

# Getting what you deserve: navigating work and welfare after a cancer diagnosis

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*Transformation of European welfare systems: challenges, problems and future prospects*

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## Summary

Across Europe there are increasing numbers of older working age people experiencing long term health conditions, including cancer. Symptomatic of an ageing population and consequent ageing workforces, it represents a significant and ongoing challenge to labour markets at both a local and national level. Older workers with long term health conditions such as cancer often recourse to state welfare during their illness, with many navigating a return to their specific workplace, or the labour market more widely. It is this navigation, between work and welfare in the context of long term ill health, that is the focus of this paper.

It draws on qualitative interview data from multiple perspectives; older workers (aged 50 years and over), employers (including line managers, occupational health staff and human resources staff), healthcare professionals and staff from a cancer support charity. Participants were sampled via their connection to a cancer-specific employment support service in the UK. Analysis was informed by constructivist grounded theory.

A key finding from this study was the observation of how both the UK state welfare apparatus, and workplace policies and procedures functioned to compel employees back into the workforce. It was apparent in participant narratives that both institutions employed an acute and short-term model of illness, that did not accommodate the material circumstances of older workers with cancer.

Judicious use of 'deservingness' as a decision-making tool with regard to the support (financial or otherwise) offered to older workers with cancer featured in the data of both work and welfare post diagnosis. It was used in an administrative sense in terms of individuals' entitlement to out of work sickness benefits. When acutely ill, older workers with cancer were able to access state welfare with (relative) ease. However, as their cancer transitioned into a collection of longer term and fluctuating symptoms they found the conditions attached to entitlement increasingly challenging, and were forced back into the labour force, ready or not.

Employers utilised deservingness with more nuance, but with similarly material implications. Effectively, they categorised their employees with cancer as deserving or underserving over time. This categorisation related to the delivery of sick pay, redundancy pay, and in particular, reasonable adjustments in the workplace – a legal entitlement for UK workers with cancer, as it is defined as a disability under the Equalities Act (2010). These adjustments were framed explicitly by employers as a reward for employees who they perceived to have met subjective and individually held expectations of how they should behave. Specifically, they rewarded older workers who evidenced a desire to return to work as soon as possible.

This paper highlights the arbitrary and subjective decision making in relation to the support offered to older workers diagnosed with cancer. It argues that policy makers and employing organisations should forgo the rhetoric of deservingness, and instead respond to the material realities of older workers experiencing long term ill health.

## Key words

Cancer, deservingness, disability, employment, entitlement, welfare

## Cancer and work

The risk of getting cancer increases with age (Cohen, 1994). Thus, in the context of ageing populations and consequent ageing workforces across the Global North (and increasingly the Global South), the number of working age people diagnosed with cancer is expected to rise (Maddams et al., 2012). In the UK, over 100,000 working age people are diagnosed with cancer each year (Cancer Research UK, 2018a). After musculoskeletal and stress related health issues, the disease has been identified by UK employers as one of the main causes of long term sickness absence (Young and Bhaumik, 2011). Half the annual total economic cost of cancer to the country (approximately £7.6 billion) is due to premature death and time off from work (Luengo-Fernandez et al., 2013). However, despite being the primary

cause of premature death in the UK (NHS, 2018), people with cancer are surviving longer and often approximately two thirds of people in work when they are diagnosed return to work (Mehnert, 2011).

However, this is often in the context of experiencing long term symptoms as a result of their illness and its treatments. Symptoms can include chronic fatigue, cognitive dysfunction, pain and incontinence issues (Cancer Research UK, 2018b) as well as comorbid conditions including mental health issues (Budania et al., 2014; Mitchell et al., 2013). Employees diagnosed with cancer often take substantial sick leave from work (Mehnert, 2011) and temporarily or indefinitely recourse to UK state welfare benefits.

## The UK legislative context for working age people with cancer

There are cancer specific protections and/or caveats in both workplace and welfare policy in the UK. Importantly, cancer is defined as a disability under the Equality Act (2010). This categorisation means that people with cancer are entitled to protection from in/direct discrimination and harassment in the workplace, as well as requiring that employers of people with cancer make all reasonable efforts to accommodate an employee's additional needs resulting from their condition. Workplace accommodations can include alterations to the physical working environment, working hours and/or organisational policy (Gov.uk, 2018). This is to allow employees (or job applicants) with cancer to work and apply for jobs on an equal footing to their non-disabled peers, though the efficacy of these workplace protections has been subject to extensive critique (William, 2016; Bambra and Pope, 2007; Foster, 2007).

There is a cancer specific caveat to the main out of work sickness benefit in the UK, Employment Support Allowance (ESA). This is an income replacing benefit that can be contribution or income based and is awarded at two rates. Recipients of ESA at the higher of the two rates are considered too ill or disabled to participate in the labour market. Recipients of the lower of the two rates either only receive the award for 12 months (contributions based) or have to engage in 'work related activities', including CV writing workshops and training as a condition of their award (income based). The lower rate is paid at the same rate as the main unemployment benefit in the UK, Job Seekers Allowance (JSA). People receiving treatment for cancer receive the higher of the two rates until the conclusion of the 'fit note' (previously referred to as a sick note) provided by a medical professional. At the conclusion of their sick note they are subject to assessment, as with other claimants.

That cancer is singled out specifically within UK work and welfare policy makes the condition of particular interest to sociologists and social policy scholars. The implication is that people with cancer are deserving of, or entitled to protections that perhaps people experiencing other conditions are not, which is reflected in the extensive funding of cancer related research and growth of cancer focused charities. However, there are observed differences between how the provision of charity is viewed in public opinion in comparison to the provision of state welfare (Fong, 2007; Loseke, 1997). It is suggested that at least part of the general disdain for public welfare is related to the construction of some of its recipients as less deserving (Skocpol, 1995).

## Debating deservingness

The concept of deservingness as applied to sick and disabled people is not new and there is an extensive body of literature that explores historical and contemporary categorisations of the 'poor' on this basis (Appelbaum, 2011; Katz, 1990; Howe, 1985; Piven and Cloward, 1972). An issue for UK governments has been to ensure that individuals' conditions are genuine and justify the continued contribution of their working peers to finance their support through alms or charity, and later taxation and welfare. Historically the UK has largely maintained an administrative model of disability (Finkelstein, 1993), positioning disability as a problem that requires definition, classification, registration, administration and control by officials. It creates a distinction between those who are able to work, and therefore expected to do so, and those who are not (Stone, 1984). This division is apparent in the tiered provision of ESA; the lower rate of which is paid at the same rate as the main unemployment benefit, and is conditional on the recipient participating in work related activities. The suggestion implicit here is that this group of disabled people have lives that are no costlier than their unemployed non-disabled peers and that they are able to engage in activities that make them more work-ready. Academics have argued that this situates them as undeserving. Shirkers instead of strivers (Garthwaite, 2011).

Survey-based research from van Oorschot (2000) has suggested that public opinion on welfare deservingness centres on five key criteria; responsibility, identity, attitude, reciprocity and level of need. The first requires that the recipient of welfare is not responsible for their situation. The second situates the recipient as like 'us', and not 'other'. Attitude relates to recipients of welfare being adequately grateful for what they receive. Reciprocity reflects the responsibility of the welfare recipient to earn the support they receive and, lastly, van Oorschot (2000) found that the public felt the greater an individual's level of need, the more deserving they were.

Largely, people with cancer are not held responsible for their illness, though increasingly, 'risky lifestyle behaviours' are associated with the condition (Macmillan Cancer Support, 2013), which involves implicit blame. This narrative may be somewhat offset by charitable campaigns, which repeat statistics of one in two, or one in three to highlight how many of 'us' will be affected, or show evocative images of children with cancer which could be understood to limit the association with blame. It can be speculated that perceptions of the severity of cancer formulate the view that people with the disease are deserving of support. In this way it is the criteria of need that is drawn on most successfully by cancer-focused charities; the life threatening and acute nature of cancer. A potential problem here then, is that increasingly, cancer is experienced as a long term and/or comorbid condition, sometimes with conditions that are stigmatised, such as those relating to mental health. Furthermore, long term reliance on welfare benefits is generally a stigmatised position (Moffatt and Noble, 2015; Garthwaite, 2011). Working age people diagnosed with cancer often recourse to state welfare temporarily or indefinitely and have identified this stigma as an issue (Moffatt and Noble, 2015).

Deservingness as a concept has been widely explored in relation to social policy and the provision of state welfare (Bambra and Smith, 2010; van Oorschot, 2000). It has remained underexplored in the context of individual workplaces and/or employer practices. What discussion there is regarding how employers respond to and understand illness centres on whether an employee's illness is genuine (Bramwell et al., 2016; Bellaby, 1990). This suggests that subjective decisions are being made about how employers support sick and disabled employees, echoing discourse regarding recipients of state welfare who are regularly framed as having connived with their doctors to overstate their condition or to have fooled medical professionals (Grover and Piggott, 2007). This paper reflects on the accounts of people who are in paid employment when diagnosed with cancer, employers, health care professionals and staff from a UK cancer support charity to explore the role of deservingness in the work and welfare navigations of people with cancer.

## Methods

The recruitment site for this qualitative research was a regional employment support service in the UK targeted at people diagnosed with cancer. A service which, by its existence, draws to attention the employment support required by people with cancer. The service worked in combination with a welfare advice service and had two specific strands. The first was to offer one-to-one support to people with cancer, including support by phone, workplace advocacy and signposting to alternative services. The second was to provide free cancer specific training to employing organisations, targeted primarily at line managers. The service shared staff with a welfare advice service.

9 women and 5 men who were in paid employment when diagnosed with cancer were recruited to this study having responded to invitation packs distributed by staff from the employment service.

Participants had received support from this service, though some could not recall the specifics. The employees with cancer represented a range of occupational classes and had held the positions they were in at the time of their diagnosis for between 1 and 34 years. All participants were over 50 years old when they were diagnosed and they had varied employment trajectories and contract types.

Interviews were conducted either in participant homes or public, but quiet cafes depending on participant preference. Interviews ranged from 45 to 90 minutes.

10 employers were recruited to the study. 7 were line managers recruited via snowball sampling, as only 3 participants responded to the initial invitation packs (2 members of occupational health staff and 1 member of human resources staff). Employer participants worked for employing organisations that had received cancer-specific training or had direct experience of managing an employee with cancer. 9 employer participants came from large organisations (>250 employees) and 1 from a small organisation (<50 employees). They represented the private, public and charitable sector. Interviews ranged from 13 to 60 minutes in length and were conducted at participants' places of work or public but quiet cafes. Across employee and employer participants, 17 employing organisations were represented.

7 members of staff from a UK cancer support charity were recruited to interview for this study. All worked within services that offered employment support or advice – either supporting people with cancer with employment issues, or providing training and advice to employers. A benefit of interviewing these participants was that they were able to draw on the practices of a large number of employing organisations and a collection of work and welfare experiences of people with cancer. The interviews lasted between 25 and 50 minutes.

Lastly, 5 healthcare professionals were recruited to this study from a variety of services including general practice, community occupational health, specialist oncology services and hospice care. They all worked in services that had referred people with cancer to employment support services. These interviews ranged from 25 to 45 minutes and were conducted at the participants' places of work.

Narrative interviews were conducted with employees with cancer (*"tell me about what you did after leaving school..."*) and line managers with direct experience of managing an employee with cancer (*"tell me what happened after your employee disclosed their cancer diagnosis..."*). Semi-structured interviews were conducted with all other participants. All interviews were transcribed verbatim by the

author. Field notes were taken throughout data collection. Participant transcripts were read and re-read, compared and contrasted to develop a coding structure. Interviews were coded line by line in the first instance and then examined holistically. This process generated participant summaries and thematic memos (Charmaz, 2014).

Deservingness and entitlement, in the context of ill health, were key analytical categories found within this study. The experiences of employees with cancer highlight how deservingness is used judiciously within both work and welfare institutions, with material implications regarding the financial and social support they receive.

## Welfare experiences

9 of the employees with cancer in this sample accessed state welfare as a result of being diagnosed with cancer. They reported difficulty in accessing information about welfare benefits having been diagnosed and evidenced a lack of understanding as to how UK welfare distribution works. Largely, they were not aware that there are benefits that are income replacing and others that 'top-up'. Equally, most participants were unsure as to whether they were accessing income-based or contributions-based awards, and found information about entitlement difficult to access. Some expressed surprise and disappointment that "*nobody's like, given us any information*" even when actively requested. Even when "*phoning around*" employees with cancer felt that they could not access adequate advice, often only getting through to "*automated services*" where they got "*pressed from one [receiver] to the other*".

An important consequence of not understanding UK welfare distribution was that their understanding of what they should claim, or receive, was reframed as an issue of deservingness rather than an issue of entitlement. This manifested in a number of participants using the perceived undeservingness of others to establish themselves as deserving. Participants used othering and shaming discourses to situate themselves as worthier of support in comparison to other benefit claimants, as has been observed in other research (Chase and Walker, 2013) These comparisons were levelled at those with what were considered to have less deserving health conditions including '*bad backs*' (said with mimed inverted commas) or to be claiming disingenuously. Employees with cancer commented on neighbours they knew to be claiming welfare benefits but whom they considered suspiciously healthy.

Immigrants were also utilised as an 'underserving' group for comparison. One healthcare professional, without prompting, stated that she was '*all for immigration and fairness*', but that there seemed to '*be an excess from European rules saying we've got to take everybody in and pay out all the benefits. Yet Joe*

*Public, who's worked his life, you know, thirty or forty years and then falls into no man's land [attempting to access welfare benefits] because he's got cancer'*. This comparison situates deservingness in relation to contribution and citizenship. A primary requirement made of UK citizens is to contribute to society by means of paid work (Frayne, 2015, Patrick, 2012, Ekerdt, 1986). To illustrate their deservingness, participants drew on their pre-diagnosis contribution as citizens, in comparison to those perceived to have contributed less.

Participants drew on their pre-diagnosis contribution to work in combination with their financial need to frame what they felt they should receive from the state. Some were surprised and disappointed to find that despite their financial need, they were not eligible for sickness related welfare benefits. One participant was incredulous, saying *"I've only got six hundred pound coming in, and they [Department for Work and Pensions] said no to us!"*. Others used the same logic to reach the alternate conclusion; that they were not in enough financial need to receive state welfare. They built these assumptions on the basis of their spouses' salaries or property ownership. Again, this highlighted some important misconceptions regarding participants' understandings of how UK welfare benefits are distributed, despite in most cases having received advice and guidance.

Beyond not being able to access adequate information participants also described problematic communication with the Department for Work and Pensions (DWP). Some received extensive correspondence, causing them stress. Others commented on the unhelpfulness of call handlers when they got in touch by phone. One participant described *"giving up"* on accessing any benefits she might be entitled to because of the difficulties she experienced trying to communicate with the DWP by phone. Another described being kept waiting for over half an hour for what should have been an immediate ring back service. A further participant explained how she had been left in tears and lodged a complaint after ringing a DWP helpline. These participant accounts correspond with anecdotal accounts in the media from DWP call handlers themselves who have drawn attention to their inability to provide an adequate service because of the targets they are set (Guardian online, 2016).

Written communication with the DWP also caused consternation for employees with cancer. One issue was the level of correspondence individuals received:

*'...I had a file like this [gestures with thumb and forefinger] from the Department of Work and Pensions, and I sent everything recorded delivery, and they were saying they hadn't got letters and I was saying I've got proof here that you have...'*



This participant felt she had to be pro-active and tenacious when applying for, and maintaining her sickness benefits, at a direct financial cost to herself. Other employees with cancer received unexpected letters from the DWP which resulted in anxiety and distress. One participant received a letter telling her that she had to go back to work, despite not even being in receipt of any state welfare benefits at the time. Alternatively, especially those in receipt of the time-limited lower level of ESA, did not receive enough correspondence. Consequently, they felt that they had been left “*high and dry*” by the DWP. One participant said she was told on the phone that state funded occupational health staff would “*get round to [her] eventually*” and a year later, at the time of her interview, had still not heard back.

The work required of employees with cancer with regard to accessing welfare was most evident in their attempts to maintain their respective rewards. Though many were initially eligible for the higher rate of ESA, as time went on and their illness transitioned from an acute illness to a collection of longer term symptoms and comorbid conditions it became more difficult for them to evidence their deservingness. In particular, assessment for award was a source of stress for employees. Those that had yet to be assessed expressed fear, concern and frustration that their material reality would be ignored or dismissed. Those who had been subject to assessment prior to being interviewed for the project explained how they did not feel that their physical symptoms were recorded accurately, and that they were essentially set up to fail. The wife of one participant described how during his assessment, despite showing symptoms associated with his mental health condition he was found fit for work as “*the doctor said that he doesn't think [participant's] got depression, because they said he didn't move, he um, he didn't sweat, which he did do all that*”.

With support from UK cancer support charity staff some employees with cancer appealed what they viewed to be poor decisions made by the DWP. The process of appealing, in keeping with their wider experiences of the UK welfare system, was distressing and challenging for employees with cancer. Participants described going to appeal as “*intimidating*” and “*horrendous*”. Some were so put off by the process that even when advised that they could appeal a decision chose not to go “*through all that rigmarole*” again and stated that they “*never, ever want[ed] to go through anything like that again*”. One participant was edged closer to the labour force each time he interacted with the DWP. Initially he was awarded the higher rate of ESA but was assessed after the conclusion of his fit note and was migrated onto the lower rate, before being found fit for work after a further assessment. He was supported by a cancer support charity to appeal this decision and was returned to lower rate ESA.

Those that accessed state welfare reported poor organisation, high levels of stress and seemingly arbitrary decision making as part of their experience. One participant with cancer explained how he applied for a top up disability benefit (Disability Living Allowance) and after a six week wait got a letter saying his application had been rejected. He went to appeal at which he was awarded the highest rate of the award. He complained that *“how it can go from one to the other’s ridiculous”*. The seemingly arbitrary nature of award echoes the fundamentals of deservingness, which is a subjective and arbitrary measure for reward.

Whether by design or not, the UK welfare benefit system is difficult to navigate for people experiencing ill health, including people with cancer, despite condition specific support written into the distribution of the main out of work sickness benefit, ESA. These difficulties represented a disincentive to access state welfare, and/or challenge DWP decisions, without expert support. An implicit consequence of this was to incentivise returning to work to avoid negative interaction with state welfare, complement the explicit movement of people claiming out of work sickness benefits toward to labour force over time.

## Workplace experiences

Workplace interactions for employees with cancer were more individualised and nuanced than their interactions with UK state welfare provision. Paid employment is dynamic and features interpersonal relationships, and this was obvious in the accounts of participants, both employee and employer. Despite this, workplace sickness policies and the decision making of employers regarding the support they offered employees with cancer still functioned to complement state welfare, as described above, in propelling employees with cancer back to work.

Part of the movement of employees back toward work can be explained by the time limited nature of both their sick pay and sick leave. Though sick pay varied within this participant group from the UK from the statutory minimum (approximately a fifth of the UK median income) for 28 weeks, to 12 months full pay, sick leave was far less varied and generally concluded after 12 months of absence. At this point employees with cancer were required to decide about whether they were returning to work or making a permanent/indefinite departure. An important responsibility of employers was *“trying to establish a return to work date”*. Some employees with cancer could not afford the drop in income from their salary or wages to state welfare payments, or were not eligible for award and so felt financial pressure to return to work. For public sector organisations in the sample even workplace accommodations were to some extent temporary, as they were subject to review on an annual basis.

In addition to workplace policy driven motivations to return to work, individual employers also encouraged employees to return. Line managers in particular identified some employees with cancer as deserving of support. Employees deemed deserving were those most able, and willing to evidence a desire to return to work as quickly as possible. To calculate a potential retirement lump sum, one manager explained how part of her deliberation would be to reflect on whether her employee with cancer had *“been keeping in touch”* and whether she had *“been trying always to come back to work”*. Similar judgements were made regarding workplace accommodations. Instead of being framed as legal entitlements, employers instead framed particular offers of support as rewards for deserving behaviour, for employees who were *“good enough to come back in [a] short period of time”*. Similarly, employers appeared to withdraw support from employees with cancer they deemed undeserving, broadly those who extended their sick leave and exhibited undeserving behaviours.

Despite the best intentions of many of the employers, especially line managers who were often deeply shocked and saddened by their employees’ diagnoses, their actions still functioned to compel employees to return to work. In some instances, this resulted in employees returning to work, and their pre-diagnosis hours before they were ready.

## Conclusion

This paper focuses on the post-diagnosis experiences of employees with cancer, employers with experience of managing employees with cancer, healthcare professionals and staff from a UK cancer support charity. It highlights how employees struggled to gather adequate information regarding their welfare entitlement. It illustrates how as their conditions transitioned from acute illnesses to longer term conditions they found it more difficult to access welfare benefits, some of which were time limited. Similarly, participants struggled to challenge welfare award decisions without support. Employees with cancer either found themselves moved nearer to labour force, ready or not, or in fear that they would be.

A further contribution of the paper is to identify how workplace processes complement state welfare apparatus by promoting speedy returns to work. Employing organisations had time limited sickness policies. At the conclusion of sick leave employees diagnosed with cancer were expected to make decisions about whether they would return to work or not. Those able to demonstrate enthusiasm about returning, and particularly those who did return to work quickly were rewarded, often with workplace accommodations, even though they are a legal entitlement for employees with cancer.

Deservingness featured in the post-diagnosis work and welfare experiences of employees with cancer. It functioned to undermine the idea that some support, both financial and social, was an entitlement, and required that employees with cancer meet a number of obligations both in relation to welfare and paid employment despite cancer specific allowances in both workplace and social policy. Though employees with cancer experience varied symptoms that are often long term, fluctuating and/or comorbid with other conditions, both workplace and state support are predicated on short-term models of illness that propel people with cancer back toward the labour force and/or workplace. Ideas about who is deserving, and who is not, are highly subjective, and judgement made on that basis are experienced as arbitrary and inconsistent. To have work and welfare institutions proliferating the false dichotomy of un/deserving recipients of support is deeply problematic, and inherently unfair.

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