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The Locus of Our Dis-ease:

Narratives of Family Life in the age of Alzheimer’s

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Alzheimer’s and the distance between parents and children were both diseases of contemporary life, unlikely to go away (Hegarty 1995: 132)

The spectre of Alzheimer’s disease (whether its legitimacy as a category is accepted or contested) dominates contemporary popular cultural discourse around both ageing and dementia. The historical trajectory of this diagnosis, from its initial description in 1901 by Alois Alzheimer as ‘a peculiar disease process of the cerebral cortex’, to the name of a dementia ‘epidemic’ in the latter stages of the twentieth century has been attributed to the conjunction of a complex of disciplinary, economic, social and political factors. The medical anthropologist, Lawrence Cohen, explores the medicalization of dementia as one effect of the development of Geriatric medicine as a distinct research field that needed to separate “normal” ageing from particular disease pathologies. “Senility” as Cohen puts it, “is split into the existential condition of “normal aging” and the purified pathology of dementia” (2006, p5). This disciplinary ‘will to power’ also intersects with the economic interests and burgeoning power of global pharmaceuticals from the mid twentieth century onwards and the identification and development of potentially lucrative new markets. Alongside this, is the emergence of new and powerful constituencies such as the American Seniors Association, and advocacy groups in the UK such as The Alzheimer's Society each of which organise themselves around this kind of model of normal and pathological aging and make their claims for social, political and economic recognition on this basis. Medical sociologists such as Jaber Gubrium identify one of the 'functions' of the medicalization of dementia as a way for caregivers to manage the more disruptive aspects of the behaviour of the person with dementia (1986). The division of the disease into a series of stages, each with its own characteristics, provides a narrative structure in relation to which the experience of the disease can be plotted (often regardless of whether the behaviour and symptoms of the person with dementia actually follow this model). As Cohen notes, "one of the dynamics of the age of Alzheimer's is its apparent total biologization of senility: internal disease processes become not only the necessary but also the sufficient ground of all reasoned conversation on the recognition of behavioural change in late life" (2006, p7). The key point here is that the way we talk and think about dementia today is inseparable from the assimilation of a disease model that is produced, reproduced and reinforced across a range of sub-disciplines and emergent medical technologies: neurology, genetics, geriatric medicine, neuro-psychology, psychiatry. Dementia is no longer perceived to be a natural consequence of aging (despite the fact the incidence of dementia increases exponentially with age) and this shift in thinking, buttressed by a nexus of institutional practices, and research agenda and economic pressures and interests, has profound effects upon the perception and experience of living with this condition.

Alzheimer's, in this sense, is not simply the name of a disease, it is the term around which a whole assemblage of problems and possibilities circulate. Crucially, it operates not only as the site upon which a range of bioethical debates are played out but as a form of cultural production in its own right. Across multiple locations Alzheimer's – as we now know it -- has produced new commodities, new institutions, new markets, new alliances, new identities, new problems, and new creative possibilities. This essay aims to address the distinct contribution of literary culture and of a cultural materialist critical practice to our understanding of the political and ethical implications of the biomedicalisation of dementia upon the concept of family and attendant notions such as dependency, obligation, choice and individual agency. With close reference to Margaret Forster's *Have the Men Had Enough?* (1989), a novel produced at the beginning of the so-called Alzheimer's epidemic' of the last twenty five years, this essay sets out to explore the ways in which "Alzheimer's" as a historically distinct way of thinking about dementia, serves to articulate concomitant transformations in the concept of family, including notions of familial obligation, personal choice and the meaning of care.

The essay begins by locating recent governmental representations of the 'dementia challenge' in the context of the broader economic, political and social changes effected by neoliberalism. This provides the context for a consideration of the ways in which Forster's novel begins to articulate the emergent perceptions of dementia care that now dominate public discourse; a notion of caring as somehow *discontinuous* with normative familial relations and as an impediment to the flourishing of those around the person with dementia.

The Alzheimer's Show

The flyer for The Alzheimer's Show (16-17 May 2014), "the UK's only dedicated exhibition and conference for carers, relatives and professionals living and working with Alzheimer's and dementia" promises to bring together "over 60 dementia and care exhibitors" at the Olympia conference centre in London. The show is sandwiched between the usual Olympia fare of bridal shows, forensics and counter terror expos – the combination of which befits the sentimental yet intrinsically violent logic of our current historical conjuncture and stands as a sad indictment of it. At £10 in advance and £16 on the door (with £1 off for concessions), tickets are less costly than usual but the pricing scheme and the marketing information on the website regarding projected visitor numbers and their professional profile underlines the commercial nature of the project. With its combination of service providers, specialist retailers, and inspirational lectures from "high profile speakers", The Alzheimer's Show crystallises a number of key transformations in contemporary thinking about dementia. First, it underlines the degree to which the way in which we talk and think about dementia today is inseparable from the assimilation of a disease model (Alzheimer's) as the dominant category through which we make sense of cognitive impairment in later life. Secondly, it is indicative of a set of social and economic transformations surrounding the concept of care and indeed illness itself. The presence of a range of exhibitors comprising "expert" care providers and retailers specialising in the production of "tailor-made" products for people with dementia are markers of the movement of the concept of care from a primarily affective and private domain (the family) to the world of trained professionals, goods and services, "customer satisfaction" and statutory frameworks.

This shift demonstrates the extent to which the biomedicalisation of dementia occurs in tandem with a process of marketization in which the provision of services, service providers and particular commodities are addressed to individuals or health providers as consumers. In other words, the logic of the market and its values infiltrates the experience and perception of what it means to live with dementia. The "age of Alzheimer's" is characterised by the emergence of a whole economy of preventative and therapeutic interventions, pharmaceutical and alternative treatments (from Aricept through to Zinc) and products aimed at the ever growing market for dementia related goods. One exhibitor at the Alzheimer's Show offers expensive jigsaws and picture books on the basis that these products have been developed in the light of years of experience and 'research'. One sees here in the evocation of 'research', the rhetorical appropriation of a discourse of expertise entirely continuous with the notion of Alzheimer's as a complex and intractable problem for medicine. The unique selling point of this kind of consumer good resides primarily in an investment in the idea that it is the product of specialist expertise beyond the powers of ordinary people; in other words, this particular jigsaw differs from those superficially similar eleven piece jigsaws bought for recreational rather than therapeutic purposes: in every 'crisis' a marketing opportunity.

What I am trying to capture here is the way in which the medicalization of dementia and its entry into popular discourse as "Alzheimer's" has a range of effects, not least in the formation of new markets, new commodities and new investment opportunities. Indeed, the ideological investment in the promise of a cure for this thus far incurable condition serves as one of the most powerful ideological legitimations for a range of ethically contested practices from stem cell treatments to genetic research. Tracey Crouch

(Conservative Member of Parliament for Chatham and Aylesford) in a debate in the UK parliament (28 November 2013) drew upon this kind of promissory discourse in order to argue for increased investment in global pharma: "The Government must do more to promote the commercialisation of research as these companies become a vital part of the ecosystem" (Hansard, 28.11.13). This manoeuvre indicates the ways in which "Alzheimer's" as a disease that currently exposes the limits of modern medicine is evoked in order to justify particular entrepreneurial, free-market practices (which, in turn, are presented as organic, "a vital part of the ecosystem"). The fact that the promised cure is always "just around the corner" makes this form of speculation (both imaginative and financial) all the more seductive. Dementia recast as Alzheimer's Disease marks the horizon of current research and thus its most compelling justification.

A very neoliberal condition

The transformations that I have been describing point to the intersection of contemporary Alzheimer's culture (by which I mean the discourses, practices, representations and political rhetoric that constitute and flow from this disease model) and the economic and political doctrine and practices that characterise neoliberalism. Referring to the proposition that free markets, entrepreneurialism, private property and an ethic of individual choice should be the guiding principles of politics and economics, the neoliberal policies first introduced in the UK by the Thatcher governments of the 1980s (and continued under Tony Blair's New Labour and the current Conservative/Liberal Democrat Coalition) focus primarily upon the dismantling of the welfare state and the social consensus upon which it was founded. The tenet of social or collective responsibility thus gives way to a celebration of the unencumbered individual free to "choose" to interact with market as he/she so wishes. Choice, in other words, becomes synonymous with consumption, and the individual agent with the consumer. As Fredric Jameson (1991) notes "the slogan of the market and its accompanying rhetoric was devised to secure a decisive shift and displacement from the conceptuality of production to that of distribution and consumption" (266). One of the reasons why this shift is so successful in ideological terms is that it is accompanied by a comprehensive metaphysical outlook that equates the mechanisms of the free market with human nature. Thus Gary Becker (1976), one of the most prominent neoliberal ideologues, remarked "I am saying that the economic approach provides an invaluable unified framework for understanding all human behaviour" (14). We see echoes of this rhetoric in the comment of Conservative MP Tracey Crouch cited above in which the commercialism of research is recast in organic terms as an aspect of our "ecosystem".

The consequences of these shifts are complex but profound to the degree that the ideological logic of the free market has come to permeate and trouble conceptions of human connectivity at a very fundamental level. Becker's notion that human nature itself both underpins, reflects and legitimates his particular vision of laissez faire economics offers a model of human sociality wherein both public and private, formal and affective ties are shot through by the discourse of the market. In *Liquid Love* (2003), Zygmunt Bauman explores the extent to which the language of economic losses and gains, investment and risk has come to permeate popular discourse around love and relationships:

> A relationship, the expert will tell you, is an investment like all the others: you put in time, money, efforts that you could have turned to other aims but did not, hoping that you were doing the right thing and that what you've lost or refrained from otherwise enjoying would be in due course repaid – with profit. You buy stocks and hold them as long as they promise to grow in value, and promptly sell them when the profits begin to fall or when other stocks promise a higher income … If you invest in a relationship, the profit you expect is first and foremost security (Bauman 2003: 13)

Bauman's discussion of the proliferation of self-help guides and relationship manuals in which love itself is conceived of and mediated by a utilitarian and instrumentalist language of the business transaction, the cost/benefit analysis and strategic risk management offers a vision of contemporary culture characterised by a constitutive insecurity. In the contemporary "domain of life politics", he notes, "floating coalitions and drifting enmities are expected to coalesce for a time, only to dissolve once more and make room for other and different condensations" (ibid: 34) . This reduction of love and relationships to a form of exchange (the idea that we must "get something back" from our love object or else move on to a more 'profitable' partnership) has significant implications for attitudes towards care and responsibility for others who are unable to reciprocate according to the logic of this 'contract'. We see the consequences of this idea at work in popular discourses around the personal costs of caring for a disabled or chronically/terminally ill 'loved one'. For instance, in her blog *Dating Dementia*, Nancy Wurtzel notes, "I've realized that without the first-hand experience, it is difficult to fully comprehend how dementia can ruin lives". Like many similar bloggers, Wurtzel's representation of the experience of care giving produces two bodies and two forms of suffering, that of the disabled/ill person and that of their carer. In this scenario, care giving itself is perceived as a form of suffering but crucially one that is often deemed to eclipse that of the disabled or ill person themselves; in other words, this is the suffering that matters both socially and emotionally, with that of the disabled/ill person all too often placed under erasure. Without wanting to understate the impact of increasingly unsupported care-giving upon peoples' lives and relationships my point here is that there is a continuity between the incorporation of the language of the market into conceptions of human relationships and current perceptions of care/caring as intrinsically burdensome and discontinuous with ordinary emotional and familial bonds. The language of the online community that has developed around the "Alzheimer's epidemic" is characterised by the language of deficit (loss/erosion/decay) and of personal ruin which crystallises around the figure of the parent/partner who fails to recognise the identity of their carer. In this instance, the 'tragedy' of dementia is popularly conceived of on the basis that conventions of exchange and thus of reciprocal interest are fundamentally violated.

The shift in conceptions of human filiation described by Bauman as a form of "liquid love" intersects with the political incorporation of an identity politics stripped of its collectivist aspirations and reworked as self-realisation or the priority of the individual to realise aspirations regardless of difference or the "protected characteristics" enshrined in equal opportunities legislation. In *Invented Moralities* (1995), Jeffrey Weeks identifies this as an unintended consequence of the ideology of the free market, noting that "if you have an absolute freedom to buy and sell, there seems no logic in blocking a freedom to choose your sexual lifestyle, your identity or your fantasies" (Weeks 1995: 28). If this explains the superficially contradictory recognition of gay 'rights' (via the pink pound) by Conservative administrations in the UK, then it is important to emphasize the degree to which this process is contingent upon the postulation of a relationship between "rights" and spending power. The ideological power of neoliberalism is tied to an assertion of the "end of history" apparently manifest in the end of the class struggle as conceived of in Marxist political thought (cf.Fukuyama 1992). However, the social consequences of this economic and political doctrine play themselves out in the decimation of "the protected coverings that embedded liberalism allowed" and the establishment of "flexible labour markets" based upon "short term contracts, chronic job insecurities, lost social protections and often debilitating labour" (Harvey 2005: 168 & 170). The production of "disposable workers" (Harvey 2005: 170), "human waste" (Bauman 2003(a) & and 2003(b)), "surplus humanity" (Davis 2007) or "revolting subjects" (Tyler 2012) expose the disjunction between the ideological self-representation (and thus legitimation) of neoliberal economic policies (as the key to "self-realisation") and the violent consequences of their implementation for the working class, poor women, migrant workers, disabled people and ethnic minorities such as the Roma.

We can identify the place of Alzheimer's in this formation in the rhetoric of David Cameron's recent "Dementia Challenge" launched in the UK in March 2012. Describing dementia as the "one of the most important issues we face as a society", Cameron states his determination "to go further and faster on dementia – making life better for people with dementia and their carers, and supporting the research that will ultimately help us slow, stop and even prevent the condition"(Cameron 2012:3). The foreword to the policy document frames the problem of dementia from the perspective of a personal empathy for the individual's experience of living with the condition. "Imagine", he notes, "feeling confused and afraid because close friends and relatives seem like strangers; being unable to leave the house alone because you might not be able to find your way back; or seeing the fear in your loved one's face, as they struggle to make sense of familiar surroundings" (ibid). However, the staged familiarity of this rhetoric belies a strategy that exposes some of the most acute fault lines in neoliberal discourse. Although this document opens with an appeal to the difficulties experienced by individuals in the face of dementia, the strategy itself is oriented around a primarily economic evaluation of the 'cost' of care. The government site devoted to improving care for people with dementia notes that the disease costs the economy £23 billion a year and estimates that by 2040, the number of people affected is expected to double - and the costs are likely to treble. This reframes the notion of the impact of dementia upon the individual in favour of the assertion of an imminent resource crisis. In fact, the current and projected 'costs' of the "Alzheimer's epidemic" does not actually represent real spending but represents a figure of which 55% is accounted for by estimating the value of work done by unpaid carers. It therefore serves a primarily ideological function as far as it represents what appears to be a very large sum of money, the allocation of which will have significant social and economic effects. (It is worth bearing in mind here that current funding of the NHS amounts to £108.9 billion per year).

It is also important to note here that Cameron's more recent speech calling for global action against dementia uses the resource implications of dementia to call for closer relationships between medical researchers and the market, the incentivising of "partnerships between science and business" and tax breaks for any company that creates "intellectual property in the UK". Presenting dementia as "one of the greatest threats to humanity", Cameron draws upon the disease model of dementia in order to justify the further incursion of market forces into health care provision in the UK on the grounds that the solution to the problem of dementia lies in investing in global pharma and biotechs.

Whilst the Dementia Challenge strategy document details funding opportunities and a range of dementia initiatives, the notion that the lives of those with dementia and the work of their carers should be supported is brutally undercut by the coalition government's onslaught on welfare spending in the name of "hardworking tax payers". The effects of the latter objective mean that precisely those individuals and families whose emotional needs are apparently paramount are actually the subject of a swathe of cuts to local government funding and social care budgets. Research by Fernandez, Snell and Wistow on changes in the patterns of social care provision in England between 2005 and 2013 identifies widespread reductions in the period, amounting to a 26% reduction in the number of recipients of care (Fernandez et al 2013). One might view this as a failure of 'joined up thinking' or alternatively as an indication of the appropriation of the 'problem' of dementia for particular ideological ends in so far as the spectre of Alzheimer's offers a powerful image of the social and economic effects of the demographic changes we face thus justifying a range of austerity measures.

It is not incidental that "Alzheimer's" emerges into public consciousness as the name of a medical, social and economic crisis in waiting in the same period that sees the implementation of neoliberal economic policies in the UK under Thatcher and the USA under Reagan. A review of journal articles in the MEDLINE database indicates that the concept of care as burden (and of "caregiver burden as a recognised construct in this scholarship) emerges in precisely this period alongside the process that sees dementia re-constellated as "Alzheimer's Disease". The first journal article to describe the various costs of dementia care was published in 1980 (Zarit et al) and contributions to this 'problem' have proliferated since then in tandem with the kind of societal shifts I touch upon above. We also need to view this particular notion of the costs of care in conjunction with what can only be described as a relentless will to legislate around care and care-giving in the post-war period. This is something that has occured alongside the division of care into various domains of expertise and which has operated according to a 'top down model' in which the people who require support are deprived of much of a say in the matter. In terms of dementia, there are, of course, reasons for the emergence of this so called 'crisis of social care' tied to the demographic shifts and problems of longevity identified in every piece of literature on dementia that one comes across. However, what I am interested in exploring here is the way in which this particular way of thinking about dementia as "Alzheimer's Disease" comes to articulate a broader range of societal transformations and the ideological tensions that traverse them. This is to argue that Alzheimer's operates as a key ideological element not only in contemporary debates around the perceived crisis in social care and the consequences of an ageing population in terms of resource but also in our understanding of the affective dimensions of care and of the family as its traditional locus. It is here that I would argue an engagement with the imaginative literature of the age of Alzheimer's provides an important critical insight into the political and ethical implications of the biomedicalisation of dementia upon ideas of family and attendant notions such as dependency, choice and self-realisation.

Structures of feeling

I want to turn here to the concept of 'structure of feeling' – which is a term developed in the work of Raymond Williams, a scholar whose contribution to the elaboration of a politically engaged critical practice (cultural materialism) cannot be overstated. I think that an engagement with Williams' work allows us to interrogate the debates about Alzheimer's that I have been talking about in relation to the cultural forms (ideologies) through which people understand both themselves and the world around them. For Williams (1977), the challenge faced by critics is the tendency of any analytical or critical description to transform its object into something finished or complete, "formed wholes rather than forming and formative processes" (128). What this fails to grasp or encapsulate, he suggests, is what he calls the "undeniable experience of the present", the space "within which we may indeed discern and acknowledge institutions, formations, positions but not as fixed products, defining products" (ibid). His aim here is to identify forms of "feeling and thinking" which whilst "social and material" are not fully articulate or definite (ibid.131). This endeavour is, in part, about acknowledging social and cultural process and the interplay of what he terms dominant, emergent and residual elements in any culture, but it is also about acknowledging those elements of experience, forms of consciousness or feeling that fall outside systemic beliefs/world views and institutional practices. Structure of feeling, for Williams describes the "cultural hypothesis" through which he endeavours to capture this tension between systemic elements and emergent social experience. His interest in imaginative literature is in its capacity to capture this sense of dynamism and in its reflexive engagement with the interaction between societal and regulatory structures and interpersonal, social and cultural formations. His argument is that the ways in which language and the experiences it encapsulates are mediated in literary discourse through the use of particular generic and formal conventions and techniques serves to expose the kind of ideological tensions and changes in meaning that are often "masked by a nominal continuity." (ibid)

My reading of the imaginative literature that has emerged in tandem with the Alzheimer's epidemic of the last twenty years confirms Williams' recognition of the significance of imaginative literature in the expression and negotiation of the tensions between what he calls "practical and official consciousness" and emergent ways of "feeling and thinking" (ibid.131). One point that needs underlining is the fact that the incorporation of Alzheimer's into popular consciousness produces a plethora of novels in which the consequences of caring for someone with dementia and its impact upon familial relationships is placed at the centre of the narrative rather than at its periphery. This is to say that dementia and caring become significant enough problems to initiate narrative rather than provide merely contextual detail. This shift arguably reflects the extent to which the biomedicalisation of dementia and thus the separation of this form of cognitive decline from notions of “normal” ageing constitute it as a qualitatively different experience. The obligation of family members to look after each other which, in a sense, goes without saying in earlier periods, suddenly emerges as a problem around which questions of choice, guilt and coercion coalesce. Margaret Forster’s (1989) *Have the Men Had Enough* offers a meticulous anatomy of the emotional and social pressures that circumscribe care and dependency as they are played out, predominantly amongst the women in a family in which the grandma is increasingly incapacitated by dementia. The narrative alternates between the first person narrative perspectives of grandma’s daughter in-law, Jenny, and Jenny’s daughter, Hannah. In so doing, it enables an exploration of different perceptions of the difficulties of caring as they are experienced by each woman, each at a different point in their life and each with different degrees of responsibility for others. However, this very structure also presents the meaning of care and the limits of familial obligation as potentially irresolvable problems in that these differing narrative perspectives cannot be resolved into a singular response. There is a sense throughout the novel that grandma’s dementia presents the family with an intractable problem for which no obvious solutions are forthcoming. It is also worth pointing out that Forster portrays care as a problem for everyone except the disabled recipient and object of this discourse – grandma – who is not given any kind of voice but whose needs are at the centre of the narrative as it unfolds.

In the novel, Jenny’s perspective is informed by what is presented as an intuitive but problematic desire to protect her husband from the practical and every day aspects of care-giving, by her occasionally fraught relationship with her teenage children, and by a tense combination of obligation and irritation towards both grandma and Bridget, her husband’s sister and grandma’s primary carer. Her narrative account of the trajectory of grandma’s decline and death in residential care moves through a whole raft of emotional responses from the anger that characterises displaced guilt through to frustration and despair. In contrast to this, her daughter Hannah’s narrative records the family’s relationship to her grandmother’s needs at one remove: she is involved with aspects of her grandmother’s care, but is not an active participant in major decision-making, nor is she expected to shoulder the kind of responsibility that her mother and her aunt, Bridget,take on. Her narrative is often interrogative, organised around a series of questions that primarily revolve around her desire to make sense of Bridget's relationship and commitment to her mother:

> What I want to know is:
> How can Bridget stay so cheerful?
> How can she forsake Karl for Grandma?
> How does she manage to spend any time with Karl at all?
> Why does she not want to spend more? (Forster 1989: 132)

Hannah's questions structure a critical response to Bridget's commitment to her mother's care through the adumbration of a set of concerns about the quality of her happiness and the conduct of her relationship. Her speculations implicitly suggest that Bridget cannot really be cheerful and that she should prioritise her relationship with Karl. This evaluation of her aunt's choices is arguably shaped by the kind of broader cultural assumptions about the priority of some relationships over others that I identified earlier in my discussion of Bauman's (2003) concept of 'liquid love'. Hannah's questions are underpinned by a partially articulated notion that caring for the elderly is intrinsically burdensome and unproductive; in other words, spending time with grandma is not only incompatible with "cheerfulness" but it is also inappropriate given the presence of Karl as a more suitable object of affection. Significantly, Hannah also voices an uncompromising critique of her mother's desire to 'protect' her father and brother from the day-to-day difficulties that caring for grandma presents. In this respect, Hannah vocalises what could be described as a feminist critique of the traditionally gendered dimensions of caring but does so from a position that is infused by a characteristically neoliberal conception of the individual as the locus of all value. (Bridget's choices are incomprehensible to her niece precisely because they appear to sacrifice self-fulfilment for filial obligation).

A significant proportion of Forster's novel is devoted to the articulation of different familial responses to grandma's need for care. This is primarily oriented around the ways in which these responses are shaped by a combination of particular and contingent factors–gender and the economic dimensions of care clearly play a role, as do personal choice, family history, and other unforeseeable and contingent events. This multi-perspectival approach underlines the extent to which there is no disinterested or neutral position from which to address the difficulties with which the family is presented. Yet it also appears that these emotionally charged responses are preferable to the so-called ethic of professional detachment. This emerges clearly in the descriptions of the locked ward in which grandma eventually dies. Here Jenny's narrative describes a malignant social environment that reduces individuals to problems or inconveniences whilst over-stretched staff struggle to meet the needs of their charges:

> No one came forward to greet us but it was tea time, everyone was busy. All the old women were seated round a long table being fed. There were four staff for the twenty women. The noise was terrible–wild cawings as though a clutch of rooks had settled there. One woman banged all the time with a spoon on the table and another shouted, 'About bloody time! About bloody time!' over and over. I pushed Grandma to the table, glad that I was behind her and could not see her face. The four staff members, in yellow overalls, stared at us, I asked if the Matron was around. I said we were expected. One of them went off, grudgingly it seemed and came back with a small squat woman in a blue and white uniform … While she addressed me, a white-haired sweet-faced old woman got up from the end of the table and shuffled down to stand beside me. She put her hand on mine and made some sound I could not distinguish. 'Go away, Leah,' the Sister said. 'Go on, off with you, don't bother the lady'. I said she wasn't bothering me and asked Sister what she had been trying to say to me. 'She's deaf,' Sister said. 'Nothing she says makes sense, don't let her bother you, it doesn't bother us." (ibid: 202)

This passage is interesting in that it registers discomfort at the indifferent attitude of the ward Sister towards her patients but also expresses a degree of collusion with this perspective at the level of the descriptive language that Jenny uses to describe the women she sees. Her description of "wild cawings" and the transformation of the women into "a clutch of rooks" is echoed in the Sister's reduction of Leah to her deafness and her description of the "sound" that Jenny "could not distinguish" as nonsensical. This language serves to reduce the women they describe and their endeavours to communicate into something meaningless and animal. Indeed, it is interesting here that Jenny's descriptive language enacts a far more violent assault on the personhood of the women she views than the Sister's impatient, professional indifference. The whole passage expresses a violence at the very level of representation that underlines the malignant effects of this particular kind of institutionalisation and its impact upon people with dementia. There is a kind of horror in this related to the de-individuation that characterises the organisation of social care and the structural asymmetry of the professional caring relationship. The ward provides the women with basic elements of 'care' – food, security and help with washing and dressing – but does so without paying any attention to the particularity of the person. It is interesting to note that Jenny states some relief that she cannot see grandma's face – as if the exchange of glances would confer a degree of mutual recognition at odds with the dehumanisation of the other women and thus the decision to place her on the ward.

The culture of the locked ward is deliberately contrasted with the love manifest in Bridget's relationship with her mother in the sense that this embodies a form of care that is reciprocal and symbiotic; interdependent rather than dependent. Bridget does not conceive of her responsibility towards her mother as a burdensome obligation. However, this kind of relationship is presented as both atypical and unsustainable. It is precisely the notion that Bridget's desire to care for her mother is, in itself problematic, that serves as the catalyst that prompts narration. This very fact implies that this choice is both questionable and troubling enough to merit (and to sell and to market) a novel.

Forster's novel was published in 1989 prior to the kind of debates around welfare that are currently dominating governmental and media discourses but during the high point of Thatcherism and the particular form of individualism it fostered. The novel also predates the legal recognition of the rights and needs of non-professional carers in the UK. However, we can see in the younger character Hannah's narrative an endeavour to work through the relationships between her notion of the priority of the needs of the individual, gender politics and the problem of caring for someone who is no longer able to care for themselves. What I think we see emerging in Forster's novel is a fundamental shift in the notion of the family as the locus of care. This is evident in the very fact that the narrative focuses only upon the disputes, suffering and difficulties that emanate from the last stages of grandma's life. It is taken as read that the presence of a dying relative causes problems for the family, particularly those members of the family whose residual sense of obligation precludes them from simply putting grandma in a residential home. Operating alongside this, is the idea that Bridget's decision to place the care of her mother at the centre of her life precludes her from realising what should really matter in the form of "self-interested" choices with regards to career aspirations and romance. We see here, in embryonic form, the articulation of a notion of relationships as primarily instrumental or reducible to some kind of cost/benefit analysis. In other words, when Hannah asks why Bridget chooses her mother over her relationship with Karl, the question is oriented around the belief that the relationships that matter are those that involve "getting something back" for oneself. This perception of the priority of individual need over ones responsibility to others is bound up with the belief that supporting another represents a threat to personal autonomy. Bridget is certainly presented as making puzzling and frustrating choices as far as the rest of the family is concerned –her desire to care produces guilt, anger and occasionally pity but it is always the site of discord.

A question of form

In his analysis of late capitalism, Fredric Jameson (1991) describes a formation in which there is no longer any space or hinterland that operates outside the logic of the commodity. The major subjective consequence of this is increased atomization and reification. These are phenomena that begin in the period of capitalist modernity when small scale production is replaced by the division of labour in the industrial factory system and later processes such as post-fordism. This process reaches its height in our contemporary juncture with the kind of commodification of affect described by scholars such as Hardt and Negri (2000) and a culture in which the logic of the marketplace permeates life itself to the degree that everything from our Amazon browsing history to Facebook status updates are incorporated into the production of surplus value. In *Have The Men Had Enough?* we see how the family itself, especially the new generation in the shape of Hannah relate to the world in fundamentally individualistic terms. We can trace this through the use of the narrative technique of point of view. As Jameson argues, this narrative device emerges alongside the development of the nineteenth century novel and functions both as a reflection of the social and subjective experience of atomization, mediating "between the "superstructures" of psychological or lived experience and the "infrastructures" of juridical relations and production process" (Jameson, 2006, p.140), and as an imaginary compensation for this experience. The key point here is that although capitalism is about class rule, the interpellation of the individual is a crucial element in its ideological project; the notion that the individual is at the origin of meaning and action in the world both occludes the reality of class struggle and confers an illusion of individual agency. In earlier forms of literary realism (the set of conventions that underpin Forster's novel), the use of point of view or focalised perspective is often framed within an omniscient third person narrative. For better or for worse, this form of narration serves to articulate a sense of shared communal values or class consciousness that operates 'outside' the narrative, and therefore serves to orient, anchor or stabilise the position of the reader in relation to an ethical or political evaluation of the text. However, the use of different narrative perspectives in Forster's novel is not framed by a third person perspective – and this is indicative of a loss of shared values or sense of collective endeavour at the heart of the family itself.

What the novel plays out then, is an incapacity to orient individual experience in relation to those structural coordinates that determine the 'quality' of that experience. We are offered different perspectives on care but little sense of the wider social, economic and political determinants that underpin these perceptions and practices. At the level of both content and form, Forster's novel is unable to provide any kind of imaginary resolution (to borrow Jameson's formulation in *The Political Unconscious*) to the questions it raises. The only way the story can come to a close is with grandma's death -- an event which operates outside the logic of the plot which is primarily driven by the conflict between the different family members. Far from addressing the problems of care that both Jenny and Hannah's narratives explore, this conclusion simply removes the origin of the problem but does so in a way which does not affect any particular transformation or learning on the part of the family. There is a sense here that the novel cannot move beyond the cognitive/cultural limits of the model of ageing, dependency and dementia that it -- at times -- appears to critique.

The novel raises two questions then. First, what do we understand by the concept of family in the age of Alzheimer's? And second, related to this, what do we understand by notions such as autonomy and individual self- realisation in this context? There is an obvious paradox in the notion that caring for a family member is at odds with the needs and aspirations of the individual and that the necessity to care somehow disrupts one's desired life narrative in that the reality of our ultimate and inevitable impairment always already consigns these beliefs to failure. However, it also gives rise to a culture in which to be disabled or old or chronically ill is to be an "unfair burden"; to be that which impedes or disrupts the fantasy of unfettered autonomy for the family member charged with your care. One sees in this what Slavoj Zizek describes as the onslaught of instrumental/objectivised 'alienated' public exchange' into the private sphere wherein support for another is reduced to its cost in a whole number of senses. Ultimately it is the person with dementia – grandma -- who embodies the problem, rather than the ways in which her dementia is perceived by the different family members and in the narrative as a whole. The novel plays out the failings of the social care system, questions the vestigial sexism that shapes both the men's (and Jenny's) attitudes to this problem and expresses the nascent effects of the kind of individualism that Thatcherism fostered, verbalised in Hannah's narrative. However, the particular conception of dementia at its centre means that it remains caught between the logic of these positions and is therefore unable to move beyond them to imagine a new sociality or collective response to the problem of caring and its impact upon the way we think about family relationships and the meaning of love itself.

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