because I should be able to do this.

There is nothing they can do.

The biggest deterrent, mentioned by over 1/3 of the respondents was

Fear of being seen as incapable of caring for my child & the possible repercussions

Q7 - Network of Support

Do you have a network of support (family/friends) to call on?

Responses

1073 responded

540 (50.3%) said yes

533 (49.7%) said no

Q8 - Causes of Stress

As a parent carer, right now, which of these is causing you stress?

Responses

1086 people responded

Top Five Concerns:

- Education
- Mental Health - Your child
- Mental Health - you and/or your partner
- Health - your child
- Finances

Main Concerns:

Education	705	64.98%
Mental Health - your child	686	63.23%
Mental Health - you or your partner	609	56.13%
Health - your child	589	54.29%
Finances	562	51.80%
Health - you or your partner	545	50.23%
Social Care	409	37.70%
Transition to adulthood	364	33.55%
Benefits	332	30.60%
Employment - you or your partner	265	24.42%
SEND Transport	173	15.94%
Safeguarding issue	170	15.67%
Employment - young adult	117	10.78%

Other Concerns

- Adaptations
- The Paperwork - so many forms
- Challenging Behaviour
- Constantly battling/fighting for support
- Effect on siblings
- Housing
- Lack of provision

lack of hoists/ changing beds

sandwich caring

Sibling welfare - no support for them

The Biggest Concern

The future - What happens when I am not here?

Q9 - Carers Assessment?

Have you been offered a Carers Assessment in the last five years?

Responses

1086 responded

- 286 said yes - 26.34%
- **705 said no – 64.92%**
- 95 said other (8.75%)

What is it?

Common responses:

- What is a Carers Assessment?
- Asked for one but still waiting.
- Asked for one but told we don't meet the criteria.
- Offered one but still waiting for it to be completed
- Told they no longer offer them for parent carers of children under 18
- Still waiting to even meet our social worker

one of the children I care for lives in a different county so each authority says it is the other ones responsibility to support me.

Disability team won't do one unless its through the EHCP and the EHCP LA people say they don't do it so being passed around.

I rang and requested one but was told my daughter was not disabled enough for me to access!

Q10 - Useful Assessment?

If yes, did anything change as a result?

Responses

296 responded

- 49 (16.8%) said Yes
- **182 (61.33%) said No**
- 64 (21.88%) said Other

They gave me a swim card

I got £300 for pilates

At a time when respite is really vital to me - even though I told SS I think I might have depression as I find it difficult to cope and my relationship with partner breaking down - they still cut my respite by 3 nights

Got carers grant to help with cleaning. It is on a prepaid card which took 6 months to organise and does not work.

I was told I am not a carer with needs because I was managing my Son's direct payment and team of support Workers.

- We now have a great social worker and some respite which has made a huge difference to our family.

Told there was such a long wait list, there was no point

Q11 - Prescribed Medication

Have you been prescribed anti-depressants or anxiety medication in the last five years??

Responses

1081 responded

- **567 said yes – 52.45%**
- 438 said no – 40.52%
- 76 said other – 7.03%

Been on anti depressants for 11 years

Of the 7% who said no, they then went on to comment that they had been offered them but had said no.

So over 59% of parents carers have been offered or prescribed anti-depressants or anti-anxiety medication.

I need to be able to exercise and diet and I haven't got time because of my caring responsibilities

GP suggested anti depressants but I'm down because of my circumstances not because I have a chemical imbalance

One of the common themes from parents was:

I have never advised my GP of my mental health difficulties.

Why?

Daren't - SS would use it against me

Q12 - Other Comments

Any other comments you would like to share not covered in the questionnaire?

Responses:

251 people responded

Parent carers who work as well as care are often left in a poor financial situation due to fluctuating income as a result of having to take unpaid leave from work when holiday has been used up to attend hospital appointments or care for sick children. In our family we cannot pay our bills if one of us has to take a week off.

Because my husband and I are not screaming for help, we don't get any.

Respite has been cut by 80%. Means I can't go out. Increasing loneliness and isolation for me and my children.

As a parent, it is hard to share your stress and struggle with caring for your child as it can be misinterpreted as a kind of negative feeling towards your child. It's as though you either love them or it is hard. In reality, both feelings sit side by side as a parent carer and straddling both worlds creates feelings of guilt. I think our desire to not be negative about our children stops us sharing the problems we face (including fight for respite).

Being a carer is a extremely isolating. The society that we live in allows for these people to go unnoticed and ignored mostly. Extended family is often not close by and community spirit, in my experience, is virtually non existent.

As parents, our health needs come last. I have cared for my boys whilst recovering from a ruptured cyst (and on Tramadol), recovering from whiplash & shoulder injury from car crash

Despite having to watch my daughter day and night, I got told by social care because she is under 18, everything I do is classed as parenting!

Before I had children, I assumed that disabled children and families were supported to live well. Now I see how wrong I was.

Fighting for my child's entitlement shouldn't be so slow, difficult and expensive

Due to missing services for my son and daughter I have not been able to do the physio that I need to do to manage my own (minor) disability. This has resulted in me suffering pain and having mobility issues.

Have had 2 large breakdowns in the last 5 years. Had to drop down to a zero hours contract in order to ensure holidays etc were covered. Financially now we are in a mess which increases my stress levels.

Carers are undervalued and under supported, the whole SEN system is at breaking point, not enough money and not enough resources to support those that need it. Cut backs means support is not available until things are in crisis at best, so nothing to prevent things getting to that point. A recent episode of ill health would have meant my children went hungry if it wasn't for help from local church, and that is with a concerned friend informing social work that we needed help. I was just out of hospital and expected to carry on with full caring duties.

I mainly just wish I could get a good nights sleep every night and not feel so incredibly tired all the time. And I mean ALL the time.

It's not caring that is the main issue, but dealing with the various services and their bureaucracy, judgemental values and cuts to their budgets.

My carer's assessment agreed that my depression was caused by caring and that ongoing counselling would be beneficial but won't help to provide it. They say NHS can provide it. NHS say they can't.

My coping strategy right now is I will deal with it when my son dies, but he has outlasted Drs predictions by 5 years already - can I hang on long enough?

I want to be a mum and parent, whilst I'm largely an unpaid administrator, coordinator, advocate and sleep deprived mover and maker and doer of what needs to be done (this would usually be the role of several otherwise full time paid jobs).

Being a carer to autistic children means all your energy is focussed on them.

I feel that any illness that affects me, worries me so much because who will take care of everything? All the appointments, the meetings, the search for services. Everyone relies on me.. I can't be ill, yet I am.

Feel ill most times, but when my Sen kids are going through the process of primary to secondary transition, Annual Reviews or Statement to EHCP transfer, my health really deteriorates. The whole process feels against us instead of in our favour. We have been through 6 SEN tribunals in the last 4 years and already seeing a 7th later this year. Its a constant battle and one very lonely road.

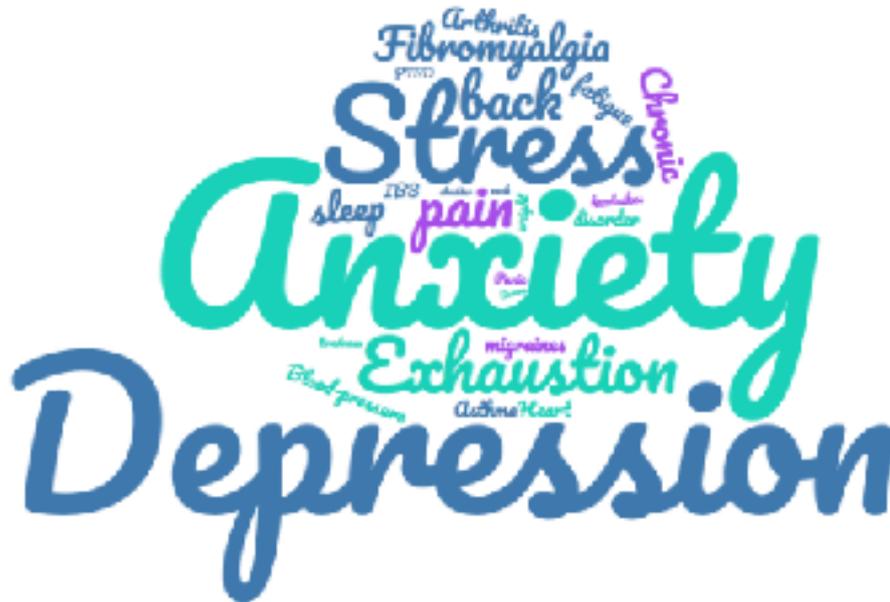
Everyday is filled with stress and worry, while trying to juggle appointments, school issues, college problems, transport issues, homework battles, medication, endless phone calls to the people who never call you back . In the middle of all this we are trying to keep a normal family life ! It's like climbing a never ending mountain.

Schools only want children without complications, due to league tables, LA don't want to spend money so ignore health consequences, EHCP is so vague it's meaningless but can only tackle school aspect in court (cannot afford judicial review) it's all a mess and my daughter is I'll, stressed and out of school, again. There is no help, there is no hope, it will not get better.

Q13 - Health Issues

Would you will be willing to share the details of your health issues (i.e. your diagnosis or symptoms)? *Optional*

Responses



477 responded

- Anxiety was mentioned by 231 of the respondents
- Depression was mentioned by 220 of the respondents
- Stress was mentioned by 138 of the respondents
- Exhaustion was mentioned by 102 of the respondents

Conclusion

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When almost 90% of parent carers are saying they have experienced ill health in the last 5 years they believe to be related to their role, there is a problem.

When we speak to non parent carers, there is a general belief that it is our child's diagnosis or condition that causes us the most stress. However, it is obvious from the responses that the biggest stress for the families is the system, not their child.

Having to learn to navigate a system that is poorly funded allows parents no time to care for themselves. Parent carers told us they could not get to the doctors or just "did not have time to be ill". Other parent carers told us that they knew medication was not what they needed; they needed time to get outdoors and have some time alone however, this was not an option.

Parents feel they have the responsibility of holding their LA, CCG, school and others accountable. They would prefer to spend that time focussing on being mum/dad and making time for their own self care.

All of this added stress leads to poor health, a large percentage of parent carers on medication, family breakdowns, inability for parent carers to find or keep employment and as a consequence, increasing costs for Local Authorities and health providers.

Recommendations

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- Full support from a multidisciplinary team at the point of referral.
- Clear and flexible pathway for support.
- The best practitioners to be involved - whether they are mainstream or specialist
- The care management to fall to the first referral to avoid ping pong effect and waiting in new queues to be seen by anyone.
- Joint work between health and social care
- Person centred inclusive support that promotes independence
- Treated with respect and an understanding of the impact of being constantly let down
- Commissioners that understand the changing needs of individuals as they get older
- Commissioners that understand prevention and that placing this at point of referral and in the community will save money in the long run.
- A navigator that will help families through the maze of policies, procedures, benefits etc
- Timely support to families in order to minimise stress and support their wellbeing
- With good support, families will be able to work and keep on with their life with positive benefit to their wellbeing.