



Big girls knickers: finding serendipity - when *love of life* triumphs over loss of self! Eventually! Through resonance rather than alienation.

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Love laborers' experiences of losing themselves is going unnoticed by society, despite how regularly it is experienced. Alienation happens slowly; it is a state in which you feel alone, worthless, and meaningless. Your sense of self diminishes. The loneliness one feels as a carer is indescribable and carries much sadness; relationships get strained and lots of them break up, as the priority becomes the person you care for. I speak for myself in this paper, but I am not alone in this experience. Being a carer is a responsibility undertaken when a loved one needs extra care, support or supervision to go about their daily routine; it requires energy, time and effort. This kind of care is ambiguous, for it is often a routine part of family life. It has benefits and gives a sense of accomplishment, but it can also have an adverse effect on carers' lives. This paper represents my personal experiential experience of being a carer through autoethnography.

Who am I? I am Pam, the eldest of four, responsible, practical, reliable, caring, and kind, sometimes funny and intellectual (since I escaped back to college). Let me take you through my education, in parallel with being a carer from an early age to the adult carer I am now and what happened along the way.

My awareness of equality and inequality, as well as ability within disability, came from home life and my educational experience. Being the eldest often carries responsibility, but when the adult in the house 'opts out or 'cannot function,' you soon learn to take on more responsibility, simultaneously losing parts of your childhood. With the significant caring duties I conducted, I can now see how detrimental they were to my development.

As the eldest of four, I always tried to 'care,' to 'love,' and to 'support' my parents and my siblings. Was this the beginning of me not caring for myself, I wonder? Did I take on the identity of carer because I am a girl with attached gender scripts? On reflection, I now see myself fitting in with society's expectations. Since I was ten years of age, even before my father left my mother, I shopped for food, cooked family dinners, and had to neglect my schoolwork to do so. This dynamic was amplified when my father left my mother. She was traumatised, as this life-changing experience stopped her in her tracks, and she withdrew from the family. At the time, she opted out completely, I had to become the 'adult' even more and took care of my siblings. On reflection, I can say today, that I was a young carer, having to become older in my years before I should have. But as I write here, I am undoing how gender roles conditioned me within the household. Back then, looking after my family was my way, as a child, to try and be accepted - dare I say, to be loved.

I experienced gender-based inequality firstly within my home life and secondly in education with regard to subject choice. In secondary school, I wanted to do the subject technical drawing. My dad would not let me, "it's a boy's subject" - that was the end of the story! It took me a while to prove that this was not so; I later attended a technical drawing course - and did exceptionally well in it.

At twenty, I realised the importance of equality; consciously I created an equal space in the youth clubs I set up. Whether one had an ability or a disability, no matter what gender you were you had access to all activities.

It was the 90s and I had employment outside of my home. When I found myself pregnant, I hid it from work until I heard the words: "your contract is being renewed". I declared I was pregnant, the words changed, "your contract is not being renewed." The good old Catholic church had intervened. It was a catholic youth service I was working for in the 90s, and although I was in a relationship, the issue was that I was unmarried. I was going to be a mom, something I had always wanted to be. Within two years, I had a second son. My caring instincts kicked in, and my relationship failed. But I did not, as a mother. Instead, my inner voice kicked in: "Put your big girl knickers on Pam!" (They are sometimes needed after pregnancy too!) I thought of the many types of young people I had worked with, and I knew I was who my child needed as a parent. I pledged to be the mother that my mother never was. I vowed to be there for my children, encouraging them and willing them on in this world.

On reflection, my sense of unfairness enabled me to not allow inequality to stop my sons or me from doing or trying anything that we wanted to. They excelled at whatever they put their hand, head, and heart to: gaining sports accolades, playing rugby to a prominent level, becoming third best amateur chess player in Ireland, having their undergraduate research published in numerous journals, excelling at computers and art design (see attached artwork- appendix i).

Despite the adversity of poverty, lack of services, little intervention, and being a solo parent household, all three of us got to college, first my eldest, then my youngest, then me. I was in college for a second time but ... if I am to tell the truth ... I was a transient student. I was only 60 per cent present, as I had to deal with so much to get my sons through their courses, advocating for them and their needs, whilst doing my college work. At the first college we attended, their access to support services was difficult to deal with: policies that said something was available as a support, but practices that did not deliver in real-time. Yet, our experience of another college was that they could not have been more helpful, and they had no issue with the possibility of me advocating for my son if I needed to. It went without issue or question. I learned that as a carer you are invisible, not seen nor heard when dealing with services. But sometimes you get lucky, like with our second college experience.

I have learned to parent/care as best I can and not beat myself up regarding failure, especially as I come to see that it is due to a lack of service provision. My investment in my sons will pay off when they fly my nest. That does not mean that as a carer, my mind, body, and soul does not diminish. I have fibromyalgia - a condition I have developed as a carer from wear and tear on my body. It is something I have to mentally bypass in my fight to function normally without pain. Somehow my brain decides what can make me weak. Only

once did I lose control of my willpower; at the time, my youngest was in his leaving certificate year, and my fibromyalgia kicked in. I barely got him to school, came home, washed breakfast dishes and had to get into bed for four hours to then collect him. After, I would get into bed for another hour to be able to cook dinner and last until bedtime to help with homework and meet his other needs. I eventually recovered from that bout and will not allow anything like that to happen again. As a carer, you eventually learn to listen to your body and get your brain to resist any bodily malfunctions, as best it can, because you are needed 24/7. This is a reality of life as a carer; we are too afraid to show our weaknesses and try to stay strong to get from one end of the day to the other for those we love. This is part of the experience of self-alienation.

In my early thirties, I began to remove myself from family and friends as the boys took up all of my non-work time. I lost trust in people, beginning with the service providers who let us down repeatedly. My self-care and self-love diminished, as did any possibility of intimacy. I was losing my essence as a woman and human being, but you would never have known. If you looked at me from outside of the home, when outside, I dressed well, had make-up on; I was friendly, and bubbly. Still, to this day, I try to do this for myself. In education, I am trying to claw back a previous version of me who believes in herself. She is getting there slowly. Education has been part of that healing process, resulting in feeling my brain come alive through academia via sociology. I am still a solo parent and a carer to two amazing young men, but the lack of services made me an island and isolated me more from a world that was disappearing from me day by day. So - if I may say so - I did learn how to 'put my big girl knickers on' and climb out of the hole I was in.

I refuse to allow my life to be on hold anymore. As I have become more comfortable as a student and a mom, and a carer, my boys are bedding down into adulthood. I can smell more versions of freedom coming my way. I challenge the state and its institutions not to make us 'love labourers' blend into the background, as though we do not matter. When we take steps to improve our situation, the state needs not only to recognise and accommodate us but to actively put in place well-functioning support services. An example of where this was lacking, not for my sons this time, but for me, occurred in my undergraduate days. The college placement officer would not permit me to do a placement. The placement was happy with the fact I could only work 10 hours, but the placement officer disagreed. She said a job was 30 hours, and I had to abandon the placement. That placement was my link to working and networking again, and an opportunity to experience the labour market safely. As I had been a long time out of employment and could benefit from work experience, I was made to apply for an exemption. Nine months later, a bill came in for me to repay 4100 euros to my funding provider, making me worry financially along with my other life worries. Everything I have outlined here would logically challenge service providers, education systems, and welfare systems to make our lives that tiny bit easier, rather than making it even more difficult when we try to change our situation.

Policy-makers and service providers need to listen to us and recognise that we are tired of advocating and not being heard or represented. Form filling, meeting criteria, and getting so many automatic rejections when seeking help, exemplify a lack of recognition, leading to further alienation. In an attempt to combat these systemic failures, I and other carers set up a support page to help parents say the right thing on the forms at appeals and reviews so that as parents/carers of a child with a disability could be successful in their

first application for payment. We explained how a carers payment application is different to a disability application, the care one needs specific information on the caring duties, and the disability one needs to demonstrate how one is not able to hold down a job due to difficulties that need to be named. With all the skills I had developed before I was 29 years of age, and the confidence I gained from returning to education, I was in a position to help families fill these welfare forms out correctly, collaborating with a solicitor who was willing to fight for the families who got a negative decision on their application. To date, four thousand members have been helped.

We carers put our best self out to the world, yet we are shrinking in spirit, and society knows truly little of that side of us. Why? Because it is claimed by governments that carers and people with disabilities are adequately taken care of in budgets and by other kinds of informal support they assume society provides. That is not the case. Budgets do not show when a secondary benefit is taken from us. Government rhetoric does not recognise how we are trying to survive on an extremely low income nor how this is proving more stressful each year, as you get deeper and deeper into poverty. And we cannot revolt in numbers as we continue to have the caring duties responsible for our position in the first place.

So, my freedom comes from being in education, and the hope that one day I may get the chance to challenge unfair policies. Through sharing an accurate representation of my and other carers' experiences, change may happen. Therefore, my time in education is not only an escape for me, but something that has another underlying reason: to try to give back and be an educated voice in challenging the policy.

Is there a more positive note on which to end my autoethnography? At 47 years of age, I decided I wanted a change. In addition to trying to get back into education, I wanted music back in my life. So I scrimped and saved to begin going to gigs. Oh my lord - I was like a teenager again! I am in the process of reversing all of the alienation from my life as a carer that I have experienced. Better still, I get to volunteer and see bands for free. Where do I volunteer? The disability stands at festivals and gigs, of course! Through my personal experience as a carer, I have the bonus of understanding and seeing a person as a person, not a person with a label stating their disability. Much fun I had at the 'Electric Picnic' music festival every year, and some of these people have become family: an annual music family-get-together, where we are humans enjoying the bands performing. No labels - apart from the one that says 'Music Lover.'

I am realising that I need to step back from my children, who are now adults in their own right. Bit by bit, I facilitate this through education and music festivals. Plus, another joy has come into my life: sea swimming. I do it all year round. I feel reborn. I am grounded with nature again, feeling so healthy and reinvigorated in the madness of the cold water.

This account of my everyday lived experience has allowed me to give voice to the 'losing of myself.' The challenges I faced in my life, when dealing with institutional systems, may still not be solved when the next person faces them. But, I hope that the voices of carers may be explored more and that the awareness and understanding this engenders may begin to inform the practices of those who can affect policy and bring much-needed change for love labourers, so that we are and will always be recognised rather than hidden.

I have demonstrated how alienation can creep into one's life as a result of lack of support, policy and not being included in decisions that affect love labourers. Our lived experience needs to be heard so that more can learn that it is possible to free oneself from alienation. I must add, it is sad when a Microsoft dictionary does not recognise the word carer and wants to change it to career! I may want a career too! We are hidden even in Microsoft programs. Nevertheless, I am doing the best I can to achieve this by studying. Steedman asks the reoccurring question "how we have become to be who we are?" (1986, p. 1662). My layperson's understanding of this is that I am from working-class parents, who, through their hard work, rose to the status of middle class, thus in some way giving their children the hope that you can change your circumstances. I will be forever grateful for this hope, as well as for my capacity to see ability within disability. It has taken me on some life journeys - some good, some not so good. I can honestly say that writing an autoethnography has enhanced my ability to continue the progress I have made in this respect. I feel a release of old baggage and a hunger to continue to revive myself through my education and my renewed love of life.

References

Steedman, C. (1986) *Landscape for a good woman: A story of two women*. London: Virago Press.

Appendix

