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CARNIVAL AND DEMENTIA: IS IT HERESY?

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Do members of the audience feel that they know something about dementia? About a third to a half. This is not surprising given its cultural visibility. Do people have a direct knowledge through family, friends or neighbours? This question is asked, not to be intrusive or exposing, but to clarify our respective positions-the difference perhaps between the mere attitude and the more proactive and engaged position of a stance. The distinction is important because I may, probably will, be saying things which may challenge the cultural and medical take on the disease. Whilst I will talk about dementia there are of course many dementias and although they share an underlying pattern of gradual loss of cognitive functions and behavioural change, every person who develops dementia does it differently, at their own pace and with their own very specific presentation.

My stance is that of an ex NHS clinician who worked for decades in older people's services and who latterly developed and worked in a memory clinic taking many hundreds of clinical histories and hearing stories about dementia. Sometimes, when describing my work to people they would tilt their heads in a counselling mode and say things such as "I don't know how you do it...it must be so sad..." Of course it was, but this was a clinic in which there was a surprising amount of laughter which could be either alarming or a comfort to people in the waiting room. The laughter was a carnival driven, universal laughter – with, not at – an aspect of carnival Bakhtin describes as reinforcing ones place in the world 'he who is laughing belongs to it' (Bakhtin 1984, p.12). He would argue that we have lost some this equalising laughter in modernity and the negative satire of today. Martin Amis' Grace Pepperdine in *Lionel Asbo* (2012) is not a portrait of dementia driven by compassion and empathy. The laughter in the clinic was generated by stories of the scrapes, escapades and predicaments of early memory loss. Lost cars, puddings served with main courses, the repeated purchase of unlikely items and the wearing of many layers of clothing including the toilet mat worn as a shawl fastened with the old fashioned nappy pin. The patient, her daughter and I, agreed that it was a creation worthy of the most

avant garde of fashionistas and out did anything Vivian Westwood might create. One of these escapades, or a series of events, would have occurred which had concerned either the person or others to seek referral to the clinic so the laughter was predominantly created with people at the start of the diagnostic process.

Dementia is as we know a long illness and the predominant discourse, perhaps the only discourse available, is that of the medical model. Psychologists and other social commentators such as Oliver James have tried to offer an alternative reading but they lack the heft of the medical model which drives the headlines and the media coverage which is relentless.

I am not saying that dementia is fairy-lights and fun but there were enough stories to make the clinics hugely engaging, and interesting. When looking at the portrayal of dementia in contemporary fiction it is usually understandably respectful and serious and the sometimes daftness of dementia was never related in fiction until I read *Half the Kingdom* (Segal, 2013). It was the book I had been waiting for in the same way, that ploughing through literary theory not much of it made me laugh or smile until I came to Mikhail Bakhtin, a literary and cultural theorist who has a chapter on the history of laughter. He was clearly my kind of person.

Bakhtin (1984) is most renowned for his concepts- dialogism, polyphony, heteroglossia and carnival. Although I think they all have something to say about dementia, it is the concept of carnival to which I want to turn in relation to *Half the Kingdom* (Segal, 2013) and dementia.

The key aspects of carnival are the breaking down of barriers, overcoming power inequalities and hierarchies and the reforming and renewal of relationships. In carnival there is no maintenance of the status quo. This could be a definition of dementia. There is free and familiar contact between people, there are misalliances, there is crowning, whereby the previously unimportant becomes principle only to be de-crowned later, and there is parody. It is of course, a concept which is contested on both historical and political grounds.

Let us accept carnival as Bakhtin describes it while accepting that there are constraints and limitations in its cultural power of elucidation. It is not as pervasive and powerful as dialogism and polyphony which has been absorbed into of the oeuvre of French literary theory.

Bakhtin's concept of carnival is developed in his book *Rabelais and his World* (1984) where he draws on literary and historical sources about medieval carnival and festivity where anything goes. In carnival, life is subject to its own laws, the laws of its own freedom. He describes carnival as a time out of life when the normal rules are suspended for a brief and defined period of turn-about and inside-out-ness. It is not Notting Hill or Mardi Gras. In his introduction to the book Michael Holquist (Bakhtin, 1984, p.7) reminds us that 'carnival does not know footlights...it does not acknowledge any distinction between actors and spectators.' It is not spectacle, it is not seen, but lived. There is a point where this is true of a dementia. As insight fails the person lives their own life to their own individual beat developing their own internal rhythm, eating only marmalade sandwiches, conversing with the television and turning night into day. This is a freedom of sorts and often happens in a complete unawareness of the havoc and anxiety they may be causing supporters so I am not saying that it is easy. It isn't, it is probably the most difficult period of care and support, it is hard to reassure people that it will end, that things will change, as carnival does, because the following stage of the dementing process is one of increasing physical frailty and an ever increasing absence of the old self.

What carnival may do is offer an alternative construction to behaviours which the medical model would describe as BPSD, the Behavioural and Psychiatric Symptoms of Dementia. Selling it to families using the term carnival might be difficult but not impossible. As a model it offers a different understanding to that of the 'second childhood' in which behaviours which are hard to comprehend are so easily construed as naughtiness.

Half the Kingdom is a carnivalesque novel. It begins with a nonagerian telling a health care assistant in no uncertain terms that 'You do not, you do not tell me to relax! I will not relax,' (Segal, 2013, p.3). We already have a carnivalesque inversion, as this is not how ninety year olds are meant to behave. The action takes place in a New York Hospital ER department a place to be viewed as outside officialdom—which it turns out to be. The key players are Joe Bernstine the terminally ill retired director of the Concordat think tank, Lucy, widow of his great friend who is a "barely literate seventy five year old poet with emphysema," (Segal, 2013, p.10). Joe heads the Wide Open Eye group and employs Beth, his angry daughter, Benedict, Lucy's son and Al Lessor the computer whiz kid. Together they are researching an

encyclopaedia for *The Compendium of End-of-World Scenarios* (Segal, 2013, p.5) and working on titles such as *The NO-NONSENSE Guide to TERRORISM* (Segal, 2013, p.8). Here Project Head Cold (Segal, 2013, p.7), by which a strategic delivery of an epidemic cold germ means that both armies run out of tissues and want to go to bed not war, is given a degree of credibility. Here is parody and the carnivalesque turn-about. The reversal of hierarchies means that the oldsters are in control. Such positions are negotiated throughout the novel with many observations about being old, and in being particular an old parent. In dealing with the decomposing apple stuck in the tangle of wires behind the computer she says to her great friend, Joe's wife:

Today in the office I knew that picking up a grown son's sweats from underneath his chair impinges on his liberty so I did it quick, quick, like gulping forbidden food before the calories register... (Segal, 2013, p.22).

Restaurants are chosen because they have accessible loos on the ground floor and Lucy muses about why the literature does not address the bodily functions we all share- a classic aspect of carnival. Following a spate of copycat, fast onset Alzheimer's disease, the Wide Open Eye group are used by the doctors to investigate what might be going on, this may be an act of terrorism in the post 9/11 world and they investigate by direct observation. They become ethnographers. The 'youngsters,' Benedict and Beth, pose as Social Workers and Lucy and Joe get themselves admitted.

The narrative, delivered in short vignettes is farce and carnival of the highest order. One of one of the aspects of Bakhtin's carnival is language and one of the most comical episodes is Benedict mis-reporting a patient as a manager of a pepper rather than paper, mill. Here we have the inversion of the non-expert becoming expert, false information becoming reified- as I'm afraid it can be in medical notes.

Through the eyes of Beth and Benedict we come to know the back stories of the 5 people admitted through ER:

- Ida Farkasz- brought in by her neighbour
- Ilka Weiss, brought in by her daughter who is experiencing the social work department as Kafka writing 'slice of life fiction' (Segal, 2013, p.57)
- Francis Rhinelander who always hears music

- Samson Gorewitz who liberated himself from a care facility, tagged behind a family en route to the beach, couldn't tag himself back as his stroke was mistaken for sunbathing and nearly drowned as the waves crept up the beach. He is visited by his double act sisters.
- Luba

All these people admitted to the ER develop fast onset overnight Alzheimer's disease and will find themselves on The Seventh Floor which has been opened as an emergency reception centre.

It is on this 7th floor where we see the most contentious aspect of Bakhtin's carnival in full glory. Grotesque realism is a controversial and complicated concept linked with the degradation of the body – particularly the female body. Grotesque images are linked to copulation, pregnancy, old age disintegration and dismemberment. This does not seem a promising view for the 7th Floor and yet there is a profound honesty here about the materiality of the ageing body that is not matched in any other novel featuring dementia. For Bakhtin degradation is not accepted in the commonsense view but as incessant reminder that we are all flesh. The ravages of old age are described in throughout the narrative, even before the 7th floor we see Ida Farkasz 'the crooked old woman' glaring at Lucy over 'the top of her glasses that must have been fitted when the face was better fleshed, because they were on a slide down the nose to a hairy chin,' (Segal, 2013, p.52).

On the 7th floor there are, what Segal (2013) describes as a "congregation of gargoyles":

The huge old black woman might have been poured to overflowing into her wheelchair; her mouth stood open as if there were no room inside for the endless lolling of her purple tongue. The freakishly long thin, banged up old Don Quixote wore an anachronistic smile and so did the little stick figure manikin next to him, and next to him, her waist bent at a ninety degree angle, was the prototype of Hansel and Gretel's witch, whose crooked nose met with her stubbled chin. And when Hope turned to Nora's loved face, she saw it rammed down to the left into the shape of an earlier phase of the human type: Nora was watching an old peasant that we don't see on the New York Streets,

who was unbuttoning her dress. She reached her navel as the Sabbath elevator opened its doors to discharge its cargo on the Senior Centres 7th floor, (Segal, 2013, p.125).

We have the description of uncovered buttocks up tight against the cot sides of hospital beds – a view which would and should make the Care Quality Commission throw up their hands in horror.

The descriptions are tough but not malign, slack jaws and drool are honest and empathic confirming carnival as non-spectated but lived.

On the 7th floor there is not only the grotesque realism of carnival but parodic inversion of something which Google have not yet invented. This is the:

'Twice Told®, a plastic head band with a built in nano-computer that translates the movements of eye and facial musculature of the person sitting across from you and tells you “You’ve told this story to this person before” *before* you have started telling it once again, (Segal, 2013, p.139).

On the 7th floor the reports on the ‘sixty-two-pluses’ (Segal, 2013, p.163) admissions are ready- including the ones on Joe and Lucy, admitted as observers. What has intrigued Joe is that:

...all our vitals are good. The terrorists’ problem is two pronged: they have to drive us insane while they keep us indefinitely alive. We are dealing with an enemy of enormous sophistication, ingenuity and patience. They are able to imagine a west entirely populated by demented, heart healthy centenarians, (Segal, 2013, p.150).

This is carnival addressing not only the indignities and fears about old age but the social issue of dementia as ‘burden’ which dominates the headlines.

Throughout the novel there are deeply poignant 7th floor situations, for example ‘boys and girls cannot be in the same room, even ones that have been legally married these five and forty years,’ (Segal, 2013, p.150). Jenny, Joe’s wife, and not involved with Wide Open Eye offers an alternative view of old age as optimistic and kind. She had confessed to her doctor that she had not been taking her antidepressant pills because she didn’t feel depressed. She saw noticed and appreciated nice things

happening around her, mothers smiling at babies, cabbies rushing to ensure a teddy bear is not left behind, but the doctor with ‘the awkward air of a man not getting a joke. He said ‘It takes time to combine the right medications in the right dosage (Segal, 2013, p.20) and so Jenny is admitted to the 7th floor diagnosed with bipolar depression stuck in the phase of euphoria.

The nakedness of grotesque realism unites us as readers and humans anticipating the 7th floor. Lucy, now in a hospital gown, observes herself reaching behind herself to undo the tie at the back of her neck and the one behind her waist. She has not been identified as part of the Wide Open Eye observation group because she had placed her belongings in a patient property bag and thus for the kind but forceful aide— despite her protestations— she has become a patient and thus equal on the 7th floor. The fragility of ageing with dignity is all there in the ties of hospital gowns and a plastic bin bag.

Is this a heretical stance? Yes, I think it is, because it subverts the medical discourse and thus medications for BPSD.

This is transgressive, dangerous writing about dementia and ageing unparalleled in my navigation around contemporary fiction. We have dementia as central in a satirical parodic novel. I think that the age of the author is important. At age eighty five Segal does not need to show a false respect for old age. As a reader we know that most of the inhabitants on the 7th floor are cared about, but this is not a pretty old age. As the ‘youngsters’ have to bear witness, it is us. We are the future inhabitants of the 7th floor. There is no otherness.

Lore Segal’s history as number 152 in the Kinderstransport and subsequent experiences in foster care in the UK made her into what she described as ‘an unwilling anthropologist’ in her 2011 Bookslut interview. We see the echoes of observation in the Wide Open Eye group. The great Maggie Kuhn- now I suspect forgotten but immensely formative for me both professionally and personally – was herself forced into retirement from a job she loved, and so she set up the Gray Panthers, the great American campaigning group and campaigned actively against the Vietnam War. She could, she said, because she had nothing to lose. We have nothing to lose and much to gain from reading Lore Segal’s dark satire but we have a lesson to learn- always take your own bag, using a patients property bin liner is

likely to lead you sooner than you may wish to the 7th floor, a place which ultimately awaits us all.

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