

# EMPOWERING PEOPLE WITH DEMENTIA AND THEIR CARERS/ FAMILIES/SUPPORTERS TO MAKE INFORMED DECISIONS ABOUT TREATMENT FOR CHANGED BEHAVIOUR AND PSYCHOLOGICAL SYMPTOMS

The Empowered project is funded by the Australian Government under the Dementia and Aged Care Services Fund.

Enclosed in this brochure are the Empowered 10 Essential Facts about changed behaviour or behavioural and psychological symptoms of dementia (often known as BPSD), medications used to treat BPSD and your legal and ethical rights surrounding treatment and care.

These facts are based on rigorous evidence from academic literature and the knowledge and experience of the Empowered experts comprising psychiatrists, geriatricians, social workers, pharmacists, scientists, dementia advocates and people with dementia and their carers.

To find out more about the project and locations of our nation-wide seminars, please visit our website

<http://empoweredproject.org.au>

You can also learn about other ways Capacity Australia is supporting decision making capacity and protecting the rights of those with impaired capacity at:

[www.capacityaustralia.org.au](http://www.capacityaustralia.org.au)

or find us on twitter and facebook.



## USEFUL SUPPORTS AND CONTACTS

- Capacity Australia – [www.capacityaustralia.org.au](http://www.capacityaustralia.org.au)
- Dementia Australia – [www.dementia.org.au](http://www.dementia.org.au)  
National Dementia Helpline 1800 100 500
- National Prescribing Service – [www.nps.org.au](http://www.nps.org.au)  
Dementia Support Australia - administering the Dementia Behaviour Management Advisory Service (DBMAS) and Severe Behaviour Response Teams (SBRT)  
[www.dementia.com.au](http://www.dementia.com.au)  
24-hour helpline number is 1800 699 799
- Dementia Centre for Research Collaboration – [www.dementiaresearch.org.au](http://www.dementiaresearch.org.au)
- Aged Care Complaints Commission - 1800 550 552  
<https://www.agedcarecomplaints.gov.au/>

## COMMONLY PRESCRIBED PSYCHOTROPICS

– this list is a guide and not all-inclusive

CLASS OF PSYCHOTROPIC	DRUG NAME	BRAND NAME
Antipsychotic	Risperidone	Risperdal
	Olanzapine	Zyprexa
	Quetiapine	Seroquel
	Haloperidol	Serenace
Anti-depressant	Citalopram	Cipramil, Celapram, talam
	Sertraline	Zoloft
	Mirtazapine	Avanza
	Venlafaxine	Efexor
	Fluoxetine	Prozac
	Paroxetine	Aropax
Benzodiazepine Hypnotics/ Anxiolytics	Diazepam	Valium
	Oxazepam	Alepam, Serepax
	Alprozolam	Xanax
	Temazepam	Normison, Temtabs
	Galantamine	Reminyl
Anti-dementia drugs	Donepezil	Aricept
	Rivastigmine	Exelon
	Memantine	Ebixa



# CHANGED BEHAVIOUR AND PSYCHOLOGICAL SYMPTOMS IN DEMENTIA –

## WHAT YOU NEED TO KNOW ABOUT DRUGS, CARE AND YOUR LEGAL AND ETHICAL RIGHTS.

### Empowered Supporters



Dementia Support Australia



dementia australia



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

FACT	QUICK LOOK	FURTHER DETAIL
1	<b>Changed behaviour and psychological symptoms are as common in dementia as memory loss.</b>	Dementia is frequently associated with changes in behaviour and psychological symptoms. The person with dementia might say or do things that they wouldn't have previously. Up to 90% of people with dementia experience these changed behaviours and/or psychological symptoms. These are often referred to as BPSD (behavioural and psychological symptoms of dementia) and include agitation, aggression, hallucinations, wandering, apathy, depression, disinhibition and anxiety.
2	<b>Changed behaviour and psychological symptoms have many causes.</b>	Changed behaviour and psychological symptoms have a number of causes. They may be caused by changes in the brain associated with dementia, the person may be unwell (eg. have an infection or be in pain), or commonly the person has an unmet need that they cannot express such as loneliness, hunger, thirst, boredom, discomfort related to temperature or noise, or a need for nurturing/intimacy. Sometimes the person is having trouble understanding or making sense of their environment.
3	<b>Non-drug treatment first always – drugs are a last resort unless the behaviour is severe or dangerous.</b>	The approach to prevent or minimise distress for the person with changed behaviour and psychological symptoms should always be without medicines first, unless the behaviour poses immediate risk to the person or those around them.
4	<b>The best way to address changed behaviour and psychological symptoms in dementia is to find out why they are happening.</b>	The "trick" to the non-drug approach is to work out the biological, psychological or social/environmental cause including unmet needs. Is the person physically unwell? Do they need something and can't express it? Are they in pain, frightened or lonely? This is very individual and may also be influenced by personal life experiences. It is important to adapt care to the person as no one size fits all. This is "person centred care". There is scientific evidence that many non-drug solutions work, including music therapy and training staff in communication and understanding the individual needs of people with dementia.
5	<b>"Never say never" about drugs in dementia: sometimes medicines can be helpful but they have a number of side effects, some serious.</b>	Only after non-medicine approaches have failed, if the person is very distressed or the behaviour is severe or dangerous should medication be considered. Paranoid delusions may cause distress and respond favourably to medications. Some medicines used to help changed behaviour and psychological symptoms have serious risks associated with them such as sedation, falls, stroke and death. These medicines are called antipsychotics and belong to a larger class of medicines called psychotropics. A list of common psychotropics is on the back of this brochure. THIS LIST IS NOT ALL-INCLUSIVE. If used, medication should be started at the lowest dose, response and side effects monitored closely and the dose of medicine adjusted accordingly. A review should be done at least every 3 months to see the medicine is still needed. Anti-dementia drugs (which are misnamed because they don't stop dementia) also have a role in improving cognition and function. If pharmacological management is used, this should complement, not replace, non-pharmacological approaches.
6	<b>It is essential to get this right at the end of life, i.e. up to the last 12 months of life.</b>	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. Unmet needs such as pain, anxiety, fear, and loneliness or physical causes of distress need to be identified and responded to. Medications aren't effective in treating delirium at the end of life. It is also important to focus on the person's wishes and priorities in regard to end of life care.
7	<b>Consent before use: doctors must obtain consent first for the use of drugs in dementia.</b>	All doctors (including GPs and specialists) are required to obtain consent from the person themselves where possible, or if they cannot give consent, from their proxy or substitute decision maker, often called the person responsible, for prescribing medicines used to help changed behaviour. This consent needs to be informed i.e. the material risks and benefits of the drug need to be explained. The only exception is in an emergency and then consent must be sought as soon as possible after administration of the medication.
8	<b>People in nursing homes have rights around care and security of tenure.</b>	People in nursing homes have rights concerning care and their tenure. They can't be "evicted" simply because of what others perceive as "bad behaviour". 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" BPSD, 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	<b>Recognising there is diversity in dementia and modifying care appropriately.</b>	The Australian government has acknowledged the importance of recognising the needs and rights of groups such as Lesbian, Gay, Transgender, Bisexual and Intersex (LGBTI) communities, Culturally and Linguistically Diverse (CALD) communities and Aboriginal and Torres Strait Islander (ATSI) communities in aged care. Also, the "same sex partner" (assuming they are recognised as such) has the same rights as any spouse to act as the Person Responsible or Statutory Health Attorney to give proxy treatment consent on behalf of a partner unable to give consent themselves.
10	<b>People with more advanced dementia do not do well in hospital.</b>	It is important to try and manage changed behaviour and psychological symptoms in a familiar environment such as the care home, whenever possible. People with dementia may be at increased risk of complications and harm if transferred to hospital, including fractures, head injuries, skin tears, pressure injuries, infections, inappropriate sedation and death. When hospitalisation is necessary, hospital staff can work with carers and supporters to understand the person and provide safe and high quality care.