

# CARING FOR THE DEEPLY FORGETFUL: COMMENTARY ON 'BIRDIE' SHORT STORY

SANDRA LATIBEAUDIERE

You would not expect Birdie, a woman with dementia, to cause such a stir using her pen and wit. And so, care workers who do not understand the disease and its stages will not know what to make of her and how to deal with her behaviour.

According to the National Institute of Aging (2021), Dementia is a collective a term used to describe any condition that causes a deterioration in a variety of different brain functions such as memory, thinking, recognition, language, planning and personality. The two main types are Alzheimer's disease and vascular dementia. There is also mixed dementia in which there is evidence of Alzheimer's and vascular disease. Other types include dementia with lewy body and fronto-temporal dementia. The prevalence of each type varies across region with Alzheimer's disease being the most common with 50–60% of cases, vascular dementia varies from 15% of the cases in Latin America and the Caribbean to 20% in Europe and 50% in Japan (Wolters & Ikram, 2019). But, a 2012 study of 2,943 elderly persons—conducted in Jamaica by Mona Ageing and Wellness Centre—found that vascular dementia is the most pervasive. Vascular pattern dementia accounted for 33% and 50% of those defined as Alzheimer's also had vascular disease (Eldemire-Shearer et al., 2018).

Alzheimer's disease has three stages: mild (early), moderate (middle), and severe (advance). I believe Birdie is at the early stage evidenced by symptoms such as short-term memory loss, misplacing things and forgetting names, and subtle personality changes. But it is at the moderate and advanced stages—when persons living with Alzheimer's are unable to perform activities of daily living inclusive of dressing, bathing, eating, toileting, and movement around the house and instrumental activities of daily living, such as driving, meal preparation, shopping, and taking medication (Plummer, 2016, pp.51–52)—that family members will, with great personal pain, put their relatives in a nursing home. This decision often leads to feelings of guilt, as the perceived sociocultural expectations are that relatives are obligated to care for their older family members and to do otherwise will earn you the mark of shame for being disloyal and abandoning your relative.

Unfortunately, many older adults at the early stages of the disease find the experience of living in a nursing home to be constraining and dehumanising. Due in part to the fact that nursing homes function mainly as institutions, in that residents have scheduled times to do particular activities (Birdie is awoken at 5 a.m. to bathe, a set time to pray, eat, go to bed), there is limited personal space (“even though you would swear say this is my room and everything in it belong to them door pushing nurse who love bright with me. If was really my room. I would have a key”), and individual choices are taken

away ("Miss Birdie, wake up, is time to bathe. What you mean bath time? You see how outside black; how not even fowl leave them roost yet?"). In fact, the nursing home model tends to warehouse older adults (Birdie is left to her own means and no social interactions except when the nurse comes to perform the routine ADL tasks, "I wanted some sensible conversation" ; "three weeks since that (incident) and now they keep me in this back room... I get lost dreaming... I am going pale from no sun"), especially those with dementia, and treat them using the medical model that focuses only on their physical needs. A person living with Alzheimer's is not a shell or child. It is not surprising that Birdie's behaviour would be deemed oppositional and defiant to the care workers, such as the practical nurses, occupational therapists, and social workers because they are the professional experts and she is just the passive recipient of care.

This notion of "the professional as expert" serves to centralize the unequal resident (passive recipient of care)-worker (expert) interactions. For social workers working in these kinds of institutions it can be ethically problematic for them as the dual character of the profession as "caring and oppressing" (Dominelli, 2002) is most prominent. In a Gleaner article titled *Nursing Home Anarchy - Government Loses Handle On Ballooning Rogue Facilities* it was reported that there were more unregulated nursing homes than registered ones and that older adult residents were at risk for poor outcomes, such as neglect and abuse, due to poor practices in relation to staff-patient ratio, untrained personnel, etc. (Davis, 2019).

For social workers, in particular, to optimize the experience of persons living with Alzheimer's in nursing homes will require an ideological shift and some practical steps. The social work profession is framed by two ideological influences that inform the profession's practice, namely casework (micro practice) and social justice (macro practice). For a long time, the profession has given the primacy of place to casework which invariably sees social workers acting as agents of control thereby maintaining the status quo to the neglect of human rights, social justice, and social change. Social workers working with persons with Alzheimer's in nursing homes will most likely do so in an administrative capacity. They will be required to adapt a critical social work theory that not only recognizes oppression (the erasure of the individuality of the person with Alzheimer's; "she rip me clothes off, strip me down to nothing then rub me close to raw in the cold water") and its causes (ageism, "Miss Bird's complaints are simply the words of an aging woman resisting change...challenge with adjusting") but will be expected to respond using appropriate micro-macro level interventions such as tailoring programmes to meet the needs of the person with Alzheimer's at the different stages of the disease; balancing social, leisure, productive, and spiritual activities; talking to the individual, not at them; and seeing the individual as a person ("when I just reach here, I remember feeling pleased that someone finally agreed with me that teatime could be any hour...but I was wrong...they wake me up with an ice bath to balance me out"). By taking this kind of approach the person living with Alzheimer's is at the centre, it is based on strengths and abilities; the focus is on building partnership, collaboration and inclusion; the language is humane and supportive, for example, person-first language; and most of all it is transformational. In this framework, caring for someone living with Alzheimer's disease he or she is seen as unique, more than the disease, and with each interaction the care worker enters the world of

the person with Alzheimer's. It is only in this way can social workers in nursing homes and similar institutions make a difference in the lives of the deeply forgetful.

Sandra Latibeaudiere, MSW

Coordinator of Programmes

Alzheimer's Jamaica

Lecturer

Department of Sociology, Psychology, and Social Work

The University of the West Indies, Mona

sandra.latibeaudiere@uwimona.edu.jm

### References

- Davis, K. (2019, March 10). Nursing home anarchy - Government loses handle on ballooning rogue facilities. *The Gleaner*. <http://jamaica-gleaner.com/article/lead-stories/20190310/nursing-home-anarchy-govt-loses-handle-ballooning-rogue-facilities>
- Dominelli, L. (2002). Anti-oppressive practice in context. In R. Adams, L. Dominelli, & M. Payne (Eds.), *Social work: Themes, issues and critical debates* (2nd ed., pp. 3–19). Palgrave.
- Eldemire-Shearer, D., James, K., Johnson, P., Gibson, R., & Willie-Tyndale, D. (2018). Dementia among older persons in Jamaica: Prevalence and policy implications. *West Indian Medical Journal*, 67(1), 1–8. <https://doi.org/10.7727/wimj.2017.133>
- National Institute on Aging. (2021). *Basics of Alzheimer's disease and Dementia: What is dementia? Symptoms, types, and diagnosis*. <https://www.nia.nih.gov/health/what-dementia-symptoms-types-and-diagnosis>
- Plummer, P.Q. (2016). Families providing care across generations: Pickle in the middle. In S. E. Crewe & C. Galding-Cole (Eds.), *African American caregivers: season of care practice and policy perspectives for social workers and human services professionals* (pp. 51–62). Nova Science Publishers.
- Wolters, F. J., & Ikram, M. A. (2019). Epidemiology of vascular dementia: Nosology in a time of epimics. *Arteriosclerosis, Thrombosis, and Vascular Biology*, 39, 1542–1549. <https://doi.org/10.1161/ATVBAHA.119.311908>