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From Daughters to Carers: Our Story of Studying and Working in Higher Education whilst Caring for our Parents

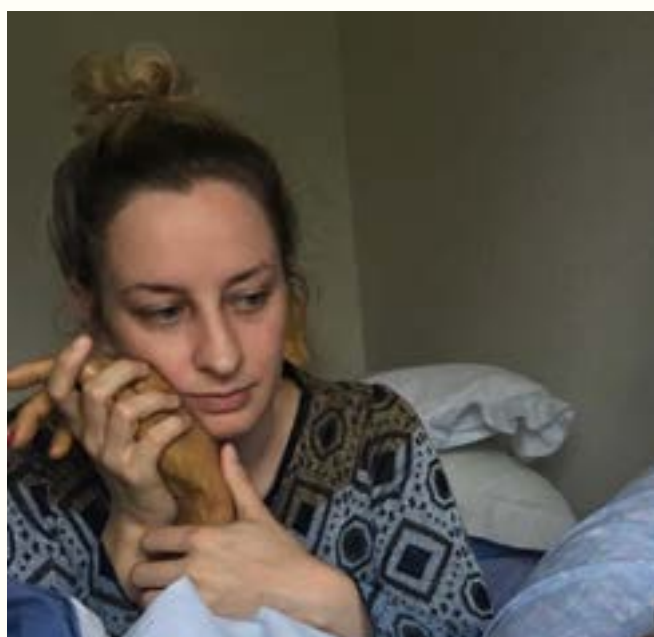
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In 2014, when we were undertaking our PhDs, we got a phone call from our mum to say she had terminal cancer, with a prognosis of just two weeks to two months. Immediately, our role shifted from being daughters, who as young adults in their early 20s were still in some respect cared for by their mother, to being carers for their mother. We were studying and living 2.5 hours away from her, but went to see her straight away. Once two weeks and two months had passed we realised the prognosis had not been accurate and that we had no idea how long she may remain with us. As the Dr responded to our mum when she asked this question at a later consultation: 'how long is a piece of string?'.

We decided to follow our mum's instructions to 'carry on as normal', and continue with our PhDs. However, we were not as 'present' in our studies both in person or mentally as we were beforehand, as our mum was constantly on our minds. It is really important to remember that 'caring at a distance' is still very much caring; it is emotional labour, all-consuming and draining; for instance, constant phone calls to check how someone is, whilst not getting the same peace of mind you may have from seeing them in person.

We were undertaking our PhDs, in a pre-Covid context, where working off-site and flexible working was not as common as it is now. As it happens, our mum did amazingly, exceeding all expectations, living for five years past her initial prognosis. This meant our caring



responsibilities followed us from being students, into our careers, and our ultimately our roles as Senior Lecturers at different institutions.

We don't recall ever telling any colleagues about our mum's illness. After five years of being a 'carer at a distance' during the week, and in person most weekends, caring had become such a banal and everyday element of our lives that it wasn't even something we felt a need to mention. It seemed 'normal' to us, and in fact abnormal that others did not have this extra role to juggle.

When our mum passed away, Samantha remembers a colleague stating that it must have come as a huge 'shock', intimating that the death had been unexpected, and this is when she realised that she had not been open about her caring responsibilities, not intentionally, but like we say, because it had become so ingrained. Indeed, it was only once she became a parent to two young children that she was signposted to the Working Parents and Carers network at her institution.

Once our mum passed away, our worries and concerns were diverted immediately to our dad, who was now widowed and 20 years our mum's elder. Three years after our mum passed away our dad suddenly got confused and had speech difficulties. He was initially misdiagnosed as having a urine infection, then dementia, and later a stroke. Within a month, his symptoms escalated so suddenly that he had lost all speech and mobility. Finally, we got the correct diagnosis of a brain tumour and he passed away just 48 hours later. This was a completely different caring experience to caring for our mum; the intensity of the caring needed meant we were phoning our dad four times a day, driving down there multiple times a week (sometimes there and back in one day) to check he had taken medication; be present for a fire safety check; take to doctors and hospital appointments, and the administration with trying to arrange formal care etc. On top of caring for our dad and our full-time jobs, we had between us five children under the age of three, for whom we also cared for. Needless to say, our caring responsibilities were a full-time job on top of a full-time job.

Whilst all of this was going on, Samantha had been offered a new, more senior, post at another institution which she was supposed to be starting in the midst of our dad's escalating illness.

Unfortunately, due to not being able to push back the start date, and not being permitted flexible working in a way that was needed, she had to turn down this opportunity for career progression.

It is important not to shy away from the impact caring responsibilities have on careers. Whilst we would not change the additional quality time we spent with our parents, the thousands of hours of caring, travelling, phone calls, and emotional upset and the impact this has on the ability to progress in careers and take new employment opportunities should not be dismissed. We would urge students and colleagues to be open and honest about their caring responsibilities particularly to trusted colleagues; to consult any institutional caring-related policies; and to engage with any internal or external caring and support networks that may be accessible. We would encourage line managers to really consider how caring responsibility can impact opportunities to progress and to factor this in when considering any gaps in CVs, for instance regarding opportunities for internal progression.

When our mum passed away we wrote the following journal article, which reflected on our experiences of caring at the end of life: Wilkinson, S. and Wilkinson, C. (2020). *Performing care: Emotion work and 'dignity work' - a joint autoethnography of caring for our mum at the end of life*. *Sociology of Health and Illness*. 42. (8). pp. 1888-1901, available via this link: <https://onlinelibrary.wiley.com/doi/full/10.1111/1467-9566.13174>

We found the process of writing this paper cathartic and would encourage others to consider whether written reflections on their caring experiences would be useful for them. The more stories we can share of caring experiences, the more appropriate support can be put in place.



Welcome to BGU, we hope that everyone has now settled into their studies for 2023.

If you are caring for someone whilst studying, we recognise that juggling your studies and your additional responsibilities can be very difficult. At Student Advice we offer support in the hope of making your studies feel more manageable. Carers are encouraged to get in touch so that we can discuss financial and emotional support.

Due to the unpredictable nature and demands of caring roles, students may also be provided with a Carer's Support Plan that provides leeway in relation to assignment deadlines, tutor contact and attendance. Please contact Student Advice on **01522 583600** or studentadvice@bishopg.ac.uk to discuss your support needs.

If you think you're entitled to the Carer's bursary, worth up to £1000 each academic year, make sure you apply by scanning the QR code.



Art by Susanna Mattham



Identifying yourself as a Carer

According to Carers Trust 73% of people in the UK who have provided unpaid care have not identified themselves as a carer.

I used to be one of those people. Seven years ago, my mum was diagnosed with heart failure, and I suddenly found a whole array of extra responsibilities on my plate to juggle. Pharmacy runs, many trips to a specialist hospital in Cambridgeshire, food shopping, cleaning, and providing emotional support. It felt like overnight everything had been turned upside down, and I suddenly had someone else to worry about and consider with every plan I made.

At the time I didn't realise that I had taken on caring responsibilities for my mum, as her only child I was just helping her as she needed, and as I was juggling the responsibilities alongside full time working, I assumed that I wouldn't count as someone's carer. It wasn't until I started learning more about young carers in school for work that I realised that what I was providing for my mum was care, and an extra responsibility which affects my day-to-day life. I didn't need to be registered as a carer to identify myself as one, and in doing so I was able to research and find out information, advice, and support.

The biggest thing I learnt was the importance of speaking about my situation and seeing what support I can get. As a member of staff at BGU I found speaking to my line manager valuable, she supported me in using flexible working to meet my caring responsibilities, and as she was fully aware of the situation it meant when emergencies happened, she was really understanding.

I am also a student at BGU and when starting the course I knew it was important to find out the procedures for if I needed an extension, this made me feel more comfortable studying as I have learnt over the years that caring responsibilities can change and increase and decrease with how stable the condition is for the person you are caring for.

My advice to other students would be to contact Student Advice if you think you may have caring responsibilities. They can talk this through with you and help to put a support plan in place for any adjustments that could be made to support you while studying. You can contact them on **01522 583600** or **studentadvice@bishopg.ac.uk**. You can also find out further information about support for students with caring responsibilities here: <https://www.bgu.ac.uk/student/student-advice/students-with-caring-responsibilities>

For members of staff, I would recommend speaking to your line manager or the HR team. It is worth them being aware of your extra responsibilities even if there isn't anything you think you need to support you in your role currently. BGU also has a new policy for staff with caring responsibilities which you can find on the website.

Carers First and Co-production

What is Co-production?

Co-production is when an individual influences the support and services received, or when groups of people get together to influence the way that services are designed, commissioned, and delivered. The difference between co-production and other forms of influence and participation is that, in coproduction, people with lived experience play an equal role in both designing and delivering services, rather than making suggestions that professionals are responsible for deciding upon and implementing. True co-production is more than involvement or participation, and it allows people who use services to have equality with Managers and staff. They are potentially involved in all aspects of a service, from planning to delivery.

Co-production at Carers First

At Carers First we acknowledge that carers have relevant expertise through their lived experience. Our aim is to ensure that carers are not passive recipients of our services but are equal partners in designing and delivering activities to improve outcomes.

Involving carers in as many aspects of our work as we can, will help us to improve the service we already have, and design services that carers really need and value. By working alongside each other to gather knowledge, make decisions and problem solve we can create meaningful, relevant, and quality services and policy that continue to reflect the issues that are important to unpaid carers. Carers will feel more valued, listened to, and understood.

We have recently completed Co-production activities with specific groups of Carers within our community, this provided useful insight and we are now making changes to our service and the way in which we support these carers.

We need you!

Our next Co-production will involve, Parent Carers, Working Carers and Young Adult Carers (ages 16-24). If you would like to get involved in our Co-production activities, please get in touch by emailing volunteer@carersfirst.org.uk and put Lincs Co-production in your subject heading and we will be in touch with you.

How else can I get involved with Carers first?

We have services that can only run through our team of amazing volunteers, these include Telephone befriending and check in & chat calls. We also offer student placements to help gain skills and experience in supporting carers. If you would like more information or would like to apply please visit our website, email **volunteer@carersfirst.org.uk** or speak to your placement advisor.

**Carers
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 CARERS
 GUIDANCE
 REFERRALS
 WELLBEING
 INFORMATION
 UNPAID
 AWARENESS

Online Resources for Carers

Need help to arrange services on behalf of the person(s) you care for?

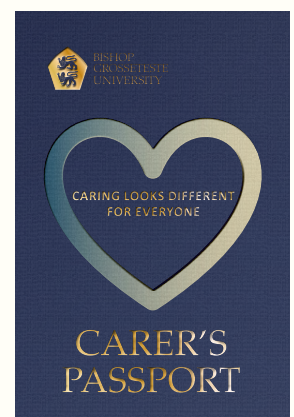
Based on carers' insights and experiences, our three factsheets share tips from carers on managing health matters, power of attorney, and dealing with services from banks to utility providers.

Please note that these factsheets are based on carers' personal experiences and are for general information purposes. Information may also vary depending on your UK nation. If you require advice on your situation, please email advice@carersuk.org or advice@carersni.org if you live in Northern Ireland. For more information on managing services for someone else, visit our managing someone's affairs page.

www.carersuk.org

Carers Passport Scheme

The Carer's Passport scheme continues - any student carers wishing to obtain one should contact Student Advice so that they can begin the process by including the adjustments that can be put in place by the University. The document can then be used to include any additional details you wish to share with staff of the University to help make them better aware of your circumstances.



Navigating the challenges of fitting yourself into what was a pre-occupied space.

Stefania Brien and Leanne Leverton

A special thank you to Stefania Brien (Health and Social Care Alumni) who was brave enough to have a conversation with me.

As you embark on your university journey you may have come to a crossroads where your Caring role has changed. This can be due to many differing reasons and may have reduced or even stopped. A conversation was started with former carers as a way to gain a unique insight, so that we could offer useful ideas and suggestions for this new university term. Whilst we are aware Caring looks different to everyone, we hope that some of the content will be beneficial for both students and staff.

Firstly, we would urge you to talk to student advice (or your line manager/HR) as it maybe that you are still a carer. Remember that support as a carer is offered and delivered in many different ways so you may still be caring but in a different way or for less time than before.

If your care role has completely ended or changed due to bereavement, divorce, ending a relationship, starting university, alternative care being implemented allowing your self-time to adjust is key. The process of adjustment will be different for everyone but during our open conversation this we talked about the importance of time to adjust taking as long as it needed.

Reclaiming your identity “as you” came up in conversation time and time again. Depending on what the circumstances were. For some this may feel exciting, for others this may feel daunting and even confusing.

Spend time getting to know the university seeing what is on offer. You have the time to decide how you would like to recalibrate your life and this takes as long as it takes. Some of the carers we spoke to were struggling to say “yes” I can join that; I can go out or I can stay later, as they had not been in this situation for many years as the care role had been their main focus during down time. For others the space was overfilled as they were so used to caring for a considerable amount of time, they had almost replicated this with other activities and roles. Remember your wellbeing is important take time to recalibrate it may be supportive to seek support via [https://www.bgu.ac.uk/student/student-advice/wellbeing\(students\)](https://www.bgu.ac.uk/student/student-advice/wellbeing(students)) and <https://www.bgu.ac.uk/employee-well-being-benefits> (staff).

Top tips that we have found worked are to be open to new opportunities. Spend time writing a list of any hobbies or interest that you would like to pursue and see what is available. A good place to start to explore at BGU, is YOUR STUDENTS' UNION <https://bgsu.co.uk/> or Employee wellbeing and benefits <https://www.bgu.ac.uk/employee-well-being-benefits>



Call out

If you have any interesting stories, art work, poems, crosswords or ideas or want to be part of the carer network at BGU please email Leanne.leverton@bishopg.ac.uk

I care • he cares



she cares • they care