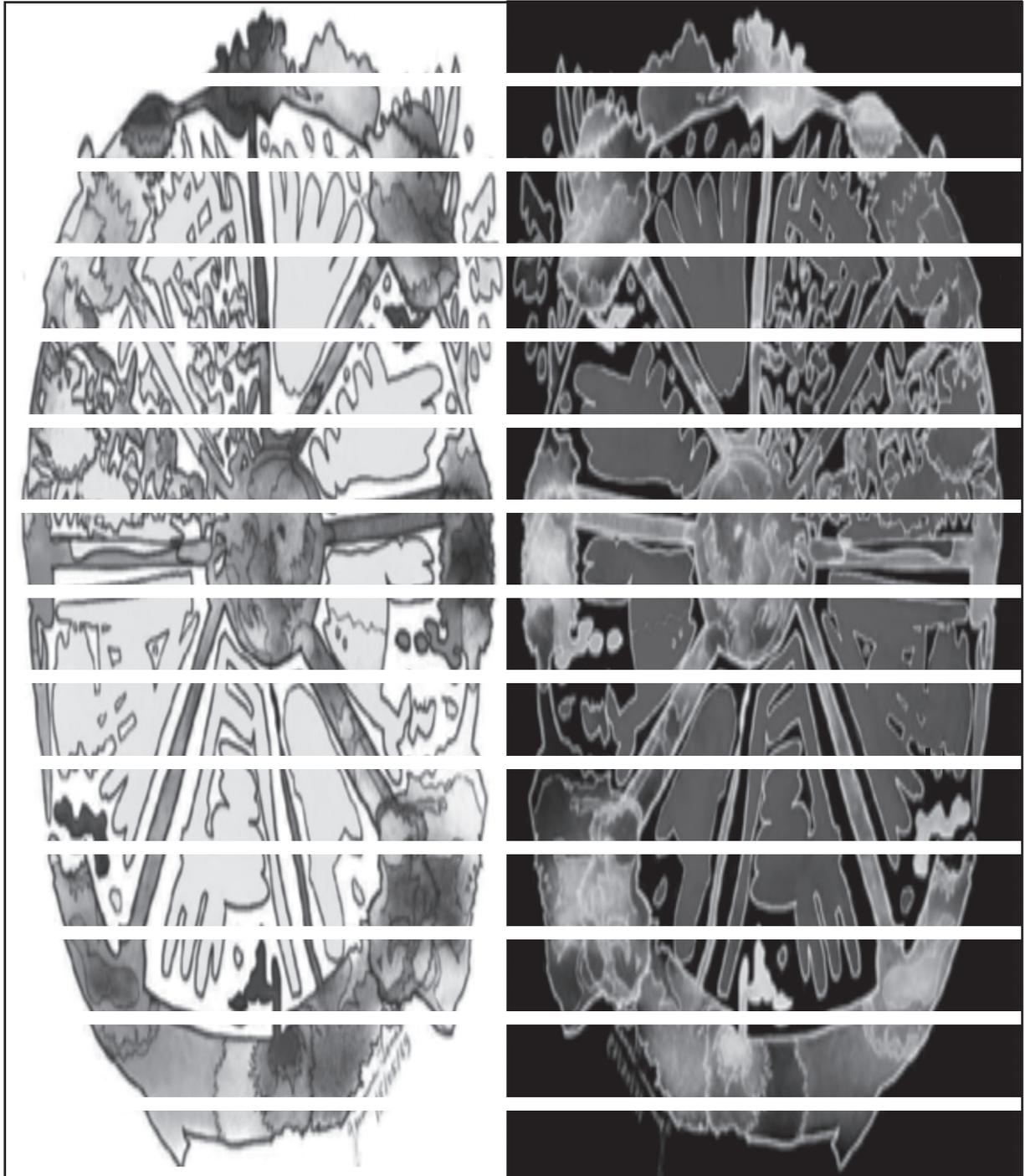




## Chapter 15

### Appendices





## Appendix 1 Notes on recording the Behavioural Stage and Summary Table

Behavioural Staging is used to assist in care planning for people with dementia; persons with a probable diagnosis of late-onset dementia of the Alzheimer type (DAT) and those who have had slow, progressive vascular dementia. Evidence of on-going difficulties with short-term memory, attention and logical thinking ability is required before working out what stage a person is in. (This method of staging is used like a **'shorthand'** for describing details of a person's needs and abilities.)

Where someone does not fit into a stage exactly (e.g. perhaps due to: an early onset form of Alzheimer's; the rarer forms of dementia; large strokes, mixed types of dementias; concurrent physical illness or a history of mental health problems), do not try to make them fit into a stage. Use 'Split-Staging', which is done according to individual behaviours or abilities (see below).

Many residents with dementia living in care homes remain undiagnosed, (Dementia, 2010 report). Where a diagnosis is suspected, but as yet unconfirmed, using the Behavioural Staging as a guide to plan care cannot harm anyone.

This staging framework describes four stages, and three transition phases which occur between stages.

**The name of the stage represents the 'hallmark behavioural feature' of the stage.** Within each stage there are 'high', 'medium' and 'low' levels of functioning. It is not possible to predict how long a stage will last (it can be months, up to five years), since this depends upon many factors, such as - how rapidly the dementia is progressing, physical health, age, motivation, medication, the quality of stimulation care and support).

### Rules for using Behavioural Staging and Split-Staging

1. Mark the descriptors that apply. Not everyone will fit neatly into a stage, or a transition phase. If they don't; use Split-Staging (see 5).
2. Place the person in the highest stage possible which represents their usual best functioning ability. (During 'lucid moments', it is possible for a person to function briefly at one stage higher than their normal level of functioning.)
3. There is a stage before Stage 1 (mild cognitive impairment), which is usually only recognized after it has passed. It is therefore not so relevant to dementia-care settings. If you sense a person's cognitive abilities are changing, and wonder if they may be in Stage 1 - assess and collect information about their difficulties and mistakes. The abbreviation "**S1?**", can be used to alert staff that this person requires extra careful observation and additional assistance.
4. Often, as a person approaches the next stage, they will, for a while, have characteristics of both stages at the same time. This is called being 'in transition between stages'. It is shown on the graph as 'transition circles'. This is recorded as: **TS1-2**; or **TS2-3**; or **TS3-4**.

The Transition from **S1 to S2**, is sometimes referred to as **'the magic circle'** - because when Factual Memory ability worsens noticeably, a person often becomes less aware of their mistakes, less critical of themselves and others, more physically relaxed, and happier. As the ability to inhibit (or brake) the expression of particular thoughts and feelings becomes damaged, they are expressed increasingly freely as they occur - regardless of who is present. Disinhibition happens when there is insufficient memory space/capacity to: work out the context and rules for using social manners; be as aware of what others are doing in relation to oneself; fabricate good (plausible) excuses and lies to cover up mistakes.

5. If the person has behaviours that spread across several stages, use the 'Split-Staging' approach to describe them. I.e. Describe memory, language, physical, and emotional abilities separately - according to what stage each is in. (For example: a 63 year old male, who has been diagnosed for 3 years with the early onset form of DAT may be Stage 3 in language ability, Stage 2 in orientation and emotional expression, Stage 1 in physical activity level.)

**Summary Table - of Behavioural Stages of Alzheimer-type dementia (GMM Jones, adapted from N Feil; 1985)**

<p><b>Stage 0 – 1</b> 0 = no signs 0+ = 1st signs appearing</p> <p><b>Memory Bookcase Model equivalents</b></p>	<p><b>Stage 1 Mal-orientation (intermittent difficulties)</b></p> <p>Factual Memory Bookcase has a wobble; mistakes noticeable. Dementia may not yet have been formally diagnosed, if people can put on a good social façade.</p>	<p><b>Stage 2 Time confusion (obvious disorientation)</b></p> <p>Factual Memory Bookcase has collapsed; no top bookshelf on which to store new factual memories according to time. Emotional and Sensory Memory Bookcases used.</p>	<p><b>Stage 3 Repetitive movement (perseveration)</b></p> <p>Emotional Memory Bookcase may be getting a slight wobble. Sensory Memory Bookcases used to supplement decreased sensory-perceptual abilities.</p>	<p><b>Stage 4 End-stage withdrawal</b></p> <p>Emotional Memory Bookcase difficult to assess. Use Sensory Memory bookcases.</p>
<p><b>Item</b></p>	<p><b>S1</b></p>	<p><b>S2</b></p>	<p><b>S3</b></p>	<p><b>S4</b></p>
<p><b>Mnemonic</b></p>	<p><b>MAL</b> – things not going well increasing difficulties with: M = factual memory, learning new facts A = attention L = logical thinking / problem solving</p>	<p><b>DIS</b> – loss of some abilities</p> <ul style="list-style-type: none"> <li>• dis-orientation in time</li> <li>• dis-location in place</li> <li>• dis-inhibition of thoughts and feelings</li> </ul>	<p><b>REP</b> – repetition / perseveration</p> <ul style="list-style-type: none"> <li>• repeated words</li> <li>• repeated movements</li> <li>• repeated pleas for help and contact</li> </ul>	<p><b>END</b> of life care</p> <ul style="list-style-type: none"> <li>• pain-free</li> <li>• senses stimulated</li> <li>• still connected</li> </ul>
<p><b>Hallmark Behaviours</b></p> <p>These characteristics are the most important ones for determining the stage a person is in</p>	<ul style="list-style-type: none"> <li>• often tense from fear of losing control and of others noticing their mistakes</li> <li>• mistakes are intermittent; others notice but may often dismiss or excuse them</li> <li>• dementia not usually diagnosed yet</li> <li>• social façade can camouflage difficulties</li> <li>• denial, blaming, lying confabulation, may be used to hide mistakes*</li> <li>• when anxious, fearful, corrected, criticized - can be defensive, critical, even aggressive</li> <li>* near end of S1 these abilities are lost since they require considerable memory</li> </ul>	<ul style="list-style-type: none"> <li>• permanently disoriented in time and increasingly in place</li> <li>• memory mistakes are frequent and obvious</li> <li>• less aware of mistakes and others present</li> <li>• when fearful of being alone, lost, or in an unpleasant social atmosphere, asks to go home (to a safe feeling of home)</li> <li>• mistakes the identity people who look or feel similar to well-known others</li> <li>• cannot lie or use façade to camouflage mistakes</li> <li>• disinhibition increasingly evident; thoughts and feelings readily expressed. This makes for fun and spontaneity if not taken literally and personally</li> </ul>	<ul style="list-style-type: none"> <li>• person is often alone</li> <li>• repeated words and movements for stimulation are miniature versions of work movements</li> <li>• very limited language: run-on phrases, repeated words</li> <li>• repetition increases when contact and sensory stimulation are limited, e.g. when person is isolated for being noisy</li> <li>• reduced mobility, may still weight bear, but rarely walks without assistance</li> <li>• very poor vision, eye-movements and ability to maintain eye contact</li> <li>• often appears to be 'staring' and distant</li> </ul>	<ul style="list-style-type: none"> <li>• seems to be withdrawn; like in/ out of hibernation</li> <li>• often seems to be asleep since eyes are often closed even when awake</li> <li>• little movement and vocalization</li> <li>• sitting and in bed</li> <li>• risk of under-stimulation and of person withdrawing further into self if left in bedroom without contact</li> </ul>

<p><b>Defences and sense of self (Ego)</b></p>	<ul style="list-style-type: none"> <li>• sense of self often seems threatened; defences used even more than before to maintain preferred 'self image'</li> </ul>	<ul style="list-style-type: none"> <li>• ego defences reduced</li> <li>• pre adult identity may be evident</li> <li>• adult defences can be used in lucid moments</li> </ul>	<ul style="list-style-type: none"> <li>• prior sense of adult self is rarely evident</li> <li>• ego defences is not evident</li> </ul>	<ul style="list-style-type: none"> <li>• sense of self is not possible to assess</li> </ul>
<p><b>Key fear and need:</b> to be safe and feel safe by:</p>	<ul style="list-style-type: none"> <li>• to be treated like a normal respected adult <i>versus</i> someone frail or like a child</li> <li>• being helped to live as much like a normal adult, with as much autonomy (independence, control, choice) as possible</li> <li>• being separate from people in S2 and S3, rather than confronted constantly by worst fear</li> </ul>	<p><b>to feel 'safe and useful in a home-like place <i>versus</i> being or feeling lost and having to seek memories of safety</b></p> <ul style="list-style-type: none"> <li>• feeling useful in a home-like or work-like environment with: <ul style="list-style-type: none"> <li>- a warm, pleasant social atmosphere</li> <li>- familiar activities, objects and tasks</li> <li>- a caregiver present, in view</li> <li>- presence of people of the same stage, who are often mistaken for familiar 'others', and are not judgemental or critical of them</li> </ul> </li> </ul>	<p><b>to be acknowledged, helped to participate <i>versus</i> being silenced and isolated from others</b></p> <ul style="list-style-type: none"> <li>• by being encouraged to use of whatever speech possible</li> <li>• being with people in S3 so others are not upset by their vocalizations - telling them to 'be quiet'</li> <li>• help people reminisce and feel stimulated through their senses with activities involving movement, bright colours and music</li> <li>• being with others in S3</li> </ul>	<p><b>to be stimulated and connected to life through sensory contact <i>versus</i> being abandoned</b></p> <ul style="list-style-type: none"> <li>• by sensing the frequent presence of others</li> <li>• being in lounge/living areas, even briefly, with familiar things happening</li> <li>• having extra one-to-one, gentle contact before death</li> </ul>
<p><b>Key difficulties for caregivers and others</b> if person is feeling threatened, unsafe and unhappy</p>	<ul style="list-style-type: none"> <li>• person remember things well, but others only briefly (hours to days)</li> <li>• caregivers may point out or correct mistakes, argue or try to persuade them</li> <li>• deny memory difficulties when threatened</li> <li>• may ask for help but reject it, repeatedly</li> <li>• may become verbally and physically aggressive (sharp, curt, mean)</li> <li>• staff may take aggressive tone or threats personally, although it could be directed to anyone present, out of frustration or fear</li> <li>• misplaces things, often upset until found</li> <li>• collecting /hoarding of objects may start</li> <li>• may accuse others of conspiracies, cliques, stealing, poisoning, excluding, ignoring them</li> <li>• want to be near normal elderly and staff;</li> <li>• demands may seem like 'attention seeking', <i>versus</i> fear behaviour</li> <li>• is capable of many normal things, but often cannot sustain them accurately (including phoning family, police, MP, Care Home inspectorate) to report perceived wrong-doing;</li> <li>• may manipulate residents in S2 and S3</li> </ul>	<ul style="list-style-type: none"> <li>• person often feels lost and sad - except if they think they are home (with parents, spouse, children) working, or doing familiar tasks and activities</li> <li>• hard to understand what the person is talking about due to their difficulty using names</li> <li>• staff may not know if orienting or lying is helpful, or what other communication options exist</li> <li>• person needs to be with others to feel safe</li> <li>• shadowing and clinging can feel oppressive</li> <li>• may takes others' things if they look familiar</li> <li>• may try to escape and go home when feeling frightened</li> <li>• making eye contact often results in S2 people wanting to hold onto you to stay close</li> </ul>	<ul style="list-style-type: none"> <li>• often difficult to get eye contact with person</li> <li>• content of speech is mostly unintelligible</li> <li>• person calls out often - for no apparent reason seemingly</li> <li>• person often seems in a daze and difficult to make any contact with</li> </ul>	<ul style="list-style-type: none"> <li>• patience and attentiveness is needed to notice minimal responses that may incite distress</li> </ul> <p>Note: a person may appear to be in S4 because of having been under-stimulated and isolated in S3; with daily stimulation person may improve to their real (higher) level</p>

<p><b>Memory and cognitive changes</b></p>	<ul style="list-style-type: none"> <li>• short-term factual memory mistakes are increasing but intermittent, so person may seem to be deliberately uncooperative</li> <li>• person has difficulty learning new facts; may get only partial information and focus on a few (emotionally laden) details</li> <li>• decreased ability to sustain attention</li> <li>• logical (rational) thinking difficulties</li> </ul>	<ul style="list-style-type: none"> <li>• short-term factual memory difficulties are very obvious</li> <li>• emotional memory is good although person may not be able to communicate their perceptions / memories accurately</li> <li>• usually able to recall distant memories</li> <li>• further decreases in attention ability</li> </ul>	<ul style="list-style-type: none"> <li>• longer-term (distant) memories also seem to be diminishing</li> <li>• attention is very limited (if touch is used person may remain more aware of presence of others)</li> <li>• severe visual perceptual difficulties</li> <li>• sensory memory used (though senses are altered and diminished)</li> </ul>	<ul style="list-style-type: none"> <li>• additional changes to emotional memory, sensory memory and attention are presumed to be present and diminished</li> <li>• other abilities not possible to assess accurately</li> </ul>
<p><b>Logical thinking ability</b></p>	<ul style="list-style-type: none"> <li>• use of rational logic is becoming intermittent</li> <li>• increasing use of emotional logic is evident</li> <li>• the quality of 'excuses told' decreases as person loses insight into their implausibility</li> </ul>	<ul style="list-style-type: none"> <li>• rational logic replaced by emotional logic; things are (become) what I need them to be to meet my present need</li> </ul>	<ul style="list-style-type: none"> <li>• sensory logic used i.e. familiar movements are linked to memories - which fulfil the need for stimulation and participation</li> </ul>	<ul style="list-style-type: none"> <li>• not possible to assess accurately</li> </ul>
<p><b>Disinhibition: incontinence of thoughts and feelings</b></p>	<ul style="list-style-type: none"> <li>• disinhibition occasionally present despite use of good social manners; person may realize their gaff and apologize</li> <li>• disinhibition increases in the transition S1-2</li> </ul>	<ul style="list-style-type: none"> <li>• disinhibition apparent through loss of social etiquette</li> <li>• may include uncharacteristic swearing, flirting, blunt/rude comments, overly familiar touching (e.g. mistaking other for spouse or someone familiar)</li> </ul>	<ul style="list-style-type: none"> <li>• decreased vision and awareness of surroundings and of others, may look like additional disinhibition e.g. scratching, picking nose with others present</li> </ul>	<ul style="list-style-type: none"> <li>• not enough communication and movement present to assess this</li> </ul>
<p><b>Orientation/ awareness of</b> - age - time - place - others</p>	<ul style="list-style-type: none"> <li>• knows own age</li> <li>• usually aware of present time (some small errors in date, date, month)</li> <li>• can read the clock</li> <li>• can become lost in own neighbourhood</li> <li>• recognizes familiar others</li> <li>• is aware of, and usually distressed by the presence of those less-oriented than them</li> </ul>	<ul style="list-style-type: none"> <li>• does not know own age or others' accurately</li> <li>• may alternate between thinking they are old or young; may not know the season or place</li> <li>• recognize familiar others; may mistake name</li> <li>• may think they are living with parents, that their children are young, they are still working</li> <li>• can be lost even in own home or room, and mistake it for elsewhere</li> </ul>	<ul style="list-style-type: none"> <li>• unaware of size of a room, or where it is</li> <li>• has own sense of time and place depending on what cues are picked up from the environment</li> <li>• usually recognizes friendly faces and mistakes them for family/friends - rarely tries to name them</li> <li>• still has lucid moments</li> </ul>	<ul style="list-style-type: none"> <li>• does not appear to recognize family or friends, but is aware of the sound of human voices and music</li> <li>• awareness of time not possible to assess</li> <li>• lucid moments still possible</li> </ul>
<p><b>Language and communication</b></p>	<ul style="list-style-type: none"> <li>• usually proper, adult (may be very formal to impress)</li> <li>• some difficulty finding words, usually nouns/names</li> <li>• may lose thread or ending of a story or conversation and need help to continue</li> <li>• difficulty making comparisons accurately (others may not understand the incorrect use of deliberate metaphors and assume content is literal)</li> </ul>	<ul style="list-style-type: none"> <li>• relating facts is replaced by sharing feelings and observations</li> <li>• Speech sounds increasingly like poetry; sentences becoming shorter, content vague and condensed, accidental metaphors</li> <li>• may lose thread of sentence</li> <li>• names replaced with simpler / made-up ones</li> <li>• swearing/expletives may start</li> <li>• may start stammering at start of a sentence</li> <li>• express thoughts/feelings spontaneously</li> </ul>	<ul style="list-style-type: none"> <li>• speech is very limited</li> <li>• run-on repeated phrases (word salad)</li> <li>• few complete sentences</li> <li>• repeats words that are stimulating to say: may be swear words / expletives</li> <li>• may 'echo' others' words, sing, hum, whistle</li> <li>• expresses feelings with voice tone/movements</li> <li>• may shout, scream, and wail when upset</li> <li>• unaware others can't comprehend them; will continue to speak if others respond</li> </ul>	<ul style="list-style-type: none"> <li>• words are rare</li> <li>• vocalizations are usually repeated vowel sounds</li> <li>• usually responds when touched</li> <li>• in lucid moments may express a clear, brief phrase</li> </ul>

<p><b>Vocal tone</b></p>	<ul style="list-style-type: none"> <li>• clear, well articulated</li> <li>• when upset voice is sharp and loud</li> </ul>	<ul style="list-style-type: none"> <li>• usually pleasant and mellow</li> <li>• may hum, sing and whistle spontaneously</li> </ul>	<ul style="list-style-type: none"> <li>• slow, soft, lower voice than previously</li> <li>• may whistle silently, or hum</li> </ul>	<ul style="list-style-type: none"> <li>• inconsistent, cannot describe</li> </ul>
<p><b>Attachment Behaviour:</b> to obtain contact of others for safety / comfort</p>	<ul style="list-style-type: none"> <li>• when fearful, want to be near/with oriented people, and staff</li> <li>• may become very close to one or two other persons/caregivers. May demand their presence and help, to the exclusion of all others; will confide in them like a best friend</li> </ul>	<ul style="list-style-type: none"> <li>• seek to hold-onto, follow, stay with, and help staff or residents to be/feel safe</li> <li>If this fails, behaviour changes to frequent asking about parents (or spouse, children, friends) calling out and searching for them; trying to leave to find them; crying, pacing</li> </ul>	<ul style="list-style-type: none"> <li>• rocking back and forth</li> <li>• less active versions of S2 behaviours</li> <li>• does not have sufficient vision or mobility to follow others, or strength to hold onto others for very long (may try to hold onto hand or clothing when a person leaves them)</li> </ul>	<ul style="list-style-type: none"> <li>• sometimes soft crying sounds and small repeated movements</li> </ul>
<p><b>Lucid moments</b></p>	<ul style="list-style-type: none"> <li>• very insightful and aware of circumstances</li> </ul>	<ul style="list-style-type: none"> <li>• seem like S1; trying to use best manners, names; aware of being old (not exact age)</li> </ul>	<ul style="list-style-type: none"> <li>• seem like S2; may use some brief, complete sentences that are comprehensible</li> </ul>	<ul style="list-style-type: none"> <li>• seem like S3; words, phrases; comments, greeting</li> </ul>
<p><b>Humour</b></p>	<ul style="list-style-type: none"> <li>• humour is still very evident if a person feels safe; mostly literal;</li> <li>• may have difficulty with subtlety</li> </ul>	<ul style="list-style-type: none"> <li>• laughs readily if others are laughing; at silly sayings; songs, rhymes</li> <li>• literal and situational humour</li> </ul>	<ul style="list-style-type: none"> <li>• laughs less frequently; may laugh at saying or singing some words or 'slapstick' type situations</li> </ul>	<ul style="list-style-type: none"> <li>• reports of people laughing at 'slap-stick' type events</li> </ul>
<p><b>Appearance of eyes and visuo-perceptual changes</b></p>	<ul style="list-style-type: none"> <li>• clear, sharp, focussed eye contact and normal eye movements</li> <li>• increasing loss of colour vision (blue, purple, green part of colour spectrum)</li> <li>• increasing loss of depth-perception, night vision, figure/background contrast, and peripheral vision</li> </ul> <p>Note: vision and visual problem-solving worsens in next stages</p>	<ul style="list-style-type: none"> <li>• eyes bright and focused but move less quickly</li> <li>• difficulty following movement of people, and images on TV</li> <li>• difficulty with the small eye movements needed to read</li> <li>• cannot problem-solve all illusions: e.g. may misinterpret reflections, patterns</li> </ul>	<ul style="list-style-type: none"> <li>• eyes increasingly appear to be staring, unfocused and looking downward</li> <li>• difficulty recognizing familiar people, objects accurately (agnosias)</li> <li>• may use visual memory (eidetic vision, like day-dreaming with eyes open), as a substitute for poorly seen surroundings</li> </ul>	<ul style="list-style-type: none"> <li>• eyes may be wide open when person finds visual focus</li> <li>• can be difficult to get eye contact</li> <li>• often opens eyes to strong stimuli and close one-on-one contact and hand-holding</li> </ul>
<p><b>Reading and writing</b></p>	<ul style="list-style-type: none"> <li>• can usually still read and write if vision is corrected with glasses</li> <li>• can still notice most errors in writing and try to correct them</li> </ul>	<ul style="list-style-type: none"> <li>• can still read large-print but often not paragraphs.</li> <li>• some writing may still be possible but is becoming illegible (drifts from lines, incomplete)</li> <li>• unable to notice and correct mistakes</li> </ul>	<ul style="list-style-type: none"> <li>• may read single words in large print</li> <li>• may still try to write, doodle or draw - sometimes even with their eyes closed, as they seem to be 'picturing' doing so in mind's eye</li> </ul>	<ul style="list-style-type: none"> <li>• no evidence of reading or writing skills</li> </ul>
<p><b>Energy levels and time of day</b></p>	<ul style="list-style-type: none"> <li>• often tired from trying so hard to 'get things right'; but this may not be noticed by others unaware of the effort</li> </ul>	<ul style="list-style-type: none"> <li>• usually most alert in the mornings, after 'siesta time' and after evening meal</li> </ul>	<ul style="list-style-type: none"> <li>• may nod-off briefly (boredom, not moving, under-stimulation, fatigue?)</li> </ul>	<ul style="list-style-type: none"> <li>• sleeps, dozes, nods-off throughout day</li> </ul>

<p><b>Personal care</b></p>	<ul style="list-style-type: none"> <li>• may need a reminder but usually does basic care unassisted</li> </ul>	<ul style="list-style-type: none"> <li>• needs assistance with personal care</li> <li>• is aware of being helped</li> </ul>	<ul style="list-style-type: none"> <li>• may try to assist with some care but needs total assistance</li> </ul>	<ul style="list-style-type: none"> <li>• totally dependent</li> <li>• little effort made to help</li> </ul>
<p><b>Activities of daily living</b>  <b>washing</b>  <b>bathing</b>  <b>grooming</b>  <b>dressing</b>  <b>eating</b>  <b>toileting</b></p>	<ul style="list-style-type: none"> <li>• manages most normal tasks with some minimal cues and assistance with a stable routine*</li> <li>• may ask for help and then deny needing it, resist accepting, or resent needing it</li> <li>• misplaces items; may try to keep them in sight, or with them to prevent losing them (e.g. handbags, wallet)</li> <li>*tasks such as grocery shopping, cooking meals, household maintenance, managing own finances and replying to post are ones which show a persons mistakes and struggles</li> <li>• help maybe required to make accurat judgements (e.g. when driving)</li> </ul>	<ul style="list-style-type: none"> <li>• needs cues and prompting to do self-care tasks, and may need help to complete them</li> <li>• wants to help with and or observe normal tasks and activities</li> <li>• often think they do all tasks competently, just as well, as before (sometimes residents think they are the house-keepers or workers in care homes)</li> <li>• little awareness of limitations or danger</li> <li>• forgetfulness makes living alone hazardous</li> <li>• frequently misplacing, losing and searching for things; anything that looks familiar may be mistaken for their own things and carried along until it is forgotten</li> </ul>	<ul style="list-style-type: none"> <li>• can recall some simple, familiar tasks but cannot necessarily complete them or perform them reliably; they are done for the familiarity, enjoyment and stimulation</li> </ul>	<ul style="list-style-type: none"> <li>• needs total assistance</li> </ul>
<p><b>Continence</b></p>	<ul style="list-style-type: none"> <li>• usually continent</li> <li>• may have an 'accident'</li> <li>• may make excuses, blame others</li> </ul>	<ul style="list-style-type: none"> <li>• may have 'accident'; does not blame others</li> <li>• may be unaware of accident</li> <li>• urinary incontinence starts</li> </ul>	<ul style="list-style-type: none"> <li>• seems unaware of accidents or incontinence</li> <li>• bowel incontinence may start here</li> </ul>	<ul style="list-style-type: none"> <li>• doubly incontinent</li> </ul>
<p><b>Appearance and posture</b></p>	<ul style="list-style-type: none"> <li>• grooming, attire usually good; very self-aware</li> <li>• upright; well controlled</li> <li>• defensive posture shows in tense jaw, body muscles; 'darting' eyes observing all around</li> </ul>	<ul style="list-style-type: none"> <li>• grooming and attire are more unkempt, even with good care (e.g. don't notice stains, fix hair, pull up stockings); less self-awareness</li> <li>• posture is more relaxed; less muscle tension</li> </ul>	<ul style="list-style-type: none"> <li>• increasingly stooped posture and looking downward while sitting</li> <li>• grooming and attire are totally dependant on the help and care received</li> </ul>	<ul style="list-style-type: none"> <li>• usually sitting or lying down – often has some degree of contractures from reduced mobility and movement</li> </ul>
<p><b>Movement</b></p>	<ul style="list-style-type: none"> <li>• well controlled, quick, direct and purposeful, especially so if defensive (* assuming person is not in wheelchair)</li> </ul>	<ul style="list-style-type: none"> <li>• * often slower, more shuffling walking</li> <li>• may appear dance-like, (miniature two-step)</li> </ul>	<ul style="list-style-type: none"> <li>• repeated movements that increase in frequency when upset (rocking back and forth)</li> <li>• can usually weight-bear, walks only with help</li> </ul>	<ul style="list-style-type: none"> <li>• sits or lies; little movement except for hand holding and minimal re-positioning</li> <li>• flaccid muscle tone</li> </ul>
<p><b>Emotions/ feelings</b></p>	<ul style="list-style-type: none"> <li>• reserved, maybe defensive</li> <li>• only reveal their real emotions to a few, trusted people</li> </ul>	<ul style="list-style-type: none"> <li>• discuss emotions freely</li> <li>• do not guard their self-image; may share emotions with anyone, even total strangers</li> </ul>	<ul style="list-style-type: none"> <li>• movements and tone of voice reveal emotions</li> <li>• frequent calling-out can be a plea for contact to break their isolation</li> </ul>	<ul style="list-style-type: none"> <li>• some emotion with eyes, hand squeezes, sounds e.g. may try to hold on if contact is broken</li> </ul>

Key helping guidelines				
<ul style="list-style-type: none"> <li>• use normal social formality and distance until invited to get closer</li> <li>• avoid touch and physical closeness until invited to do so, or the person initiates it</li> <li>• acknowledge feelings that are openly exhibited (e.g. fear, anger, frustration)</li> <li>• don't pry into or expose emotions unless invited to</li> <li>(Strong, overt emotional expression can threaten person's adult self-image)</li> <li>• don't emphasize mistakes or mental frailty</li> <li>• avoid arguing, correcting mistaken facts unless absolutely necessary</li> <li>• ask questions to find out about person's perceptions or story, but avoid 'why' questions. (This requires insight and logical thinking ability; can feel threatening)</li> <li>• find out who the person most trusts/confides in (may be only 1 or 2 others)</li> <li>• include person in normal adult activities they enjoy</li> <li>• keep away from people in S2, S3</li> </ul>	<ul style="list-style-type: none"> <li>• use eye contact and touch to aid communication</li> <li>• very responsive to voice tone</li> <li>• since facts are not retained anymore, avoid using or correcting them - unless directly asked</li> <li>• unlikely to learn names, but remember the feeling of others</li> <li>• your presence is often a symbolic one, that of a close other</li> <li>• people get fearful and restless if left alone in lounges; they easily 'feel lost' and look for someone to hold onto and guide them in familiar tasks and activities</li> <li>• keep mealtimes relaxed, slow</li> <li>• reminiscence with stories, photos, objects (also about universal themes: parents, parenting, belonging to, work, gender roles, aging, leaving a legacy for next generation, sense of order)</li> <li>• music, songs, pictures, poems familiar objects and movement can improve mood</li> <li>• find the person a 'Stage 2 Buddy' companion who feels familiar: a constant safety-anchor</li> </ul>	<ul style="list-style-type: none"> <li>• try to get and maintain eye contact by facing the person; stay in visual field</li> <li>• imitate (mirror) person's rhythm, pace, movements to stay in their visual field and to make and keep contact</li> <li>• wear bright colours, and lipstick to assist reading emotions and lips</li> <li>• multisensory stimulation needed to supplement verbal communication; touch, music, singing, massage; familiar movement e.g. polishing, folding, tapping, kneading, arranging)</li> <li>• reminisce using simple themes, words, songs</li> <li>• encourage any speech to allow self-expression and prevent person losing it</li> <li>• set mealtimes to music, with others in S3; provide finger foods if possible</li> <li>• put familiar, interesting objects in person's visual field; to prevent the need for self-stimulation</li> <li>(use sensory apron/ tabard with large pockets, Velcro strips, to attach familiar items for person to explore</li> </ul>	<ul style="list-style-type: none"> <li>• keep contact; give positive sensory stimulation: touch, warmth, hand and foot massage, hand squeezing and tapping to music, nice tastes, sounds and smells</li> <li>• try to get even brief eye contact</li> <li>• speak and sing to person with kind voice intonation</li> <li>• speak in short sentences; assume person understands</li> <li>• play person's favourite music to stimulate range of positive emotions</li> <li>• provide as much texture in food as possible (e.g. mashed or sieved versus pureed food) since even 'slight chewing' is exercise and stimulation</li> <li>• decorate bedroom and ceiling for extra stimulation</li> </ul>	

### References to the Behavioural Staging

Jones GMM, (2009) course notes for the course (and DVD version of the course): "Communication and Care-giving in Dementia: a positive vision"; The Wide Spectrum Pubs, Kingswick House, Sunninghill, Berks, SL5 7BH, UK. pp229 (previous versions, 2006, 2004, 2002, 1998, 1993)

Jones GMM, van der Eerden-Rebel W, Harding J (2006) Visuo-perceptual-cognitive deficits in Alzheimer's disease: adapting a dementia unit. In: Vol 4 Care-giving in Dementia (BML Miesen & GMM Jones (Eds). Routledge, London. Pp 3-58

Jones GMM, Harding J, van der Eerden-Rebel W (2006) Visual phenomena in Alzheimer's disease: distinguishing between hallucinations, illusions, misperceptions and misidentifications. In: Vol 4 Care-giving in Dementia (BML Miesen & GMM Jones; Eds). Routledge, London. Pp 59-104.

Jones GMM (2004) Metaphors for teaching about changing memory and cognition in Alzheimer's disease: Bookcases in a library. In: Vol 3 Care-giving in Dementia (GMM Jones & BML Miesen/ Eds). Brunner-Routledge, Hove. Pp 37-66.

Jones GMM (2004) The loss of meaningful attachments in dementia and behavioural stage-specific implications. In: Vol 3 Care-giving in Dementia (GMM Jones & BML Miesen/ Eds) Brunner-Routledge, Hove. Pp 261-284.

Jones GMM (1997) A review of Feil's Validation method for communicating with and caring for dementia sufferers. Current Opinion in Psychiatry/Geriatric Psychiatry, 10; 326-332.

Miesen BML, Jones GMM (1995) Psychiatric pain re-surfacing in dementia: from new to past trauma? (C. Rowlings Ed.) Past Trauma in Late Life : European perspectives on Therapeutic work with older people. Jessica Kingsley Pub., London. Pp142-154.

Arendt T, Jones G.M.M., 1992: Clinicopathologic correlations and the brain behaviour relationship in Alzheimer's disease. in: Care-giving in Dementia (Jones and Miesen; Eds.) pp.7 26

Jones GMM, Burns A (1992) Reminiscing disorientation theory. in: Care giving in Dementia (Jones and Miesen; Eds.) pp.57 76.

Jones GMM, Ely S, Miesen B, (1992) The need for an interdisciplinary core curriculum for professionals working with dementia. in: Care giving in Dementia (Jones and Miesen; Eds.) pp. 437 453

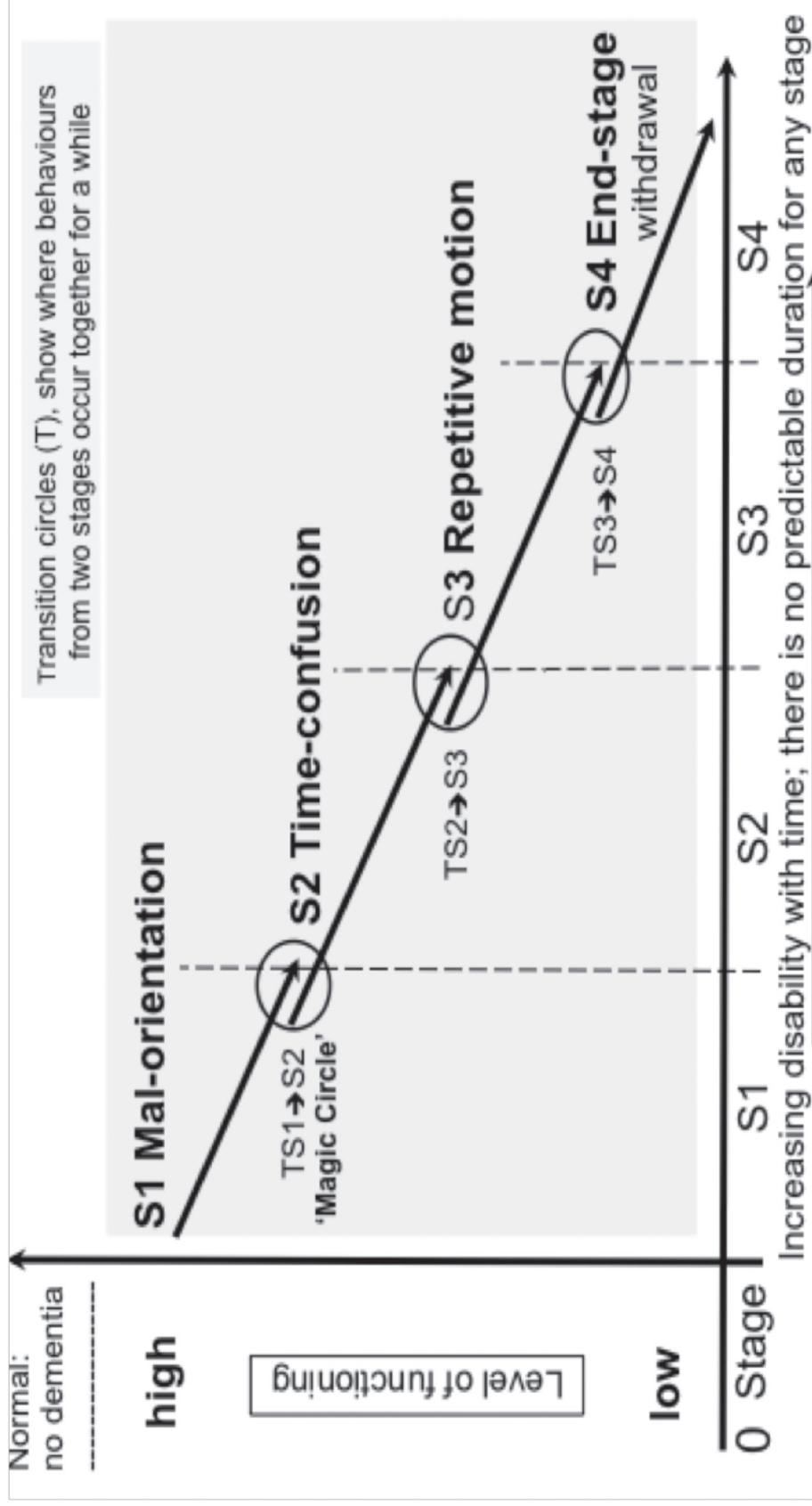
Woods R, Portnoy S, Head D, Jones GMM (1992) Reminiscence and life review with persons with dementia: which way forward? in: Care giving in Dementia (Jones and Miesen; Eds.) pp. 137 161

van Amelsvoort Jones, GMM, (1985) Validation Therapy, a Companion to Reality Orientation. Canadian Nurse, March, pp. 22 26.

### 3.4a Graph for recording the Behavioural Stage

For normal Staging: mark on graph what level the person is at, with a date next to it

For Split Staging: mark abilities separately (M for memory, P for physical, E for emotional)



It is important to note that people with dementia can be contented or not contented in any stage. This is a summary of the differences in behaviour in those states.