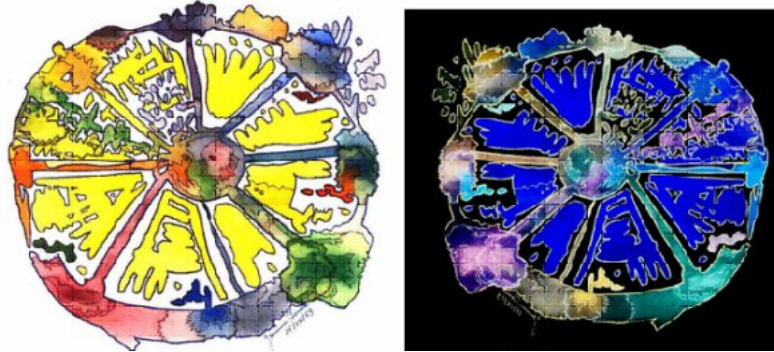


## TAD (Thoughts About Dementia) Newsletter



#41: 14th November, 2011

### The purposes of staging models for dementia

Dear Reader

The staging of dementia and specific types of dementia, is a large topic. This newsletter will be first of several on staging; it aims to clarify some misunderstandings about staging models. The view presented here, is that **every illness can be thought of as having at least three stages – a beginning, middle and end, and that in addition, many illnesses can be described in more specific stages** . Two-stage and three-stage models may not be enough to describe long, chronic illnesses. This information is presented as a backdrop to future TADs, which will consider the advantages of using the four-stage ‘Behavioural Staging model’ and ‘Split Staging’ for providing dementia-care. This model describes the majority of people with late-onset Alzheimer’s Disease (AD), and many with progressive (small-infarct) vascular dementia, but not all types of dementia.

Despite individuals being unique in their response to having an illness, it is now known that AD starts at a particular location in the brain and spreads in a known order (the Braak Stages). This means that people with AD experience the symptoms of dementia in a largely predictable pattern. If they have additional complications from other illnesses and injuries, their symptoms may progress more rapidly, but not at random. Where a person has a rare type of dementia or a complex presentation (such as multiple types of dementia or a rarer type of dementing illnesses), ‘Split Staging’ can be done. This involves describing different types of behaviours separately, but using the baseline descriptors from the Behavioural Staging model.

Collecting and scrutinizing staging models of dementia - generically, and for specific types of dementia, has been an interest of mine for over thirty years. This includes considering their original purpose, current use, accuracy, the ease with which they can be taught and learned by various groups, and their helpfulness in

assisting family carers and professional caregivers to provide bespoke, sustainable, professional dementia care.

Of the twenty or so documented models in my collection, only a few are of direct practical use for care-giving. Some were designed for other purposes - cognitive research, theory testing, initial assessment, diagnosis, confirmation of diagnosis, and care-placement categorization. Fortunately, new models are being developed to replace those that are out-dated (given the current neuroscience understanding of specific dementing illnesses, and the inaccuracy associated with the generic use of the word 'dementia').

The most useful model I've come across to date, for care-giving purposes, is the four-stage 'Behavioural Staging model' already mentioned, which has been adapted and expanded over the years from Feil's original work on 'stages of disorientation'<sup>1-7</sup>.

### **Some people have been told that there are no stages in dementia**

Last year, a manager of a dementia care home related that, on a previous dementia course, she had been told "there were no stages in dementia". She was puzzled that on my course several linked staging models were taught - to assist with observation, documentation of changes, bespoke care planning, communication and care provision. She asked about how it could be that different dementia courses could teach such different things – wasn't there any consistency in dementia education?

The answer: there's some, but it's not yet total. The concern she expressed has been around for several decades<sup>8</sup>. It's a new field, and the knowledge base is still being assembled and refined. Also, not all those teaching dementia care have had (much) experience of hands-on dementia care, or a 'core' education in dementia and related subjects. Since there is still a dearth of dementia education available, some old material is still being taught.

### **What were the manager's other concerns about stages of dementia?**

The manager had come away from her last course with at least three other ideas that were now confusing her, since they hadn't been explained in detail and conflicted with the current teaching.

#### **Concern 1**

The manager had been told: 'there's no such thing as stages in dementia; everyone has dementia in their own unique way'.

*Reply:*

*This is a puzzling statement indeed - since most illnesses are described in terms of stages. For example, if, even a brief illness, like Chicken Pox, which lasts about two weeks in children, can be described as having several stages - how many stages would be needed to describe Alzheimer's dementia, which can last over 20*

years? (Compared to Chicken Pox, even making a model with one stage per year doesn't seem like very many to describe dementia! The problem with such a model would be that few could remember a 20-stage model, so it wouldn't be well used. This is only one of the challenges involved in developing a useful staging model for care.)

*Each person is and remains unique - also in the way they experience and respond to illness, whether it is Chicken pox or dementia. Yet, despite individuals having unique 'responses to having illness', many illnesses follow a relatively predictable pattern of progression or 'illness trajectory', which can be described in stages.*

*What makes dementia more difficult to discuss than other illnesses, is that the word 'dementia' does not refer to a single illness. Therefore - strictly speaking, it is true to say that it is not possible to describe the 'stages of dementia', except in a very rough way. However, there are staging models for some specific types of dementing illnesses, and certainly so for late-onset Alzheimer's disease. (It is the most frequently occurring of the dementias and has been described using a number of staging models.) Some other dementing illnesses also seem have a common patterns of progression, and their stages have been/ are being described. With new neuroscience understanding of specific types of dementia, some old models are being refined, and new models are being developed. Not all types of dementia have staging models yet since:*

- . although it has been estimated that there are over 100 types of dementia, it is not yet known absolutely how many types of dementing illness there are*
- . many types of dementing illness are very rare, and it is difficult to find enough people to study while they are alive, and afterwards to examine their brains - post-mortem, to describe how the illness progresses and whether there are common patterns of change*
- . some types of dementia, like the sub-types of vascular dementia, do not have predictable patterns of progression.*

## **Concern 2**

The manager had also been told: 'there can be no stages in dementia because there is so much variation in the time course of the illness between people'.

*Reply: It is true that no one can predict the length of a particular person's illness, or the duration that they will spend in any given stage exactly. Neither is it possible to know what factors, besides dementia, could complicate or accelerate the progression of a person's dementia (i.e. the age of onset, the impact of other illnesses, injury, or issues related to the quality of care). However, it is possible to stage some types of dementing illness, like Alzheimer's disease, because there is a predictable pattern to the spread of the illness, in terms of which areas of the brain are affected in which order, even if not the exact rate of progression, or duration of the illness<sup>9, 10</sup>.*

## **Concern 3**

The manager had been told: 'stages are a form of label, and labels are negative

and unhelpful since they cause additional stigma’.

*Reply: There are several points to clarify here.*

*Not all labels are negative. Whether a given label is associated with stigma, has to do with the societal understanding of a particular word or term. The word dementia does have a negative stigma in society still, so it is inevitable that a diagnosis of dementia may carry stigma, but this is diminishing as a more accurate understanding is replacing old concepts and prejudices. Also, whether a diagnosis is associated with stigma is a different point from whether conceiving of an illness in terms of stages can be helpful for guiding care.*

*Labels, in the form of naming a stage, can be helpful in care settings, especially if they prevent unofficial, negative labels from being used. For example: Which label would you rather have?*

*‘Behavioural Stage 1? - being ‘mal-oriented’ (versus disoriented); struggling with new information and benefitting from cues, reminders and frequent reassurance, or -*

*‘the nasty, selfish, complaining, lying, accusing, attention-seeking, unappreciative resident in Room 15’?*

*The view that ‘labels are negative and unhelpful’ that this manager was previously taught, may have come from someone who was following the ideas expressed by the psychiatrist, R.D. Laing, and others, in the 1970’s. Though now generally considered to be dated, they came about in reaction to, among other things, justifiable concerns about uncertain, unconfirmed diagnoses given to young adults with mental health disorders, which had huge negative implications (including stigma) for them for their entire lives. The situation with people with dementia is not so comparable on several counts:*

*. dementing illnesses are increasingly considered to be neurodegenerative illnesses, like M.S.,*

*as opposed to psychiatric illnesses*

*. they generally occur in the latter part of a person’s life - after normal transition through adulthood and employment, so a diagnosis does not affect the whole of adult life of a person*

*. the diagnosis of dementia is usually not an unexpected one.*

### ***We all use labels and models***

*The reality is that we all use models, labels, and stages whether we know it or not, or like it or not. We humans instinctively compare, categorize, label, order, sequence and stage things - in most everything we do. It’s an aspect of our cognitive abilities. We also do this when we care for people who are ill and grieving. (Stages are also a sort of short-hand way of describing a cluster of features. In science, this is called modelling or model building.) In dementia-care, the helpfulness or unhelpfulness of a label is also determined by its accuracy and efficiency to guide decisions related to care-giving - the provision of optimal*

*understanding, communication and assistance.*

*The label of 'a diagnosis of dementia', can be positive and helpful:*

- . to prevent inaccurate suppositions about the cause of behaviour change- such as - that the person has become self-absorbed or anti-social, which could have the negative effect of causing 'emotional distancing' from those closest to the person with dementia – those who are in the best position to help the person for the duration of their illness, and who may need help to sustain their emotional and other involvement with the person*
- . to guide the provision of understanding and care of the professionals and caregivers involved with an the person with dementia and their family/social support system*
- . and necessary in order for family/primary carers to obtain Carer's Allowance and financial assistance*

*In summary, both diagnosing and staging are forms of labelling, but for different purposes. Making a diagnosis of dementia is done in response to trying to find **the reason for irreversible changes** in cognition, ability to function, and behaviour. Determining the stage a person is in, after a diagnosis has been made, is to identify, **where, in the known/expected course of a dementing illness, a person is**, i.e. beginning, middle, late or end.*

The manager understood these clarifications, and made some further reflections.

### **What were the earliest staging models used in dementia care homes?**

I don't know what the first staging model of dementia was, but the first unofficial one I came across in my work with people with dementia, in the 1970's, was a **two-stage model**. (The manager, and other course participants who work in care homes confirmed that it is familiar to them, and still in use.) Put simply - staff distinguished between 'the good ones' and the 'bad ones' - that is, residents with higher level cognitive ability - who could still do some tasks independently, versus those unable to communicate intelligibly and needing total assistance, including for eating and mobilizing. (*Some members of staff also used a different two-stage model with regard to residents with higher level cognitive abilities. They spoke of 'the mean ones' and the 'delightfully confused ones'.*)

The 'good/bad' model was not useful for discussions with family carers who were placing a person into the care home. Family members had a different concept of good and bad. To them, the person with dementia couldn't function independently anymore, had become *very bad* – which is why they could not continue to be cared for at home. Family, unaware of the entire course of a dementia, may have been surprised to learn that staff thought of their relative as 'good'. (This goes to illustrates why stages need to be clearly described, and also how it is that the early and late stages of dementia are easily missed from staging models).

**MMSE scores are sometimes also translated into two and four-stage models**

The manager said that, when residents with dementia were admitted to her care home, they were usually admitted on the basis of being in one of two categories - 'mild to moderate' or 'moderately severe' as indicated on the forms. She hadn't thought of this as being a 'staging classification' before, but it also seemed to be a two-stage model of some sort. On reflecting further, she realized that these two categories were likely merged - from four ranges of MMSE scores:

Scores of 20-24, are considered mild  
Score 10-20, are considered moderate  
Scores below 10, are considered severe  
Scores of zero and below – were not discussed

The manager concluded that neither the four ranges of scores, nor the two merged-score categories, were very helpful for understanding the nature of difficulties and competencies a person had, to assist staff in providing care. People with the same MMSE scores can have very different abilities and needs. (The rigid use of MMSE scores as criteria for administering anti-dementia drugs was described in TAD 12: 26 April 2010, 'The tyranny of the MMSE test'. MMSE scores can vary 3 points in an individual, from one day to the next.)

She said that the type of dementia a resident had been diagnosed with, was almost never specified on admission documentation, (nor was the year of diagnosis, or the name and qualification of the diagnostician.) In effect, all she knew of most residents when they were admitted, was that someone had determined that they had 'dementia'.

### **Many articles hint at a three-stage models without a name, description or reference**

Although there is frequent mention of 'stages of dementia' in popular reading and research articles - few of them provide a name and reference for the model being used. Many make mention of 'early, middle and late stages' - without specifying their characteristics, as if it is obvious, though it isn't that simple. This can create the misconception that there is *one single 3-stage model* in consistent use, but this is not so. On comparing various 3-stage models, it becomes apparent that, just how the stages are defined is not so consistent and many do not refer to the very last, end-of-life stage. This limits the use of some three-stage models in informing and guiding dementia care. (For a general example of differences in staging models, compare references 11-13.)

### **The staging of Alzheimer's disease needs to be taught – it isn't obvious**

Since dementing illnesses can last a long time, it is easy to lose perspective of what's happening over this time span - what changes are to be expected or not. Barbara Pointon, known from the ITV broadcast, 1999, of 'Malcolm and Barbara, A Love Story', recalled that Malcolm's early onset Alzheimer's disease, lasted twenty-two years (personal communication). It's easy to blame any and all changes on 'the dementia', and miss those things which can be helped by

immediate and additional intervention, which is why Barbara took Malcolm out of the care home, to care for him at home until his death.

### **Doctors need to be taught staging models too**

Last year, a doctor was giving a talk on dementia to some final-year medical students. He asked them to describe how Alzheimer's disease normally progressed, in an otherwise healthy person - aged 80, from beginning to end. They struggled to do so. They had not seen many people with dementia yet (some in hospital and some in care homes), and had not followed them for several years, so they did not have an accurate or detailed 'illness trajectory' in their mind. So although they had seen some individuals at particular points in their illness; they had not been taught how to 'connect the dots', and see the pattern.

### **A four-stage model is possible to teach, remember and use**

Some staging models having many stages, but they are not ideal for caregiving. Using the *Behavioural Model*, and determining what *Behavioural Stage* a person is in, can help to provide bespoke care, which is necessarily dementia-specific and stage-specific. The utility of this model is that it focuses on observable behaviours and describes 'the best' that a person can do - with the aim of supporting those functions that are becoming weaker or lost. It describes beginning and end stages, and 'levels of ability' within each stage. It describes, among other things, changes in what people are frightened of, language ability, and various coping mechanisms. If staff know what a person is fearful of, they can try to allay specific fears and to make a person feel safe (even temporarily) and function 'at their best'. If staff understand how language ability and comprehension change, they can choose the most effective communication options for assisting residents. Observing behaviour includes determining whether and how a person's sensory functioning and perceptions of time, place, person, emotional atmosphere and context have changed. Changes in sensory perception, orientation, and time-perception in particular, are essential to Behavioural Staging.

I've taught this model to professionals, caregivers, and to family carers. Sometimes, professionals have questioned whether teaching it to family carers is helpful (i.e. ignorance is bliss). My experience is that family carers benefit as much as any other group.

One striking example of this happened a few years ago. I received a Christmas card from a gentleman whose wife with dementia had been in a nursing home for seven years. He wrote that he now knew that she had been in Stage 2 when she moved there. However in the past year he had seen her progress from Stage 3 to 4. At this rate, he felt her illness was nearing its end, and he had resolved to visit her as often as possible in whatever remaining time there was. He had devised a visiting routine, so that, although she could not communicate using words anymore, he could communicate and stimulate her through her senses, as much as possible (i.e., letting her smell her favourite perfume on a handkerchief rolled into her hand, feeding her favourite flavours of yogurt, giving her hand massages,

playing familiar music CDs, singing to her, reading her well known poems and prayers, bringing her flowers, and wearing bright pullovers when he visited so that she could see him). Although she no longer seemed to recognize him by sight, she did respond positively to his presence and he wanted to let her feel/know/sense however possible, that she was not alone, and that life was good.

### **Related ideas for observations and research:**

.Have you come across any of the concerns about *staging dementia* that were raised by the care home manager?

.Were you taught any particular staging model/s?

.How many articles have you read that implicitly or explicitly used a staging model?

.How many of them provided details and references about which staging model was being used?

Best Regards,  
Gemma

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