# "I WISH YOU WOULD JUST DIE!" MANAGEMENT OF DEMENTIA WITH BPSD, AND CAREGIVER STRESS

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## ABSTRACT

**This is a case of a patient with Behavioural and Psychological Symptoms of Dementia (BPSD) causing caregiver burden in her husband. The family physician was able to lead a multidisciplinary team to manage and optimise her care in the community.**



**Keywords: Dementia; BPSD; Behavioural and Psychological Symptoms of Dementia; Caregiver Burden; Caregiver Stress;**

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## INTRODUCTION

This is a case of a patient with Behavioural and Psychological Symptoms of Dementia (BPSD) causing caregiver burden in her husband. The family physician was able to lead a multidisciplinary team to manage and optimise her care in the community.

## CASE PRESENTATION

I first encountered Madam CYK, an 82-year-old Chinese lady, when she came for her regular follow-up for her chronic conditions of hypertension and hyperlipidaemia. She was accompanied by her husband who complained that she had become hard of hearing lately. She had seen her GP the previous week and had been using olive oil ear drops in both ears, and he was keen to remove the ear wax that day. During the consultation, he had to talk very loudly to her and was frustrated when she could not understand him. This, in turn, made her increasingly agitated. When I tried to perform otoscopy for her she pushed me away. Her husband and a nurse assisting me with translation tried unsuccessfully to pacify her in Cantonese. She accused us of trying to steal her money. Her husband at this point was so frustrated that he shouted, "I wish you would just die!"

I proceeded to de-escalate the situation using verbal and nonverbal cues (putting away the otoscope, speaking slowly and softly) and allowed the husband to vent his frustration. I was able to gather that her memory had progressively deteriorated over the last 2 years. Her husband was her main caregiver and he had been having trouble with her behaviour for the last 4–5 months or so. Madam CYK was calmer now and able to answer questions, but kept interrupting to say that she wanted to take her medications and go home.

In the history (from both patient and husband), as well as from the brief physical examination, there were no indications to suggest delirium, depression, or psychosis. She had already been referred to see a geriatrician by my colleague who had seen her 3 months earlier and that appointment was coming up in a month's time. I arranged for her to be seen by myself at the Family Physician Clinic in a week's time, when her mood was better, for a more comprehensive history. She was also recruited into our clinic's bi-monthly multidisciplinary meeting.

The following week I saw her in the morning and she was accompanied by her husband and older son. Further history revealed impairments in the following domains.

- ***Amnesia***: Gradually progressive decline in memory over last 2 years. Repeats phrase that she wants to sell ice-cream.
- ***Apraxia***: Inability to dress and feed herself.
- ***Agnosia***: Difficulty recognising older son who does not live with her (see Figure 1). Has got lost outside before.
- ***Aphasia***: Difficulty understanding others and following conversations. Does not answer appropriately.
- ***Executive functioning***: Used to do the cooking, but stopped for the last 4 years as she has forgotten how to. Previously used to handle finances from business with husband, but not anymore as unable to conduct cash transactions with customers. Basic ADL independent.
- ***Behaviour and mood***: Easily agitated, mostly in the evenings when she refuses to take her night medications. Asks repeated questions. No sleep-wake cycle reversal or low mood. No hallucinations, but sometimes accuses strangers (e.g., healthcare workers) of trying to steal her money. Occasionally can talk loud and be rude to customers, but husband is usually able to calm her down.

### Risk Factors Review

- Hypertension and hyperlipidaemia.
  - o On Nifedipine LA 30mg OM and Simvastatin 20mg ON.
    No other medications/TCM or alcohol. Non-smoker.
  - o BP 160/70 mmHg, HR 72 bpm regular. BMI 19 kg/m$^2$.
- No family history of dementia or personal history of psychiatric illness.
- No signs of parkinsonism. No hyperreflexia, cerebellar signs or focal neurological deficits. No incontinence or gait disturbance. Kyphosis noted.

### Social History

She helps her husband sell ice-cream from a cart on Orchard road. Both sons help them out financially.


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**Figure 1: Madam CYK's Family History**

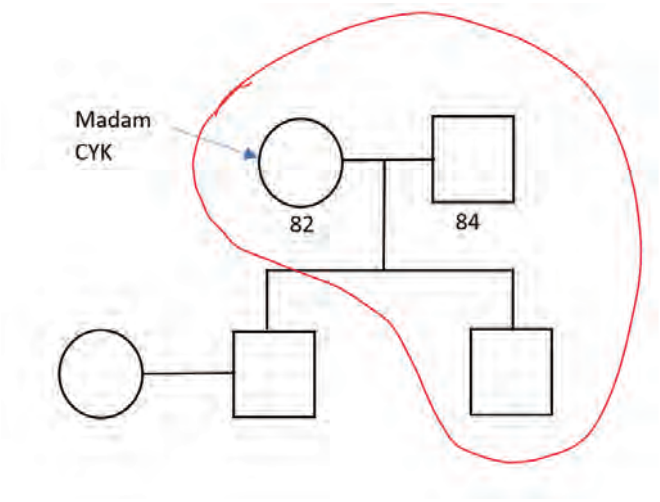


**Table 1: Investigations**

| Test | Result /units | Normal range |
|---|---|---|
| LDL | 1.73 mmol/L | <2.6 |
| Glucose | 4.9 mmol/L | <6.0 |
| Folate | 5.3 nmol/L | >13.4 |
| 25 hydroxyvitamin D | 26.2 ng/ml | >30 |
| Creatinine | 54 umol/L | 37-75 |
| eGFR | 100 ml/min/1.73m$^2$ | >90 |
| B12, phosphate, calcium, albumin and thyroid function test | normal | |

## Problems Identified

1. Dementia and BPSD
2. Caregiver burden
3. Preventive care
4. Long term care plan

## Management

### *Dementia and BPSD*

I diagnosed her to have mild to moderate dementia. The nature and course of the disease was explained to her husband and older son. She was encouraged to keep her appointment with the geriatrician to have a CT brain scan done (in view of relatively short duration of symptoms) as well as for starting cognitive enhancers (as husband and son were keen for medications). I explained that while this could not reverse her symptoms, it may help to stabilise the progression in some patients.

Subsequently, the CT brain scan done showed generalised cerebral involutional changes with disproportionate atrophy of bilateral hippocampi, as well as mild small vessel disease. This suggested a mixed (Alzheimer's and vascular) dementia.

I explained to her family that her BPSD symptoms were a manifestation of her dementia. Sensory deficits, including hearing impairment in her case, can contribute to BPSD, and so her ear wax was removed successfully.

Together with her husband and son, we came up with a strategy to address her BPSD.

- Set a daily routine, especially in the evenings, to minimise sun-downing effects.
- Speak close to her ear with a slow cadence, so as not to seem like either of them was shouting at her. This will reduce her mirroring them and getting agitated. She was referred for an audiogram to get a hearing aid.
- Learn to recognise when she starts to get agitated (e.g., when interacting with some customers) and intervene early.

Her folate level was corrected and she was started on calcium and vitamin D supplements, and is awaiting a Bone Mineral Density test.

### *Caregiver burden*

Her husband shared that he loved his wife very much and they used to be very close. He was sad that he was losing her companionship, frustrated with her behaviour, and afraid of what the future might hold for them both. He was not depressed, but his 22-item Zarit burden score was 43 out of 88 (moderate to severe burden). I empathised with her husband and son on the stress they were facing. Over time, the non-pharmacological strategy seemed to be working, as the husband reported lower stress levels and was more confident in managing her at home.

Together with our clinic medical social worker, we encouraged them to attend caregiver support groups and dementia workshops held by the Alzheimer's Disease Association. They were not keen for dementia day care at present as her husband is used to taking her to work with him, and is currently able to cope.

### *Preventive care*

I continued to manage her chronic conditions. Together with our Care Manager, she and her family were educated on falls prevention measures (e.g., clutter reduction and home modifications) for both patient and husband. She and her husband would go for evening walks most days, and they were encouraged to continue this to get adequate sunlight and stay active. They were also receptive to the idea of joining a seniors exercise programme at their local community centre.

### *Long-term care plan*

I touched on Madam CYK's long-term plans and the making of an Advanced Care Plan. Her family were coping better at home and knew from pre-morbid conversations that Madam CYK wanted to be at home in her final days. We also discussed avenues of help (such as hiring a helper, day care) when she and her husband both needed increased care.

## Literature Review on Latest Evidence

Cognitive impairment is a common complaint in the elderly, and it is important to rule out other conditions that may masquerade as dementia: delirium, depression and other psychological syndromes.[1]

BPSD can be a significant source of stress for caregivers and family members. It is important to identify what these behaviours are, decide if they need to be treated (if they negatively affect patient/caregivers), and formulate a plan with the caregiver[2]. First-line non-pharmacological interventions include reducing emotional and physical stressors, environmental modification, and setting a daily routine.[3]

Acetylcholinesterase inhibitors (e.g., rivastigmine or donepezil) can be considered for mild to moderate AD/vascular dementia.[1]

## Lessons Learnt

1. Caregiver stress is a significant problem among family members caring for patients with dementia and it is often overlooked.
2. The family physician is in a unique position to build a therapeutic relationship with the patient and her caregivers, and, by constantly engaging the family, a better outcome for the patient and her family can be achieved.
3. The family physician is also able to co-ordinate her multidisciplinary care, and arrange appropriate tertiary care and community resources.

## Clinical Pointers

1. It is crucial to differentiate between dementia and other conditions that can mimic or occur together with dementia, such as delirium and depression.
2. First-line management for BPSD should be non-pharmacological measures.
3. Caregiver burden is not uncommon and should be actively looked for and managed.

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