Breaking Point The social care burden on women

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Introduction

International Women's Day 2019 marks two years since the Social Care Green Paper was announced. Over this period, commitments have repeatedly been made by the Government to put social care on a sustainable financial footing. The Green Paper has been promised and delayed five times and the wait goes on. Meanwhile, our social care system continues to leave many to struggle without the high quality, reliable care they need.

As the State has retreated and failed to fulfil its social care duties it is women who have often paid the price. For example, currently 88,391 sandwich carers, 84% of whom are women, are providing 35+ hours a week of care with little support. Of these, 49% are juggling paid work too.

Of course, everyone's situation is slightly different but this report shines a light on what is happening to many women across the country today. It does so through telling the stories of four particular women who have had to make difficult decisions about working and caring for loved ones, putting their own lives and interests on hold.

The national picture

Each day many women are going above and beyond to care for loved ones because the social care support just simply isn't there for them. This is no small problem and the impact on women who are sandwich carers is especially severe¹:

- There are 1.25 million sandwich carers in the UK. These are people caring for an older relative as well as bringing up a family. 68% (850,743) are women.
- Sandwich carers' ages range from 20s to 60s, but those aged 35-44 are the most likely to be carers with 35% being in this age group.
- 73% of sandwich carers provide under 10 hours of caring a week but 7% provide over 35 hours per week – that's 88,391 sandwich carers doing over 35 hours each week.
- The oldest sandwich carers (55-64) provide the longest hours with 29% of them providing over 20 hours of caring a week.
- In total 78% of sandwich carers are in paid work and 49% of those carers providing over 35 hours are still in paid work.

We know the care system is underfunded and unable to cope – 1.4 million older people have unmet care needs. Despite the efforts of many committed front line care staff care quality is patchy because there aren't enough of them. Imagine trying to navigate providing care for an older relative while bringing up a family and possibly working too. That's a lot to ask of anyone and really it is miraculous that more don't reach breaking point as a result.

¹ This analysis is based on Understanding Society, wave 8 (2016-18), a nationally representative sample of people living in around 40,000 households in the UK, and restricted to those aged 16 years and older.

Sarah's story

Sarah spends her life juggling caring for her children, mother and studying to advance her career.

Sarah is a carer for her mum, Jean. Jean had a fall a few years ago when living on her own, breaking her hip. After being discharged from hospital, Jean moved to live with Sarah who became her 24/7 carer.

Sarah was studying to be a nurse at the same time as having a dual caring responsibility for her children and mother.

Sadly, due to the pressures of caring for her family Sarah has had to put her studies on hold as she simply cannot manage it all. She feels more support is needed for people in her situation to keep on caring for their loved one, with respite breaks crucial in enabling them to go on.

Juggling her caring responsibilities whilst raising two children and trying to study with no support has left Sarah near to breaking point. "It's hard work, it's exhausting, I don't think there's a day gone by in the last three years where I've not sat there and cried my eves out."

Rasila's story

Rasila has been a carer for over 40 years and this has had a huge emotional and physical impact on her life.

Rasila is a 67 year-old woman who lives in London and has been a carer for various members of her family for over 40 years. She was first a carer for her two parents, and more recently for her younger sister who has advanced Alzheimer's. Her sister's condition means she needs individual care 24 hours a day.

Rasila picked up most of the caring responsibilities but it was never her intention to be a fulltime carer. It has flipped her life upside down, she feels socially cut off and without a life of her own.

Rasila had to take early retirement in 2013, giving up her career to ensure she could care for her sister properly. She had worked hard to climb the ladder and been successful. But then had to decide between career or family. Like many, she put her family first.

Navigating the care system has been one of the biggest challenges, as she struggled to arrange care for her sister and find out about their rights and entitlements. It took 7 months to see a social worker and when she asked for respite support she didn't get it.

She does everything for her sister, from arranging appointments, making phone calls and getting her medication. She puts herself at the bottom of the list – sometimes forgetting to eat and drink, forgetting to smile. She loved window shopping and going to the library but now that is impossible. Rasila feels she has lost her own identity. "I had to choose between my family and my career."

Joyce's story

Joyce is 73 and has been married to David for over 50 years. Four years ago, their lives were turned upside down when David suddenly suffered a stroke and extensive brain damage as a result.

At first, David received homecare four times a day; he was unable to eat solid food, was incontinent and spent most of the day in bed. However, dismayed at the lack of quality in the care that David was receiving – for example, David was not being properly washed – Joyce stopped paid care staff coming to their home 18 months ago. Ever since then Joyce has been David's 24/7 carer.

Joyce has fought tooth and nail to get David into a day centre two days a week. She has been allocated 56 days respite care a year; however, the care home that looked after David during these breaks is no longer available due to being cut as a local council provider.

Joyce is no longer sure how she is going to be able to go on looking after David. The last thing she wants is for David to have to live permanently in a care home, but she cannot see how she can go on any more without more support and regular respite breaks.

"I can't look after my husband at home anymore."

Elaine's story

Elaine, who is 68, looks after her husband Michael who is 74. Elaine cares for Michael 24/7 since he suffered a brain injury which has significantly affected his ability to function – his speech and mobility have been affected and he is unable to interact fully with people. He also suffers from multiple health issues, including diabetes.

Elaine had to give up her job to care for Michael and has been his full time carer ever since. She has been supported from time to time by paid care staff, (mainly respite care) but based on her experience to date she doesn't believe that they can give him the level of care he needs.

She is angry about how the system is letting them down. Finances are tight and there is no knowing how long this situation may go on for.

This isn't the life Elaine chose or would have wanted for herself or for Michael and the lack of support has made things much harder. The health and care staff she sees and who she talks to about their situation come once and don't return so she feels the help she and Michael need just isn't there. "My life is on hold."

It's time the Government delivered

The failings of the care system mean that women in particular are often left to pick up the pieces. Many are doing their best to provide care for their family but often at great personal cost. For those who are caring for older and younger members at the same time the pressure can be especially intense.

Some are at breaking point and many more at risk of it. They want and need to look after their loved ones, most wouldn't change that for the world, but they shouldn't have to do it alone and unsupported as is happening far too often today.

For too long now we've heard a constant stream of promises from Ministers that the Green Paper will provide the answers to all the care system's problems – but the Green Paper never comes. It is crucial that this Government meets its promises and delivers improvements to a system under so much stress.

How much longer can women carry the burden of our crumbling social care system? The delays and false promises need to end.

Contact us

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