



Distress Observation Tool (DOT) – flexible frequency version

This tool can be used by family members, careworkers and health professionals caring for a person living with advanced dementia. It is a way to record and communicate the distress you have observed in the person when providing care.

Name of person completing this tool:

What is your role?

☐ Family member/carer ☐ Careworker ☐ Other Health Professional (e.g. RN, GP, Allied Health)

Date completed: Time completed:

How often do you provide direct care to this person/client/resident?

☐ More than once a week ☐ At least weekly ☐ Occasionally

Distress Observation Checklist

Distress is an experience of an emotional, physical, or spiritual nature that is unpleasant. When a person living with dementia is experiencing distress, you may observe a change in the person's usual behaviours or appearance.

What signs of distress have you observed in the person in the last hours (tick all that apply)?

- ☐ Grimacing / frowning
- ☐ Crying / moaning
- ☐ Shouting / screaming
- ☐ Restlessness or physical agitation (e.g. pacing)
- ☐ Using physical force (e.g. pushing-away)
- ☐ Aggressive physical behaviour (e.g. hitting, kicking)
- ☐ Loss of interest in usual activities
- ☐ Withdrawal from interacting with staff or family
- ☐ Withdrawal from accepting assistance with usual care
- ☐ Other – please specify:

Affix client / resident identification label here

Name of person / client / resident:

Date of birth:

Overall Distress Scale

Please tick the number that best describes how much distress you think the **person you are caring for** has been experiencing **overall in the last** **hours**

10

Severe distress (10-8)

- Significant impact on the person's daily activities or wellbeing
- Immediate review is required

9

8

7

Moderate distress (7-4)

- Moderate impact on the person's daily activities or wellbeing
- Strategies are not effective
- Review plan of care

6

5

4

3

Mild distress (3-1)

- Mild impact on the person's daily activities or wellbeing
- Strategies are mostly effective

2

1

0

No distress (0)

- Baseline or usual daily activities
- Strategies are effective

If the distress is new and/or the distress is moderate or severe then the person's nurse or GP should be contacted to review the person as soon as possible.

Please proceed to next page if the distress level is 4 or more.

Tick any of the following problems below which you think may be causing and/or contributing to the **distress** you have observed **in the last** **hours?**

Physical problems or care activities

- ☐ Pain
- ☐ Breathing difficulty (e.g. short of breath)
- ☐ Bowel issues (e.g. constipation)
- ☐ Bladder issues (e.g. difficulty passing urine or urinary tract infection)
- ☐ Nausea or vomiting
- ☐ Mouth and teeth issues (e.g. dry mouth)
- ☐ Dry or sore eyes
- ☐ Skin issues (e.g. wound dressing)
- ☐ Sleeping problems
- ☐ Muscle spasms / rigidity
- ☐ Eating problems / swallowing difficulty
- ☐ Medication administration
- ☐ Mobility issues / transferring
- ☐ Personal care (e.g. showering)
- ☐ Other – please specify:

Emotional or spiritual

- ☐ Hallucinations (seeing or hearing things that are not present)
- ☐ Delusions (fixed false beliefs)
- ☐ Communication difficulties (e.g. language barrier)
- ☐ Loneliness / boredom
- ☐ Sadness / low mood
- ☐ Spiritual concerns
- ☐ Fears or worry
- ☐ Anger / frustration
- ☐ Other – please specify:

What do you think are the **main causes** of the distress you have observed in the person you are caring for **in the last** **hours?** (e.g. top 1 to 3 main causes of distress)

Other concerns:

Family concerns:

Is there a particular time of the day or any other situation where the distress is worse?

What do you think would help or has helped relieve the person’s distress?
