



MEDICINES & DEMENTIA

Strategies to address distress

This fact sheet discusses the reasons for or causes of distress in people with dementia and suggests strategies to prevent or eliminate these underlying factors.

What is distress?

Every person with dementia is an individual who will react in their own way to events or factors in their environment.¹ People with dementia can become upset and distressed as a result of medical, physical, emotional or environmental factors² and these expressions are often indicative of an unmet need. It is important to understand why people with dementia become distressed and find ways to help or prevent it.³ Health professionals refer to expressions of distress as behavioural and psychological symptoms of dementia (BPSD).

Reasons for distress

There may be one or more underlying factors which can lead to distress or a feeling of dissatisfaction in people with dementia. Factors contributing to stress may be medical, physical, environmental or emotional (see below).² The quality or practice of care given to the person with dementia may also contribute to emotional stress, for example, use of physical restraints or disregarding their social and cultural needs.²

MEDICAL	PHYSICAL	ENVIRONMENTAL	EMOTIONAL
Sleep disruption/ deprivation	Discomfort such as pain, fever or constipation	Allowing strangers into the home	Lack of respect, recognition or trust in social interactions and relationships
Other medical conditions such as depression, urinary tract infection	Not able to communicate	Change to physical environment	Feelings of worthlessness or sadness
Delirium	Immobility	Limited care	Grief
Chronic illness	Complicated tasks	Fear	Loneliness

Strategies to overcome distress

The underlying cause leading to distress should be identified and addressed by families, friends or carers using a positive approach. People with dementia may use hand gestures, body language, facial expressions, eye contact and actions in their attempts to help their family members, friends or carers identify the reasons for their distress. Below is a checklist of suggestions to help prevent distress.⁴

COMMUNICATION	PERSONAL CARE DELIVERY	THE CARE ENVIRONMENT
<input type="checkbox"/> Speak slowly and calmly	<input type="checkbox"/> Do not disagree	<input type="checkbox"/> Ensure routine activity
<input type="checkbox"/> Avoid point finger-pointing, scolding or threatening	<input type="checkbox"/> Respect the person's thoughts even if incorrect	<input type="checkbox"/> Avoid tasks that trigger stress
<input type="checkbox"/> Make eye contact where appropriate	<input type="checkbox"/> Consider pain as a reason for distress	<input type="checkbox"/> Ask the person to take part in an enjoyable activity
<input type="checkbox"/> Use person's name/title	<input type="checkbox"/> Allow for some privacy	<input type="checkbox"/> Be flexible with meal times
<input type="checkbox"/> Consider cultural background when communicating	<input type="checkbox"/> Talk to the doctor about other illnesses such as constipation, urinary tract infection, headache etc that may be reasons for distress	<input type="checkbox"/> Ensure the environment is not noisy or cluttered
<input type="checkbox"/> Avoid correcting mistakes	<input type="checkbox"/> Offer choices	<input type="checkbox"/> Declutter table settings

Medicines to manage distress symptoms

Managing emotional stress through simple strategies and changes in the delivery of care is primarily recommended for addressing mood or distress symptoms.⁵ If medical treatment is necessary, your doctor will tailor treatment to your circumstances, for example, prescribing antidepressants for moderate to severe depression.² Groups of medicines that may be used to help reduce symptoms of distress are described below.⁶

Medicines should be reviewed regularly by a health professional and when to review depends on the medicine. Talk to the doctor or other health professional about incorporating medicine reviews into a care plan. Using a medicines list can help with managing medicines (see www.nps.org.au/medicineslist). Talk to the doctor or other health professional about the active ingredient and brand names of the medicines you are taking.

MEDICINE CLASS ^{5,7}	COMMON SIDE EFFECTS ⁷	TARGET DISTRESS SYMPTOM ⁶	EFFICACY
Anticholinesterases	diarrhoea, anorexia, insomnia, vivid dreams, urinary incontinence	agitation	delays cognitive decline by 6 months in 25%–50% of people with dementia, and 1 year in 12%–20% of people with mild to moderate Alzheimer's disease
Other medicines for Alzheimer's disease (Memantine)	confusion, drowsiness, insomnia, hallucinations	agitation	moderately slows cognitive decline
Antipsychotics	sedation, anxiety, restlessness and agitation, pneumonia, increased heart rate. Has been associated with increased risk of death	psychosis, aggression	of limited use for people with dementia
Antidepressants	sleep disturbance, headache, drowsiness, tremors, nausea, anorexia, urinary incontinence	depression	can take 2 weeks or more to see improvements in mood
Anxiolytics	falls, confusion, rebound insomnia	agitation, anxiety, sleep disorder	effective for treating anxiety but recommended for short-term use only (2–4 weeks)

Treatment decision-making rights

A person with dementia (and you, as a carer or family member of a person with dementia) has a legal right to refuse treatment.

Being diagnosed with dementia doesn't mean a person is unable to make decisions on medical treatment and management.⁸ They have the right to make decisions if they:

- ▶ understand the information given
- ▶ can weigh the risks and benefits of treatment, and
- ▶ can communicate the decision to another person.^{5,8}

Under these circumstances the person with dementia can initiate a discussion with their doctor on the risks and benefits of medical treatment for distress and have the doctor record their wishes about treatment on their medical record.

If the person is unable to verbally communicate with family members, friends or carers, they can write down their wishes about the medical treatment they want or don't want and the person making the decision on their behalf can use this as guidance.

Families, friends or carers can make decisions for the person with dementia if they do not meet the above criteria. Carers making a decision on behalf of the person with dementia should be guided by the values and expressed wishes of the person with dementia.⁹ If the person with dementia has made an Advance Directive (legally binding document stating their wishes for treatment), the carer is legally bound to follow the Directive.⁹

Questions to ask your doctor

- ▶ What are the risks and benefits of starting medical treatment for distress?
- ▶ What happens if I don't start medical treatment?
- ▶ What non-pharmacological options are there to help with distress?

FURTHER INFORMATION

Medicines and Dementia: a resource for people with dementia and their carers is available in editable PDF format for download and print from NPS MedicineWise and Alzheimer's Australia

- ▶ www.nps.org.au/dementia-brochure
- ▶ fightdementia.org.au

NPS MedicineWise fact sheets are available for download and print from NPS MedicineWise and Alzheimer's Australia.

Other conditions with dementia

- ▶ www.nps.org.au/dementia-conditions

Tips for good medicine management

- ▶ www.nps.org.au/dementia-medicines

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**This initiative is funded by the Alzheimer's Australia National Quality Dementia Care Initiative
with support from J.O. & J.R. Wicking Trust.**