NATIONAL MEDICINES SYMPOSIUM 2024

POLYPHARMACY CONSUMER PERSPECTIVE

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Dementia Advocate

AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

My background

- Former carer (10 years)/co-carer (3 years) for my wife, Glenda
- Dementia Advocate, Dementia Australia and Alzheimer's WA (14 years)
- Member, Clinical Governance Committee, Curtin Heritage Living, Cottesloe WA (an aged and home care provider)
- Member, Australian Commission on Safety and Quality in Health Care (ACSQHC) advisory groups:
    - Clinical Care Standard #5 of Strengthened Aged Care Quality Standards
    - Clinical Care Standard on use of Psychotropic Medicines in Cognitive Impairment
    - Developing Guidance Material and Resources for new aged care clinical care standard
- Consumer/stakeholder representative or co-investigator in Australian university research projects - topics in dementia care, aged care, medication management, implementation of Aged Care On-site Pharmacist program (ACOP), and strategies for dementia risk reduction

Glenda's journey with dementia

- Highly educated, high functioning careerist, wife and mother with high cognitive reserves
- Younger onset dementia diagnosed in 2010 at age 56
- Posterior Cortical Atrophy (visual variant of Alzheimer's Disease)
- Prescribed medications – anti-depressant (Escitalopram 20mg daily) and cholinesterase inhibitor (Galantamine/Reminyl 8mg daily)
- Main initial symptom – functional blindness
- Lived stimulating life at home, with family, friends and a supportive community, and travelled, for almost 10 years following diagnosis

Glenda’s journey with dementia

- In 10th year – periodic psychotic behaviours (anxiety, agitation, restlessness, delusion, paranoia, aggression, sleeplessness) behavioural and psychological symptoms of dementia (BPSD)
- Prescribed medication – anxiolytic (Lorazepam 1mg as required)
- BPSD exacerbated by withdrawal from social activities due to COVID lockdown
- Prescribed medication - antipsychotic (Quetiapine 50mg > 125mg daily over 1 month)
- Side-effects emerged

Trajectory of a crisis

- Adverse reaction to Quetiapine - leg muscle twitching and imbalance
- Minor stumbles and falls; one serious (the last) - fractured *pubic rami* bones
- 5 weeks hospitalisation
- Prescribed medications – as above (Lorazepam replaced by Clonazepam) plus Oxycodine, Paracetamol, Ketamine wafers, Valproate Sodium
- Deprescribed Quetiapine (125mg > 25mg daily) over period of hospitalisation, then ceased
- Bedridden, permanently immobile
- Dyskinesia (serious “dramatic” leg movement disorder) - Quetiapine side effect

Trajectory of a crisis

- Further cognitive decline, non-verbal, periodic BPSD
- In-room carer 24/7, music therapy and reminiscence therapy
- Very high care needs - accelerated requirement for transfer to residential aged care home (RAC)
- Dyskinesia diminished over 6 months in RAC
- RAC very risk-averse at moving from bed to nursing chair for 3 months
- Poor quality of life - functionally blind, bedridden, socially isolated, periodic BPSD

Resolution and care management

- Deprescribed all past medications over 6 months in RAC, except Escitalopram, Valproate Sodium and Paracetamol, with addition of Melatonin, which remained to end of life
- Extensive use of music therapy, reminiscence therapy and environmental changes as effective non-pharmacological interventions for BPSD
- Focused on communication needs – aural, not visual, cues and stimulus
- All of the above included in Behaviour Support Plan
- Excellent communication, understanding and support from RAC
- BPSD stabilised and quality of life improved

Insights and Understandings

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Medicines and Goals of Care: Key principles

- Person-centred approach
- Maximise functionality and independence
- Enhance quality of life
- Minimise polypharmacy; consider deprescribing
- Manage behavioural and psychological symptoms
- Promote non-pharmacological interventions; use behaviour support plans
- Tailor medications to unique needs