

## **Indicators that transition towards Palliative and End of life care in Dementia should be considered.**

We believe that the following will provide clinicians with a better guide as to when patients ought to move towards a mainly palliative approach to their care. It is absolutely the case that some of these symptoms may exist and not mean that a mainly palliative care approach is needed, but as the number of such symptoms increase, so we believe will the likelihood that such an approach is indicated.

### ***Important note***

***This is not a tool which, by getting a certain score states that a person should have palliative care, merely a tool which indicates that this should be considered and discussed. At times, the criteria might be met but palliative care not appropriate, and at others palliative care may be appropriate despite criteria not being met***

### **1a A diagnosis of dementia with severe cognitive decline (FAST stage**

**6) At stage 6 individuals may**

- a. Lose most awareness of recent experiences as well as of their surroundings
- b. Recollect their personal history imperfectly, although they generally recall their own name
- c. Occasionally forget the name of their spouse or primary caregiver but generally can distinguish familiar from unfamiliar faces
- d. Need help getting dressed properly; without supervision, may make such errors as putting pyjamas over daytime clothes or shoes on wrong feet
- e. Experience disruption of their normal sleep/waking cycle
- f. Need help with handling details of toileting (flushing toilet, wiping and disposing of tissue properly)
- g. Have increasing episodes of urinary or faecal incontinence
- h. Experience significant personality changes and behavioural symptoms, including suspiciousness and delusions (for example, believing that their caregiver is an impostor); hallucinations (seeing or hearing things that are not really there); or compulsive, repetitive behaviours such as hand-wringing or tissue shredding
- i. Tend to wander and become lost

**or**

### **1b A diagnosis of dementia with very severe cognitive decline. (FAST Stage 7) At stage 7**

- Frequently individuals lose their capacity for recognizable speech, although words or phrases may occasionally be uttered
- Individuals need help with eating and toileting and there is general incontinence of urine
- Individuals lose the ability to walk without assistance, then the ability to sit without support, the ability to smile, and the ability to hold their head up. Reflexes become abnormal and muscles grow rigid. Swallowing is impaired.

**With either**

**2a Enduring and Severe mental or physical pain** as might be demonstrated by some or all of the following

- Anger/ Frustration
- Aggression/Agitation
- Fear/ Anxiety
- Tearfulness/ misery
- Pain when still
- Discomfort on moving
- Restlessness
- Insomnia
- Calling out/ vocalization
- Wandering and persistent challenging behaviors when these appear to be driven by distress or fear
- Autonomic arousal, sweating, tachycardia, hypertension

Note in situations where distress fluctuates (perhaps most often mental distress), some distress may be appropriately tolerated, in lieu of better days.

**And/or**

**2b Severe physical dependency** as might be demonstrated by some or all of the following

- a. Significantly disabled and very highly dependent on others.
- b. Poor mobility;- unable to mobilise without the support of two
- c. Disability that puts skin care and pressure areas at risk
- d. Requiring full care with washing and dressing
- e. Requiring assistance with feeding
- f. Unsafe dysphagia assessed by a swallowing therapist
- g. severe difficulties with swallowing (this may be a symptom early on in some dementias).
- h. Unable to be left alone for other than short periods
- i. Incontinence of bladder and bowel,
- j. Problems in understanding and thus communicating basic needs–
- k. 10 % weight loss in the previous six months
- l. There may be epileptic activity/myoclonic jerking
- m. Recurrent infections of chest or urine

Note that dysphagia may be a symptom early on in Alzheimer's dementia

**And/or**

**2c Other conditions which merit palliative care in their own right**, or conditions in which as a result of the coexisting severe cognitive decline, aggressive treatment would be too burdensome for such care to be considered.