

The personal is political

Ming Ho

I never used to consider myself a political writer. I never used to consider myself a political person. That was a privilege. I was lucky to have had an early life untroubled by direct experience of injustice. Despite my mixed heritage, I never felt myself to be socially disadvantaged by race; my upbringing was comfortably middle-class. The sudden death of my beloved father in my final year of university was an emotional trauma that has reverberated through the rest of my life, but it didn't diminish my status in the world. It took a later change of circumstance to teach me how it felt to be invisible, worthless, disenfranchised: becoming a carer to my mum.

My mother, Glenys, was nine years older than my dad. When he died of cancer at the age of only 52, she was nearing retirement and I – her only child – was about to graduate and leave home. With hindsight, I believe these concurrent shocks triggered the beginnings of dementia that over the next thirty years would claim her faculties and ultimately make her dependent on residential nursing care; but at the time neither of us saw that coming.

I moved to London and gained a foothold in TV drama, working in development as a script editor; mum adjusted to widowhood and living alone, learned to drive, redecorated the house, and got a puppy. For a few years, life was good. We spoke most nights on the phone; I returned home

every other weekend, and we'd enjoy meals out, trips to the theatre, holidays, and shopping in town. The TV industry is never secure, but as a script executive, I had a staff job with a regular salary and a degree of prestige, albeit at junior level. I fully expected to build on that. As mum put it, 'You're on your way now!'

In the early 2000s, I branched out as a scriptwriter on series such as *EastEnders* and *Casualty*, a source of excitement and pride for mum. However, it was around this time that her dementia came to the fore. The classic symptoms of everyday forgetfulness and repeating herself in conversation were frustrating, but not too troublesome; but then came the incidents of losing her bank card, forgetting her PIN number, locking herself in or out of the house, paranoid episodes of mistrusting friends and neighbours, and the attendant distress this caused.

She became unable to manage her finances, and I informally took this over, along with cooking, cleaning, washing, grocery shopping, making appointments and taking her to the doctor, dentist, chiropodist, hairdresser and optician - even supervising major building works for subsidence, which mum had resisted until there were gaps in the wall big enough for birds to fly in. I didn't begrudge her that support, but the extent to which it took over my life and affected my ability to work crept up on me incrementally; it wasn't a conscious choice.

As an only child, I had anticipated that physical frailty would make mum more dependent on me in old age, but I had no understanding of cognitive disability and how it impedes planning for care – in particular, anosognosia, a condition that prevents a person from recognising their own disability. My mum was simply unable to accept that she had any care needs at all.

Consequently, she refused outside help, let alone diagnosis of the dementia itself.

Without realising it, I became her 24-hour sole carer and found it impossible to keep on the treadmill of long-running drama series, which also demand 24/7 commitment. I fell out of professional circulation; and because mum's impairment remained undiagnosed and I did not live at the same address full time, I had no status in that caring role either, unacknowledged even by mum. We were on our own, invisible to services – and vanishing to the outside world.

In the summer of 2011, I had to make the heart-rending decision to place her in residential care. I felt the trauma acutely, but once the initial hurdle was over, mum settled surprisingly well and gained strength with a regular routine and diet. I realised that while she needed someone with her round the clock, that person did not have to be me, as I had believed for so long. Her grasp of who I was had begun to erode years before; by the spring of 2014, she had effectively forgotten me, although I continued to visit her every week until her death in 2020.

So, who was I? Even I wasn't sure. Not a working writer; not a registered carer; not recognised as a daughter. My university contemporaries now held the highest office in the land; my former colleagues in TV drama had their own series; but I was nobody, not even to my mum. And over the next few years, as government increasingly mythologised the 'hard-working family' – people with children, who earn and spend – I was left in no doubt of my erasure. If an existence that doesn't generate revenue is worthless, if that decade of love and devotion, unpaid care, and lost earnings meant nothing, I was a non-person. I began to appreciate how it feels to be

unemployed, disabled, or otherwise excluded from social and political respect.

With mum in a home, you might think I was free to rebuild my career and identity, but responsibility for a loved one with dementia doesn't end with the move into residential care – it's the beginning of a whole other phase of advocacy.

I had obtained official diagnosis from a clinical psychiatrist in order to apply for Court of Protection Deputyship to manage mum's financial affairs and sell the house to pay her care fees. At this point, I became aware of the artificial divide between health and social care, the former being publicly funded, and the latter means-tested. Dementia, in all its many forms, is a degenerative disease of the brain that can progress to impact on every aspect of a person's daily activity and being. Everything you have learned since birth can be unlearned – how to walk, talk, eat, drink and manage your bodily functions; reasoning power, spatial awareness, memory that orientates you in context of time, place and family. Ultimately, as happened to my mum, it can make you bed-bound, dependent as a baby. But because there is no medical cure and very little available treatment, it is counted by the state as 'social care', not a health condition, for funding purposes.

Mum's care, latterly in a nursing unit, cost up to £1,400 per week by the end of her life; and because she owned her own home and had savings, she did not qualify for any funding for most of that time. Fair enough, you might think; if she could afford to pay for care herself, so she should. Yes, we were lucky to have assets that gave us a degree of choice and autonomy. But autonomy is a mixed blessing when you have no knowledge of social care systems. Today I know that everyone needing or giving unpaid care is entitled to a local authority assessment to signpost them to

services, however those services are funded; no-one told us that then. I had to find, negotiate and manage mum's care by myself.

In 2015, crisis in her formerly exemplary care home further awakened my political antennae. Following a change in management, standards of care fell dramatically, while lavish cosmetic refurbishments took precedence over staff cover. Just before Christmas that year, mum was rushed to hospital with potentially fatal aspiration pneumonia. There was no-one to accompany her on possibly her last journey, because there were too few staff on duty for anyone to leave the premises. I raced the 100 miles from London to be with her, fearing all the way that I would be too late, but fortunately she survived.

In fighting for her through the subsequent complaints process, I learned more than I had ever wanted to know about how the sector is run – on bare minimum cover, charging maximum fees for minimum provision, using workers on the minimum wage. Staff (mostly female) of sometimes 20+ years' experience were often still on £8.50 an hour, because they didn't have paper qualifications that trigger an upgrade in salary (regardless of practical skills that merit far more), and were unable to get those qualifications because their 12-hour shifts don't leave them time or inclination to study. The average catering budget, in homes charging up to £2,000 per week, is £4 per person per day.

The pandemic has brutally exposed the staffing crisis in social care, exacerbated by Brexit, but the sector was already struggling. Noises are now being made about raising wages, without a coherent plan to fund that rise, while government ministers and pundits who are themselves driven by money cannot see that pay rates are not the only incentive to work. Care requires social skills and personal values of compassion, empathy and

intimate trustworthiness that not everyone may possess; and conversely, poor working conditions and status, unsocial and unpredictable hours, and lack of childcare for a predominantly female workforce may be stronger disincentives to enter or stay in the sector than poor pay alone.

There is a huge gender equality issue here: social care, I believe, is always shunted down the list of political priorities because it impacts primarily on women as both givers and receivers of care; the majority of care workers, unpaid carers, and care home residents, are female.

Despite the apparent gains of feminism in the last hundred years, society still operates on the assumption that care is the natural domain of 'the family' – i.e. usually women at home – and anything beyond this is not a collective responsibility but a private facility of last resort that we don't want to think about, much less resource fairly. We see this in government exhortations for 'the family' to do more, so that it can do less; but with one in five UK citizens over 50 now ageing without children (as am I), for many that simply won't be an option.

After years of enforced silence, frustration - and yes, anger - at what I've learned has fuelled creative rage that has helped me to rediscover my voice. I started a blog – *(Dementia Just Ain't) Sexy* – which allowed me to publish my thoughts unmediated by the editorial demands of a commissioner; and in 2012 I joined an organisation called Uniting Carers (since disbanded), a campaigning arm of Dementia UK, which brought together unpaid carers for mutual support and to contribute to research and education.

Over the next few years, I attended numerous government and charitable consultations, contributed to research studies and spoke at conferences around the country; but as time went on, I became disillusioned with the

dementia industry – of which I had been entirely unaware while wrestling daily with the disease behind closed doors with my mum. I realised that at most of these events, where politicians and care professionals gathered to promote their policies, research papers, or commercial services, those with first-hand, lived experience – people with dementia and their carers – were the only ones in the room not being paid for their time and expertise, when it was they who most needed the money (let's be honest!) and validation. Despite the good intentions of many professionals in the field, at a systemic level, it seemed that we were pawns in a political game of platitudes.

Nearly ten years on, there's more public awareness of dementia as an issue, and more proactive input from charities (including Dementia Carers Count, an organisation specifically for unpaid dementia carers, whose Carers Advisory Panel I have chaired). But there has been precious little change in the way of practical support from the state. Blog posts I wrote in 2013 about government's response to the Dilnot Report (proposing a cap on individual lifetime costs for care) still stand; the situation is indeed worse with cuts to central funding. We are still haggling over who pays or doesn't pay, with no progress on reform of the actual services, whose commercial model inevitably puts profit above provision.

However, the confidence I gained from blogging and speaking out on these issues enabled me to return to drama, writing a play, *The Things We Never Said*, inspired by my relationship with my mum, which won the Writers' Guild award for Best Radio Drama 2018. Other works for radio, stage, and film have followed, and I hope to return to TV soon.

In a time of Covid, when frontline workers in health and social care, education, food production and logistics are obviously essential, I find myself asking what we can contribute as writers. I have sometimes felt

that fiction is too soft a medium for the urgent crises of our time – perhaps documentary and journalism are more worthwhile outlets? But he who pays the piper calls the tune, and journalism cannot be regarded as neutral and objective, any more than fiction. Culture wars have been weaponised. Storytelling – from English exceptionalism and nostalgia for empire to the demonisation of immigrants – has become the dominant tool of populist ideology.

Those who oppose the ‘me first’ values of the far right have to ‘take back control’ of the narrative. What fiction, and drama in particular, can achieve is empathy. Jack Thorne’s fast-response Channel 4 TV drama, *Help*, set in a Liverpool care home in 2020, is a recent example that cuts through the white noise of empty promises and tabloid slogans. That ability to make us feel, to weep and laugh, and to rage, is our greatest weapon as writers. Every action we take, every story we tell, has a political implication. I may have come to this realisation later in life, but I know now that whatever I write is political. It cannot be otherwise. And I embrace it.

Ming Ho

Ming writes for stage, screen, and audio drama. Her play, *The Things We Never Said* (BBC R4; featuring Siân Phillips and Lia Williams), won WGGB Best Radio Drama Award, 2018. Other credits include *EastEnders*, *Casualty* (BBC TV); *Heartbeat*, *The Bill* (ITV); *Riot Girls: Male Order* (BBC R4), and commissions for LAMDA, RADA, Leeds Playhouse, and Theatr Clwyd.

Born in England of Chinese/Welsh heritage, Ming wrote *Citizens of Nowhere?* for Chinese Arts Now (Southbank Centre & Edinburgh Fringe), exploring roots and identity in Brexit Britain. Its central character, aspiring

Tory politician Jane Lo, spawned short film *British People*, commissioned as part of *The Uncertain Kingdom* anthology (2020).

Ming has also worked in TV drama development, script editing series such as *Hamish Macbeth* (BBC) and co-creating *McCready and Daughter* for Ecosse Films/BBC Northern Ireland. Her play, *Exhumation*, written at the Royal Court Theatre Writers' Group, was workshopped there with director Lucy Morrison.

The trauma of gradually losing her mother to dementia over a twenty-year progression of the disease inspired Ming's signature piece, *The Things We Never Said*, and led her to become involved in campaigning on behalf of people living with the condition and their family carers; she sits on the Carers Advisory Panel of charity Dementia Carers Count and the Advisory Board of Raising Films, an organisation supporting parents and carers in the screen industries. Her blog (Dementia Just Ain't) Sexy chronicles her experiences and thoughts on the issue.

In 2019, she was Writer in Residence at Theatr Clwyd, which also sponsored her on Sphinx Theatre's Sphinx 30 development programme, a main stage play seed commission for women writers. She is currently working on two classic dramatisations for BBC Radio 4 (set respectively in Russia/Ukraine and Hong Kong/China), due for transmission in 2023, and developing TV projects.

<http://dementiajustaintsexy.blogspot.com>

A recording of this talk can be found at **writersmosaic.org.uk**

© Ming Ho