

## EMPOWERED 10 ESSENTIAL FACTS ABOUT CHANGED BEHAVIOUR and PSYCHOLOGICAL SYMPTOMS in DEMENTIA – CLINICIAN VERSION

1

**BPSD (behavioural and psychological symptoms of Dementia) are virtually ubiquitous in dementia.**

BPSD are behavioural and psychological symptoms of dementia. They affect up to 90% of people with dementia. There are a growing number of terms used in place of BPSD including changed behaviours, neuropsychiatric symptoms, reactive behaviours and need-driven behaviours. We use the term changed behaviour and psychological symptoms.

2

**The causes of changed behaviour and psychological symptoms are many and complex.**

Causes of changed behaviours are complex including biopsychosocial and environmental causes:  
(I) acute medical illness or frank delirium;  
(II) unmet needs such as pain, intimacy, hunger, temperature discomfort, loneliness, which may not be able to be expressed or understood by the person;  
(III) a response to, or an attempt to make sense of, the environment, such as fear or confusion;  
(IV) the disease process itself - structural & biochemical changes in the brain can lead to symptoms such as irritability, screaming, delusions, hallucinations

3

**Drug treatment is last resort only, if behaviour is severe or dangerous.**

Treatment is always non-pharmacological first unless behaviour is associated with significant risk/distress to the patient or others, or likely to respond to psychotropics. There is a place for positive prescribing in dementia: eg cholinesterase inhibitors and antipsychotics for paranoid symptoms and for severe agitation/aggression.

4

**Treatment of BPSD is never a 'one size fits all' solution.**

An individualised person-centred approach to changed behaviour is essential. This requires a comprehensive assessment of the causes including personal history. There is a growing evidence base for a range of psychosocial /environmental strategies, focused on "person-centred care". Evidence exists for music therapy, caregiver-based interventions or staff training in communication skills and person-centred care. Often recourse to drugs occurs when the professional care environment is insufficiently resourced or informed/educated.

5

**There is a role for the judicious and careful use of psychotropics to treat changed behaviour and psychological symptoms in severe cases.**

Psychotropics should only be used to treat agitation/aggression or psychosis in patients with dementia when symptoms are severe, dangerous, and/or cause significant distress to the patient and if non-pharmacological approaches have failed. If medications are indicated, use for the shortest time at the lowest possible dose and review at least every 3 months. Psychotropics have side effects including stroke and death plus sedation, falls, QT prolongation, pneumonia, extrapyramidal side effects. Cholinesterase inhibitors or also have a role in improving cognition and function in dementia.

6

**It is essential to get this right at the end of life, i.e. up to the last 12 months of life.**

Understanding and minimising a person's distress is crucial at the end of life, i.e. up to the last 12 months of life, not just the last few days or hours. Human rights of equitable access to health care, the relief of distress and pain, and to autonomous decision making are at stake. In patients receiving palliative care, individualized management of delirium precipitants and supportive strategies are more efficacious in treating distressing delirium symptoms than risperidone or haloperidol.

7

**Doctors must obtain consent first for the use of drugs in dementia.**

If drugs are used, they need to be given with consent, except in an emergency. Clinicians have a duty to ensure patients are aware of material risks involved in a treatment and of reasonable alternatives to that treatment. The absence of a valid consent is a factor in establishing liability for civil assault or trespass. For medical professionals, criminal responsibility could arise for murder or manslaughter (where treatment is withheld or withdrawn unlawfully) or for assault (where treatment is provided without appropriate consent or authorisation).

8

**People in nursing homes have rights around care and security of tenure.**

People in nursing homes have rights around care and in their tenure. Compliance with the User Rights Principles 2014 (s 96 1 Aged Care Act 1997) Security of tenure, is compromised when facilities transfer patients to hospital due to "unmanageable" behaviour, with threat of loss of a bed. A person cannot be asked precipitously to leave a nursing home without prior specialised and independent assessment, written notice and available alternative accommodation.

9

**The Australian government has acknowledged the importance of recognising there is diversity in dementia.**

Consider special needs groups i.e. LGBTBI, ATSI & CALD communities. The Aged Care (Living Longer Living Better) Bill 2013 allowed for expansion of the meaning of 'people with special needs' (Section 11.3(h) Aged Care Act 1997) to include "lesbian, gay, bisexual, transgender and intersex people" under the subsequent Allocation Principles 2014 (Section 26(a) and 29). Also rights under Guardianship Act 1987. The "same sex partner" has the same rights as any spouse to act as the Person Responsible/Statutory Health Attorney giving proxy consent on behalf of a partner unable to give consent themselves.

10

**People with more advanced dementia do not do well in hospital.**

It is important to try and manage changed behaviour and psychological symptoms in a familiar environment whenever possible. There are a range of negative outcomes associated with hospitalisation of people with dementia including fractures, head injuries, skin tears, infections, inappropriate sedation and death. When hospitalisation is necessary, staff must work with carers and supporters to understand the person and provide high quality care.

