

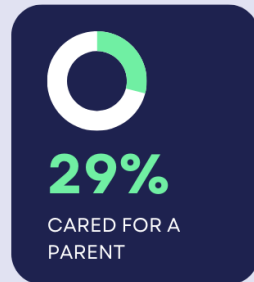
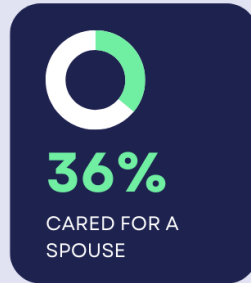
Behind The Care: Appendix Document

October 2024



CARERS SURVEY RESULTS SUMMARY

AGE OF RESPONDANTS WERE 13-81
80% OF RESPONDANTS WERE FEMALE



83% HAD NOT RECEIVED A CARERS
ASSESSMENT

71% WERE NOT RECEIVING CARERS
ALLOWANCE PAYMENT



CARERS SURVEY RESULTS SUMMARY

CARERS FAMILY & FRIENDS OFFERED THE MOST SUPPORT FOR RESPITE



52%

NO ADVICE OFFERED



30%

HAD BEEN OFFERED TRAINING



82%

DON'T GET CHANCE TO MEET OTHER CARERS



76%

HAVE A DISABILITY THEMSELVES



FOR THOSE WHO RECEIVED INFORMATION OR ADVICE - MOST OF THIS WAS THROUGH SELF RESEARCH AND CONNECTING WITH CHARITABLE ORGANISATIONS



Carina's Story

Carina is from rural east Herefordshire, cares for both of her parents. Her dad Tony, 77 has Parkinsons Disease and she has been caring for him for 12 years. Carina has also cared for her mum since a young age, Helen who is now 65 has muscular skeletal conditions that affect her mobility.

Carina talked about how her caring roles have had a big impact on her life such as having to struggle for time to get her education when she was younger, missing out on opportunities of a 'normal childhood' and even now has a loss of freedom to do things she wants.

Carina describes that some days how she just gets on with things and doesn't think about being a carer - she just gets on with what needs to be done for her parents – it's like autopilot with the routine of things that she does, but then other days her mood is low and I get very emotional and she wishes she was doing something else as its all too much.

She explained that her low mood and emotion comes from thoughts and feelings around things such as;

- For the sadness of losing her parents to their illnesses and not having a parent/child relationship like others her age
- The loss of 'what could have been her life' – maybe having a career or experiencing different places to live and travelling.

Carina said she just wants the opportunity to spend more time with her friends and maybe study to get a degree – but also simple things like to not have to get up in the night and be able to relax in the evenings but her fear of her parents not getting the care and support they need means she often just continues through these feelings- pushing them to the back of her mind.

Stuarts Story

Stuart and his family in Hereford City and before becoming a carer Stuart had a good job in electronics that he had to give up to care full-time and unpaid for his parents. Stuart described to me what a typical day looks like as follows.

“A typical day for me starts early as there’s likely things I want to get done before my parents wake so I can then focus mainly on my caring responsibilities. My caring role can vary from day to day depending on how my parents are feeling that day, but most days will include things like personal care, preparing meals, preparing medication and ensuring it gets taken at the right time of day, looking after the home, admin and paper work and ensuring my parents needs are met. I have been their full-time carer for almost 10 years now and in that time I haven’t had a proper break from caring duties. The pandemic and lockdowns made things so much more difficult as we were classed as a vulnerable household and even going out for something simple like a cup of coffee was no longer possible.

Being a full-time carer has had adverse effects on both my mental and physical health due to always putting the needs of my parents before my own needs and that has resulted in my health worsening over the years. The pandemic and lockdowns also affected my mental health as it did for many other carers in ways which I think is something our governments are unwilling to admit”

Stuart expressed his concern for the state of social services in Herefordshire but also nationally – he said they are in crisis – they don’t have the capacity or continuity to provide the basic service they should be. Stuart shared an example of this;

“About a year ago my mother had a fall and after waiting most of the night for an ambulance to arrive (as I wasn’t able to get her up on my own), I had to go and ask a neighbour for help – which in the middle of the night isn’t an easy situation. I think this could of easily been avoided if Herefordshire adult social services had loaned us a cushion that is used to lift people up in these scenarios. When I questioned this with them after my mother was helped, I was basically told that I don’t fit the (very narrow) criteria to get this kind of support and equipment”

Stuart explained that this is an example of how the lack of effective assessments and listening to the carers had a much wider impact and that we had to ‘waste’ valuable time of the ambulance service and then A&E as due to a ‘long lie’ on the ground in all the hours we waited my mother had to be taken into hospital. Stuart said that in the end they had to do some local fundraising and thanks to the generosity of locals in his area and community groups he got the cushion that was required. Stuart expressed this has brought much relief and reassurance to him in knowing he can get his mother back on her feet quickly and safely when she does fall.

Anna's Story

Anna recalled that her journey in care began at the start of Covid – it was the very first day we were in official lock down. Anna had received a call from the care agency that cared for her mum each day alongside her dad (who was her mum's main carer and had been for around 10 years). They called as her dad had fallen and become very unsteady – her dad had always been the one who was strong and looked after my mum who had reducing mobility and was frail with her dementia.

Anna said from this day on when she arrived at her parents' home to support her mum while her dad had some time to recover she become a full-time carer.

Anna recalled it was a worrying time as her dad was admitted to hospital as it turned out he had pneumonia – there was a lot of concern and tests going on for Covid 19 – which Anna recalls thankfully he tested negative for and that she was able to talk to him on the phone each day – but she said it was stressful and filled with worry with all the uncertainty around Covid 19. It was also stressful for her mum who didn't understand where dad was but also had no real comprehension of the Covid 19 pandemic and what this would mean for all of them.

When her dad returned home after responding to treatment he was weak and needed a lot of support himself – so Anna become a carer for both of her parents and juggling their different care needs but also starting to negotiate with healthcare services locally – Anna said she remembers the constant repeating of their story and needs – there was no linking up or communication between services and this was hugely tiring and time consuming. Anna was surprised that as part of the assessments how much documentation is needed and how hard this can be to obtain – things such as diagnosis letters or a letter from the GP which made some applications a two- or three-week process to complete when you have to wait. She said tied into this were moments when she felt she was coping well with juggling all their needs and then not coping at all and feeling like everything was a battle to get sorted and Anna said this is so exhausting.

Anna remembers that it took several months to build her routine and get into a pattern where she could be at home with her own partner and children and also with her parents – Anna said she did feel fortunate to a certain degree as the care agency mum had were able to continue after the 'height of pandemic' which meant she could try and share her time and her life.

In March 2022 Anna's mum passed away at home after her dementia and condition deteriorated – Anna said now when she looks back, she is so grateful that she was able to be there with her parents and spend those last few years closely with her mum and dad. Anna said she continues to support her dad who lives mainly independently but Anns support now with cooking, cleaning and making sure that he spends time taking part in hobbies etc. Anna also talked about how fortunate she was that her partner was able to keep their home life as normal as possible and support their children while Anna was in and out – Anna recognises that many other unpaid carers are not this lucky and it must have a huge impact of families and relationships.

Sue's Story

I met Sue through a carers' group that was being held in Ledbury and these are some of the things she shared with me that she sees and feels living as an unpaid carer in Herefordshire.

Sue said “it's like living with a cloak of invisibility on' being an unpaid carer – we seem to be invisible to our family, friends, organisations and local government”

Sue is a carer for her husband Mark who is living with a life limiting illness and has been since about 2016, she also provides support and care for her mother-in-law who has become increasingly frail.

Sue told us that as unpaid carer that no two days are the same really – yet it all blends into one as there is always something to do, or somewhere we have to be (appointments etc.) through to supporting my husband to do the basic everyday things such as dresses and eating. Sue said its not easy becoming your partners carer and it changes the relationship you have, but Sue said her partner would do the same for her and many dynamics change once you become a carer and you lose your identify a bit – I used to be in full time work and now I don't work at all as I had to give it up.

Caring can be incredibly lonely Sue said, it's because so much of what you do is 'done behind closed doors' its like out of sight out of mind...

All lived experience stories have been anonymised through name changes at the request of those you were willing to share with us.