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‘A beginning and not the end’: Work after a diagnosis of dementia

Introduction

This article provides insights into the working lives of disabled people, adding to a growing literature on this subject (e.g. Author a and colleague, 2012, 2015; Fevre et al., 2013; Foster 2007; Hoque et al., 2014; Jammaers et al., 2016; Mik-Meyer, 2016; Randle and Hardy, 2017;). Our particular focus is on people diagnosed with dementia, now increasingly common either through young onset-dementia or working into later life (Alzheimer’s Society, 2014). Elizabeth Draper (a pseudonym) is a co-author of this article in which she gives her account of continuing to work after developing cognitive impairments, diagnosed as dementia. Her account shows how obstacles to remaining in work can be overcome and how a working life with dementia can continue to offer opportunities for self-development or, as we shall explore later following Harding (2013), for self-making beyond ‘labouring’.

Drawing on Harding’s (2013) framework we contribute to a disability studies informed understanding of disabled people’s experiences of employment, and how they can not only survive, but thrive (Roulstone, et al, 2003). To this literature we offer insights into how disabled people can continue maintaining not only paid employment but also the strategies to moderate social invisibility (Carleheden et al. 2012).

Co-authoring

Firstly, we reflect briefly on the writing of this article. As a writing team, we are two academics (authors a and b) and Elizabeth, who regularly acts as an ‘expert by experience’ for research projects on dementia and who agreed to act in that capacity on a research project led by the authors. Authors a and b met Elizabeth while exploring how people with dementia can be supported to remain in employment, to give background and understanding as a foundation for their project. Elizabeth explained the communication techniques that would assist her while working with authors a and b, such as starting emails with brief reminders of the context in which we are known and including photographs. Author a and b took notes, with permission, at a first meeting while Elizabeth told her story. These were compiled and shared with Elizabeth. A follow up, more structured, discussion took place in Elizabeth’s home, also written up and shared.

The idea of working on this article together came about six months later when the academic authors reflected on Elizabeth’s experiences communicated on those first two occasions and asked Elizabeth if she would like to share these more widely to inform debates on the challenges that can face people who receive a dementia diagnosis.

The article’s development has been a joint endeavour, resulting from many communications over a year. In a Facetime meeting to discuss progress with the article, we tackled some potentially difficult topics. Together we discussed that we did not know how our working relationship may need to alter as we prepared the article for submission, and through the review process. Elizabeth identified that, as a person living with dementia, a commitment to inclusive communication practices was the key to ensuring she could participate fully and equally.

As well as remaining sensitive to Elizabeth's communication preferences (email including our photographs for initial contact, followed by visual methods such as face-to-face interviews, Facetime or Skype), Elizabeth proposed her co-authors should be observant of any changes in patterns of communication on her part that she had not raised or it was thought she had not noticed herself. If differences were observed, authors a and b were to raise the matter directly with Elizabeth. If there were still concerns about continuing, it was agreed author a and b would contact Elizabeth's daughter who knows her wishes relating to participation in research. We all agreed that what makes the relationship work is acknowledging it as a partnership and our ongoing reflections on how this is progressing. Elizabeth sees this as an ethical process because we talk and listen to each other and the time spent on developing the relationship enables us all to feel comfortable to ask the question 'is it time to stop?'. The approach we have adopted reflects the principles of a process consent approach which centres people living with dementia in the research process. Through our work we have learnt that this requires ongoing critical reflection on the purpose of involvement; awareness of how the person with dementia usually engages (to observe changes); ongoing monitoring of consent. It offers feedback and support (Dewing, 2002, 2007).

Conceptualizing dementia

Medicine describes dementia as 'a set of symptoms that can include memory loss and difficulties with thinking, problem-solving or language' (Alzheimer's Society, 2013:1). This is a biological approach concerned with the 'capacity of the individual' (Butler, 2009:19). We adopt Kitwood (e.g. 1992, 1997) and Nolan et al.'s (2014) approach to argue dementia is a deeply social experience, recognizing that people with dementia can be 'demeaned and disregarded' (Kitwood, 1997:4) when their subjective experiences are ignored and their

personhood undermined so that their rights and entitlement to protection from harm are erased. Kitwood's (1997) social understanding of dementia opposes the notion that people with this diagnosis lack the capacity to be moral agents and challenges the inhumanity often directed at people with dementia which can be 'malignant in its effects, even when it proceeds from people who are kind and well-intentioned' (1997:14). This article champions the notion that dementia is intersubjectively constructed and therefore interpersonal factors may contribute to difficulties of living with neurological impairment or help lessen its effects (Kitwood, 1997). The requirement is for 'sustaining social relations' (Butler, 2009:19) borne from recognition, respect and trust (Kitwood, 1997). Elizabeth's narrative brings these tensions to the fore as she navigates experiences of developing mild cognitive impairments and a diagnosis of dementia while still employed in a large NHS Trust in England.

Conceptualizing dementia in the workplace

To understand the implications of Elizabeth's experiences this article draws upon Harding's exploration of the 'human working self' which offers a distinction between work and labour (2013). Harding (2013:1) develops an argument that asks, 'what does work mean for us, what does it do to us and what sort of persons does it allow us to become?' to contend that work provides more opportunities for employees than is often considered. Harding (2013:1) argues the workplace is a forum through which workers can constitute their 'dreamed-of' future selves but that management tend not to facilitate self-making work, rather they limit the possibilities for employees to realise the selves they imagine because of management's focus on labour. Harding (2013) emphasizes the creative spaces employees can proactively construct out of the workplaces they inhabit, rather than only being the 'Other' to management. The workplace can therefore be a realm of social space for employees to

construct their ‘dreamed-of selves’, where the self produced is for oneself and colleagues outside any expectation to labour for ‘management’ (Harding, 2013:1).

As a well-respected manager based in a Human Resources Department, Elizabeth led a team of ten people and provided support to operational managers (e.g. ward matrons) with their work-scheduling and rostering. She was renowned for her expertise on the scheduling system, but her memory started to let her down. She knew something was wrong but the eventual diagnosis of dementia was a shock, only compounded when she received negative responses from her managers with whom she shared her diagnosis.

The limited literature on dementia and the workplace suggests Elizabeth’s experience is common. There is resistance to making reasonable adjustments to work practices with a tendency to retire people with dementia early when they would prefer to (and are able to) continue to work, or to performance manage them out of the organization (Cox and Pardasani, 2013). There are problems associated with redeployment (Öhman et al. 2001), and with a lack of organizational policy to guide practice (Cox and Pardasani, 2013). Many people living with dementia articulate a desire to continue to make a positive contribution at work (Öhman et al. 2001), and there is evidence that feelings of self-worth can be maintained through so doing (Mason, 2008). Nevertheless, people report feeling abandoned (and worse) when managers refuse to identify adjustments that would facilitate their continuing to work (Chaplin and Davidson, 2014). Elizabeth experienced such a sense of abandonment beginning with her line manager’s negative response when she shared her diagnosis, and which continued when she experienced a lack of knowledge or understanding among other managers. To theorize these experiences we use the work of Harding (2013) which furthers understanding of Elizabeth’s aspirations post diagnosis, and the challenges she confronts in the construction of an inclusive work context.

In constructing inclusive work contexts for disabled people, consideration of adjustments is required along with the involvement of line managers (Cunningham et al., 2004; Dibben et al., 2001) and colleagues (Swain and French, 2008). However, it can fall to disabled workers themselves to make such arrangements (Foster, 2007). While inclusive workplaces are important in helping to counter the socio-economic disparities disabled people experience (OECD, 2010), they are also important in other ways. We suggest Harding's theoretical framework enables insights into the sometimes thwarted aspirations of working people with dementia and can also show how employees can evade the violence that might be done (through normative expectations) to their self-work to 'constitute [themselves] as human while at work' (Harding, 2013:16).

(Non)recognition

Post diagnosis, Elizabeth thought there must be some knowledge within the organization regarding dementia but she was confronted with a serious failure to recognize her ability to continue working. Elizabeth requested an appointment with occupational health only to meet with professionals who knew less about her condition than she did herself, and who reflected the assumption from management that she would of course be leaving employment imminently. Harding (2013:26) suggests we should be concerned when 'conditions of possibility' that 'induce a subject' to be recognized are diminished through the categories by which employees are known because these can be over-determining and may render people invisible. That is, the distinction between subjects who are recognized and those who are not is 'power at work' as the norms which produce the subject shape the extent to which they are deemed 'worthy of recognition or representation' (Butler, 2009:138).

As Elizabeth's narrative indicates, lack of recognition can lead to social invisibility (Carleheden et al., 2012), an example being her 'deselection' from relevant meetings she

would normally have been invited to attend. The suggestion here is that the managers who Elizabeth saw as responding negatively can be understood to have re-categorized Elizabeth according to a new and denigrated category of ‘person with dementia’, someone who could no longer be thought of as a capable worker. Elizabeth explains how this re-categorization (becoming unrecognizable) happened when she shared her dementia diagnosis with her line manager and, subsequently, with other managers in the Trust. Elizabeth’s desire to continue to work while she explored the possibilities of this significant change in her life, and the implications for her life project, can be interpreted as having been denied through, for her, the ‘murder[ing of] the-me’s-that-might-have-been’ (Harding, 2013:144). Seen in this way, Elizabeth is confronted with two deaths of the ‘Elizabeth’s-that-might-have-been’; first through facing the consequences of the dementia itself, which would threaten to limit the range of potential selves Elizabeth might otherwise have become (and developed through her work) and second as a result of her employer’s mechanistic processes cutting dead any latent hope of even a limited set of ‘me’s’ still to be developed.

The sole option initially considered by management was a swift exit when dementia was disclosed. Her line manager and others put Elizabeth at risk of being rendered invisible as a valuable team leader and worker. Despite this Elizabeth persevered in pursuing her desire for ‘recognizability’ (Butler, 2015) as a legitimate worker, *as a worker living with a diagnosis of dementia*, and in doing so to effect positive change towards more inclusive working arrangements. That Elizabeth was able to continue to develop future ‘me’s’ during her time at work through these activities and post full-time employment is a testament to what she calls her ‘resourcefulness’.

Elizabeth can be seen as succeeding in her self-work and self-worth despite management (Harding, 2013). She achieved her self-making by drawing on strong relationships she had with other members of staff (often friends) able to support Elizabeth in her self-making work

and help her do the same for others both within the team and across the Trust. Elizabeth has gone on, after full-time employment, to engage in crafting new selves through a variety of activities that she has found fulfilling. One of the ‘selves’ she became was an advocate for people with dementia, a ‘me’ she has continued to develop after leaving the organization. This involved learning new skills and embarking on new experiences she had not imagined previously, for example public speaking, consulting on inclusive design and appearing on television. Sharing her experiences of dementia can be shown to have contributed to a revitalized sense of becoming (Chaplin and Davidson, 2014:2).

Interpreting Elizabeth’s account through Harding (2013) draws our attention to the extent to which Elizabeth refused the categorization of dementia as inability. She refutes attempts to dehumanize (Kitwood, 1997) and derecognize her, thus coming to ‘evade the violence’ (Harding, 2013:16) that such management responses might otherwise have inflicted. The intersubjectivity required for recognition, and hence subjectivity, was achieved through established relationships, relationships where the dementia diagnosis and evolving effects of dementia did not *over determine* Elizabeth, creating space for her to construct and work on alternative ‘me’s’ (Harding, 2013). In this sense it is less about ‘me’s-I-might-have-been’ (Harding, 2013:150) and more about the ‘me’s-I-might-become’ that are shaped by, and in response to, both the experience of dementia and others’ responses to it in the workplace. These ‘me’s’ were not conceptualized or considered as part of Elizabeth’s self-making project before the diagnosis of dementia.

Elizabeth is therefore able to construct new possible future selves through her relationships in the Trust. She challenges the category of disability as an ‘*inherently* negative’ ontology (Campbell, 2005:109 emphasis in original), of a person with dementia as being less-than-human deserving particular forms of inhuman treatment (Kitwood, 1997) or being denied as a ‘viable’ employee. Harding’s (2013) framework provides a way for us to consider

how 'management' can attempt to limit the possible selves for a person living with dementia and how this can be evaded or subverted. Elizabeth's story illustrates these new ways of conceptualizing the struggles of people with dementia to continue with their project of self-becoming through work, showing some of the ways in which work practices can enact violence through non-recognition and how workers can subvert this violence to create opportunities to further develop their dreamed-of selves.

'How long have you got?'

I was renowned for having a brilliant memory and it began to let me down badly. I'd be in meetings, looking at people, knowing that I knew them but couldn't say who they were and I'd be mid-sentence and would lose the words. That wasn't me. I didn't actually let anybody know until I got a diagnosis because until then dementia didn't even enter my head, purely because of my age (58). When I got a diagnosis I understood what was happening to me. I shared an office with a lead nurse and initially I told her because we were friends, and she was shocked but then she was there as support. Quite quickly I decided to tell my line manager because we were about to go over to an upgraded system. I was having trouble learning the new system, even though I knew the old system inside out.

It was at the first meeting with my line manager that it became apparent there was no awareness around dementia within the HR structure. I think the initial comment was, 'How long have you got?'. That's when I knew there was a lack of understanding. They openly admitted they didn't know what to do with me and assumed I would hand in my notice. I then suggested that maybe we needed to go down the occupational health route to see what support was available. When I eventually did go to occupational health (it took two months to get an appointment) they were sat at the computer on the Alzheimer's Society website

looking at the symptoms of dementia and the doctor admitted he had no experience of employees with dementia.

A beginning and not the end

At the time I was diagnosed, it wasn't the right time for me to retire because I hadn't worked everything out in my head; whether I wanted to and the finances and all that sort of thing. I put together my own plan to say, 'This is what I think I need to do, will you let me do it?'. Because they didn't know what to do with me they simply said 'Yes'.

I spoke to my team soon after the line manager. I'd already become a Dementia Champion¹ and decided to do a Dementia Friends² session with them. At the end of the session I said, 'Oh, by the way, the reason why I've just done that is because....'. You could hear the tumble-weed but actually the team were my lifesaver because they were so supportive. Every single one of them came up to me at one point and said, 'So what can we do for you? How can we help you?', and it was them that said that and not the managers. None of the managers said that. It was my team that saw the need to go, 'So what can we do to make it easy?'

I knew that to the managers I was a lost cause. I was very good at my job and very well respected and immediately you could sense they'd lost all confidence. They assumed that from that moment, I'd lost the ability I had an hour before, so it was all very negative. If I'd been a more sensitive person, I would probably have crumbled from that. They made that assumption that lots of people make with the diagnosis of dementia: that you're at the end and not at a beginning.

Self-making despite management

The team filled the gap that was left by the line managers. They were providing all the support. It was me initially saying what I needed and then they were wonderful, not saying, 'I'll do that' but saying, 'Can I work on this with you?', 'Will it help if I do the mundane stuff?' They weren't looking to take my job away. They were looking to help me to do it. I needed to work from home every other day because I could only do one thing at once. Pre-dementia I used to be able to do lots of things at once but I could no longer do that. I didn't start to make mistakes, I just started to do less. I'd be doing something, the phone would ring, I'd answer the phone but then forget what I'd been doing and have to start it all again.

It became apparent that some individual team members needed more reassurance than others. Some would quite happily come in the office, sit down and talk. Others preferred to do it by email and some, they'd just be quiet and you could see them trying to work something out and you'd have to catch them on their own and ask, 'What is it that you're worrying about?'. Humour was a big thing in the team. Pre-dementia we always used to make time for a laugh at some point during the day because our jobs were so intense. That humour had taken on an almost different role [after the diagnosis] in so far as initially they were sensitive to what I was doing but they almost thought that I couldn't laugh about it. Once I started to make fun of the situation of forgetting to do things or getting lost, their humour came back and they relaxed.

My ex-line manager was head of outpatients and saw the need for awareness of dementia. We decided to do a double act and give a talk to the managers of outpatients without telling them I had dementia. Right at the very end I said, 'So would you have noticed that I might have problems?'. Of course, it was a 'No'. We then decided to do Dementia Friends sessions with the whole of the outpatients' staff.

Towards retirement

I decided I needed to pass on my knowledge. It was important to me that the team didn't suffer in me going. There was one person I knew would be good as a team leader, because of their personality and the rest of the team respected that person. I began to show them things that weren't part of their job but would sow a seed in their mind that, 'Oh, actually, I could do Elizabeth's job'. Then as I handed in my notice we used that time to build her up to be able to take over the team.

Living on my own and only being in my fifties I had a large mortgage so, financially I knew that I had to work out what my options were. That was the only reason I retired in the end, because I had to take my lump sum to pay off my mortgage. I couldn't afford to take a lesser job because that wouldn't have paid enough on my mortgage. I couldn't have afforded to reduce my hours for the same reason.

What they should have done is to sit down with me and say, 'Let's work out what we can do. Do you want to take a lesser job? Are there certain things you enjoy more that we need to focus on?'. You haven't suddenly overnight lost your ability to do everything. You still have an awful lot of knowledge that is valuable to an organisation. If the person decides they *do* want to retire, it's having that support to work out how the hell do you do it, because it's an absolute minefield when you're not of a retirement age. My manager had to do a blurb as support for me retiring but we had to be careful. There are different levels that allow you to take some paid work if you choose to. There's one tier that, if you accept, you're no longer allowed to work whatsoever. I didn't want that because I wanted options. I didn't want doors closed.

It could have been done so much better. I was doing the managing. I needed looking after at that point rather than being the one doing it all. And some people might need help on how to tell their team. I had that relationship with my team and the opportunity to be able to tell them. I was always in meetings but I remember one particular meeting that I was suddenly not invited to. Me being me, I went to the meeting but I explained, ‘Yes, I do have problems finding words sometimes, but you just need to be patient with me and give me time. It’s your problem if you haven’t got that patience, not mine. Don’t exclude me because it might be a risk to have me at a meeting that’s got chief execs because they’ll think I’m stupid – actually, that’s their issue. Support me by enabling me to be at that meeting’. The assumption was that you can’t...it was all can’t.

New selves

It’s amazing how when you retire you find a whole new world and you begin to develop skills in a different way. Before all this I was a really private person. I used to stand up and speak in public just for delivering training, but I would never have addressed hundreds of people as I do now. So that’s developed a whole new skill in me for public speaking. I’m a member of The University of the Third Age now. I do lots of different activities that I wouldn’t have had time to do. I do so much research that I always say now that in my next life I’ll come back as a researcher! It’s interesting. It’s given me opportunities that I wouldn’t have had before. For example, a dementia memoir I have been writing will soon be in publication with a well-respected publishing house, which just goes to show that retiring with dementia is certainly not the end, but can be the start of a new life.

I belong to a support group. They were all people with dementia who come together once a month and, in the beginning, it was a very different group from what it is now. In the

beginning people were very, not negative, but they didn't have much self-worth for what they could still do. An example is one woman who hadn't been out of the house for eight to ten years because her family had said, 'Well, you've got dementia. You can't do these things and you should be in a home'. She had very little self-worth. Through people being together you can see them help each other work out what they can still do but also, it's so good to hear someone else say, 'Oh, I've got those symptoms'. It takes away the isolation that you can feel. This person that hadn't been out, she's now public speaking and can't get enough. It's transformed her life just being with other people and seeing what can be done rather than what can't be done. That's sort of our mantra now; what we can do, not what we can't do.

We all had talents before we were diagnosed, we don't suddenly lose those talents overnight, and it's simply a way of keeping active, both physically and mentally. I often refer to all this involvement as my Suduko. Keeping active like this, keeps my brain working and helps me maintain an even keel. It was very noticeable over Christmas when I decided to have three weeks off with the intention of having a rest. However, once I started again, I struggled to type a simple email. To me that showed that all this involvement is keeping my brain active and enabling me to stay stable for longer. A basic case of 'use it or lose it'. The fact that we all had a job or a career, meant that we all had talents of some sort. Everyone still has a talent post diagnosis and it's simply a case of finding new ways of using those talents or adapting them, either to remain at work or, after retirement, using those talents in different ways. It can be like a new career as we still have so much to offer.

¹ Dementia Champions are volunteers who train with the Alzheimer's Society to deliver Dementia Friends training sessions which support the creation of dementia friendly

communities: https://www.dementiafriends.org.uk/WEBArticle?page=what-is-a-champion#.WIXw_H3M5Et

² Dementia Friends is an Alzheimer's Society initiative to help people become more aware of what it is like to live with dementia and turn this understanding into action.

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