from 'the wide spectrum' website **TAD (Thoughts About Dementia) Newsletter TAD (Thoughts About Dementia) Newsletter TAD (Thoughts About Dementia) N**

Related ideas for observations and research:

. Did you know that it's impossible to have 'no memory'?

• Have you ever tried to explain (to a person with dementia, family carer, or caregiving professional) what can happen to one or more cognitive abilities in dementing illnesses, i.e. memory, attention, logical thinking ability, ordering and sequencing, learning, problem solving?

. If so, how accurate, simple, helpful and memorable were you able to make the explanation?

. If you spoke of memory, did it cover the entire course of the dementia, or just early stages?

. Could you explain apparent paradoxes like - people with dementia being able to learn and recall some types of information - but not others?

. Did you include the link between attention and memory, such that - if a person has difficulty noticing and paying attention, they cannot get information into memory?

. Did you ever consider the difference between attentional errors and memory errors?

. Have you blamed attentional mistakes on your memory? E.g. Have you even walked into a room and then wondered what you came there to get? After re-tracing your steps to the place where you were before you thought of something else (split your attention to another thing), you remembered again. You had not forgotten, but become distracted.

• Have you ever wondered how often such difficulties happen to people with dementia? And about the extra frustration when they cannot re-link to what they were going into a room for, like we usually can?

• Have you been careful to monitor what types of factual and emotional information a person with dementia is exposed to by way of what is in the newspaper headlines, on the radio or TV?

• Have you ever noticed how your mood (positive, indifferent, or negative), or the emotional tone of your body language and/or conversation can rub off on a person with dementia – usually quickly?

Dear Reader,

A former student asked for a TAD newsletter to explain the essence of two metaphor models that I teach on dementia courses. She also wanted information about the links between them. They have been published and discussed previously in various amounts of detail ¹⁻⁴. Here they are.

A 'Attentional blackboards' that usually hold a fixed number of bits of information or messages (for a brief while before they are lost or move into memory), shrink in size as a dementing illness progresses. This has two consequences; it becomes more difficult to pay attention, and only fewer, shorter messages are able to be stored.

B One, of several different types of '**memory bookcases**' within a memory library, has some damage to its structure, develops a 'wobble', and eventually collapses. Throughout this process, the information (type of memories) stored on that bookcase is not lost, but becomes increasingly difficult to access. In most but not all types of dementia the' factual memory bookcase' is the one that is damaged though the 'emotional memory bookcase' and 'sensory memory bookcases' are not. Hence, emotional and sensory memories will work best and become dominant, and caregivers can learn to work with them as it becomes more difficult (and perhaps impossible) to work with 'facts'.

Note: These models help explain the normal (uncomplicated) course of an Alzheimer-type dementing illness, and some other types of dementia too, e.g. the later stages of multi-infarct dementia. However, they do not necessarily explain what happens in rare types, multiple types of dementia, and dementia associated with serious physical and/or mental illness. In some types of dementia, emotional and sensory memory bookcases are damaged before the factual memory bookcase is (e.g. Frontal Lobe dementia, some brain tumours, some locations of strokes).

What makes these two models useful?

They explain that '**there are different ways of knowing**' things. A knowledge of this can help us to adapt communication and care interventions throughout the course of the illness. These models help explain frequently encountered questions and situations, like:

1 Why are earliest memories usually recalled best by people with dementia? [They are the easiest to access from the factual memory bookcase, even when it has collapsed.]

2 How can a person with dementia recognize and remember the name of their favourite granddaughter, but not seem to remember their daughter? [Sometimes people have to work so hard when their own children are young, that they enjoy and interact emotionally with their grandchildren more than their children. A granddaughter may have been waited for, for so long, and have given such emotional pleasure, that the new information about her is readily accessible from the emotional memory bookcase, whereas the information about the daughter, from the factual memory bookcase, is not so easy to access anymore.]

3 How can a person with dementia be mistaken about the *facts* of a story they are relating, but accurate about the *emotional mood or events* about it? [They may have a collapsed 'factual memory bookcase' which means there is no 'top shelf' anymore, on which to put current new factual memories. A person may make a variety of mistakes with facts. Such as - they may:

- . be unable to remember or relate facts accurately anymore
- . only remember a few facts, and even not the seemingly 'important' ones
- . over-emphasize or mix up the (few) facts they do remember, so that nothing sounds true or even plausible

. try to save face by 'inventing some facts' to try to look competent or to please the person they are speaking to. Despite the incorrect facts, emotional memory is working, so what is related about tone/ mood can be accurate.]

4 How can it be that a person can recall having had a birthday party last week, but not recall how old they are, or even that they are old at all? [As in example 3, age is a 'fact', and this fact may not have been stored on a 'wobbly factual memory bookcase'. However, the memories of the merriment, warm atmosphere - the special attention, singing, cake, candles, and gifts may be easy to retrieve from the emotional memory bookcase.]

5 How can a gentleman with dementia sometimes briefly know that his wife is dead, but moments later, seemingly NOT know this, and start to look for her and ask after her again? How can he 'know' and 'not know' so intermittently? [Using this model, it can be explained that: he does not know the facts of her death anymore (day, date, year, how many years ago, what happened exactly). Yet, at the time of her death and funeral he did store the feelings of loss and grief on the 'emotional memory bookcase'. Like all of us, he does not like to think of painful memories, but every once in a while, he can recall that 'she is dead', but only intermittently, because his time perception is permanently damaged. He has not been able to be oriented to time, or to update events related to the passing of time, since his 'factual memory bookcase' collapsed. Note: It is very relevant when his factual memory bookcase collapsed, in relation to the time of his wife's death. E.g. if his wife died after his factual memory bookcase had collapsed, he will not be as likely to remember that his wife died.]

Starting points for using these models

Dementia means more than '*having difficulties with one's memory*'. **Box 1** lists the most noticeable and less noticeable difficulties people with dementia have. The latter changes may take more time, or be more difficult to notice.

Box 1 noticeable early difficulties

- **M** memory (for recent facts) ⁺
- A attention
- L logical thinking ability ⁵

+ versus 'memory for the emotional flavour of things or events', or 'memory for particular aspects of physical sensations'

less noticeable early difficulties

- V visuo-perceptual and spatial ability
- **O** ordering and sequencing ability (of events, items and information)
- L language ability

The attentional blackboard metaphor

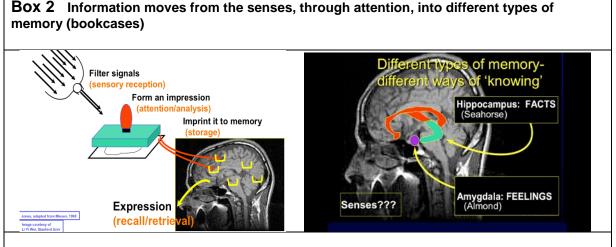
Attentional ability is part of a chain of events enabling us to notice an item of information - and perhaps for it to go on to be stored into memory. Think of attention like a blackboard surface that can hold a certain number of messages (information) temporarily. Only some messages are stored into memory – most aren't. Think of the blackboard as being located on the under-surface of a rubber stamp that can *imprint*⁶ the information that has been noticed (attended to) **into different types of memory bookcases** in the brain. See **Box 2**.

Two modes of attention

There are different modes and types of attentional ability, just as there are different types of memory. (E.g. each sense has it's own types and modes of attention). However, to keep things simple, for the purpose of care-giving, think of two modes of attentional ability:

- 1 divided (scanning, multi-tasking) attention
- 2 undivided (sustained, focused on one-thing) attention.

People have both modes, one of them is usually easier (less effortful) for a given individual to use, and is therefore a person's dominant way of *paying attention*.



Each thing we notice or pay attention to, and form a impression of, can be imprinted into different types of memory bookcases; factual, emotional/feeling and sensory. Control Centres for these types of memory have different locations; hence some are spared while others are damaged.

Each person has a different sized attentional blackboard

Attentional blackboards come in different sizes; this means people can hold different amounts of information or numbers of messages on their blackboards. The larger a person's the blackboard's size, the greater the number of messages it can hold simultaneously; the smaller the blackboard's size, the fewer. See **Box 3.** Many conditions can cause a person's

blackboard to shrink in size *temporarily*; e.g. illness, fatigue, medication, trauma, dehydration, pain, and grieving.

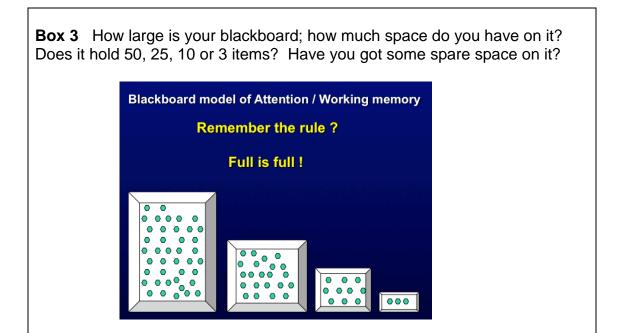
What happens to attentional ability when a person has dementia?

Dementing illnesses can cause difficulty in using or switching between the modes of attention. It also causes the blackboard to shrink in size - *permanently.* This means that the quantity of information that a person can pay attention to (process) and store on the blackboard is reduced.

"Full is full!" This is the one rule about attentional blackboards - regardless of their size. Imagine a blackboard that only holds X number of items. If it gets overloaded, by trying to put X + 1 items on it; something will be forgotten or mixed up with something else.

How small can a blackboard get?

It's not known for sure - but thinking about people I've cared for, a blackboard can get so small that it can only hold three messages - or in the end stage, three words. Hence, if we were to speak to a person with a very small attentional blackboard in phrases of more than three words, they may not be able to comprehend us. (This is why, on my dementia courses, participants practise validating a person's emotions in the simplest way possible – using just three words.) **Appendix 1**, at the end of this TAD, gives some communication tips about getting a person's attention, and matching a person's attentional mode and blackboard size. Difficulty in securing eye contact, loss of eye contact, and 'glazed expression', are the most common indicators of a losing someone's attention, and indirectly, of blackboard size.



Memory

When we remember and reminisce, we are retrieving information from different types of memory at the same time. Since it feels like *remembering* is a single process, we've thought of memory as a single ability in the past. Now that different types of memory are known about, we realize that when one type of memory becomes weakened, the other types continue to function to the best of their ability. This means that 'there are different way of knowing' As shown in Box 2. So, even if a person can no longer store or recall 'the facts' about something, they may be able to learn ⁷, (store and access) some types of information through emotional or sensory memory information.

Our difficulty, as carers and caregivers, has been that we have not been taught to understand what a person will be like (how they behave; what they can and cannot do) if factual memory is damaged and these other types of memory become dominant. When we only notice the 'wrong facts', and ignore these other types of memory ability, it means that we may fail to notice when a person is doing their best, doing something exceptional, or, when they struggle in new ways. (Cognitive testing does not yet measure these other types of abilities.)

Multiple memory bookcases metaphor

Box 4 shows different types of memory being stored on **distinct bookcases** in a 'memory library' containing factual, emotional and sensory memory **bookcases.** There is a bookcase for each sense. (These terms are more helpful for caregiving than those used in cognitive psychology.) Factual and emotional memory bookcases are the main focus here, since most is known about them.

Normal memory

Note: various changes that can happen to memory (like oft-repeated similar memories, or during traumas) are beyond the scope of this discussion.

Our memory recall is not perfect, but it seems stable enough to serve us surprisingly well for making comparisons to changing times, and reminiscing, throughout life - if we don't get illnesses and injuries that damage memory storage and/or retrieval abilities.

For our purposes, 'normal memory functioning' is when the various types of memory work together, so that when something is recalled, aspects are accessed from different types of memory storage - simultaneously, relatively accurately, and repeatedly so. We can move back and forth between different shelves within a bookcase, and between different memory bookcases, without becoming stuck in one place, (or muddled when we take in new information about the present, and update time-related information).

Although everyone notices when a person cannot *add any more information to the uppermost shelf* of the factual memory bookcase in present/very-recent time, we often forget to pay attention to the stages before that. When the

'wobble' starts, it can be more difficult to move between the different shelves on the factual memory bookcase. (Eventually, some can get *stuck, thinking about content/memories* on a particular shelf as if it were happening now.)

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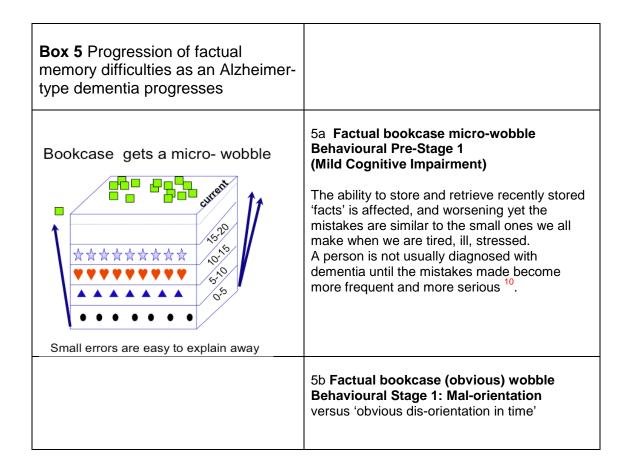
Box 4 Comparing different types of memory		
Factual memory bookcase	Emotional memory bookcase (Archetypal memory?)	Sensory memory bookcases
 stores information about facts*, linked to chronological categories or units of time, however that is perceived (unknown still). in this model, each shelf holds five years with of memories the top shelf if the one being filled with memories currently * Facts are accurate pieces of information about things like names, dates, descriptions, times, amounts, sizes Facts can be thought of as answers to questions like: who, what, where, when, how many? The question 'why' is different, since 'why' implicitly asks for an accurate understanding of the relationship between facts – it is related to 'rational logical thinking ability' ⁵. 	 stores information about the emotional flavour of things according into similar categories such as memories of : caring, nurturing women in life caring, nurturing men in life children, negative authority figures places animals events⁷ this type of memory is not usually noticed as a separate type of memory system unless the other is damaged does not provide factual information but rather 'feeling information' - to questions like: 1 Who does this person feel like or remind me of? 2 Where does this place feel like? 3 What is the (social mood) atmosphere here like, and what events does it remind me of? 	 store information associated with each sense vision hearing touch taste smell kinesthesis (a compound sense: movement, balance, body awareness in space) provides baseline expectations of what things 'should' be like compared to how they seem now. This helps us to make compensations for sensory- perceptual changes as a result of sensory perceptual changes resulting from things like: normal sensory aging (wear and tear related) age-related sensory illnesses other sensory illnesses or injuries side effects of medications
Note: although the nature of this type of information is exact /literal, it is contextual.	Note: the nature of this type of information is associative and symbolic.	Note: the nature of this type of physical information can also be associative and symbolic.
Co Co Co Co Co Co Co Co Co Co	Topic / Category	smell taste balance touch vision hearing Other book cases?

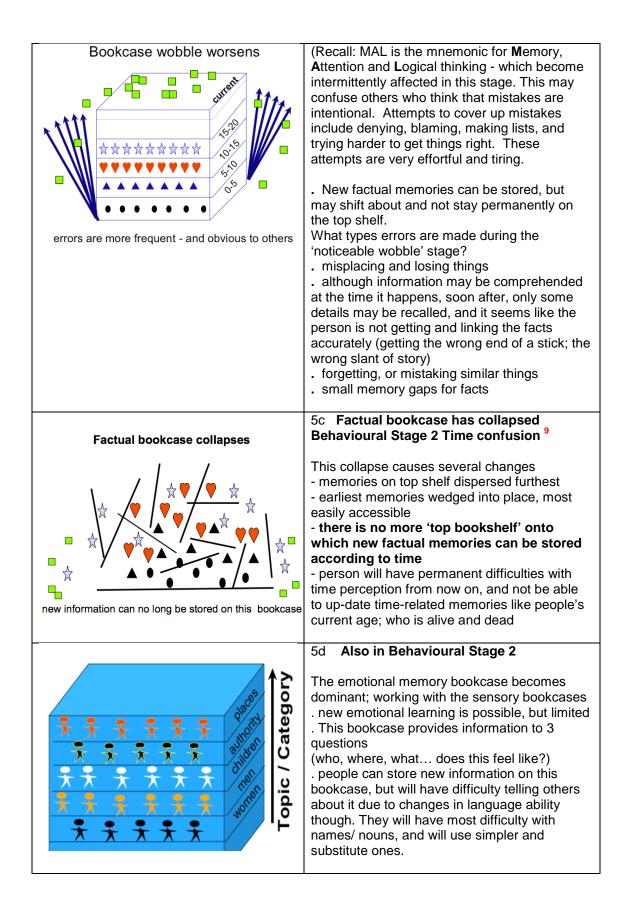
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How do memory abilities change in Alzheimer-type dementia? In this model, having dementia makes it increasingly difficult to access memories – most notably recent 'factual memories'. This memory bookcases model is supported by our current understanding of what brain structures are damaged, and in what order, in specific dementing illnesses ^{8, 9}. (This is a big change from many previous models, which simplistically suggested all memories could be lost, in reverse order. To the contrary, most carers have observed brief but lucid moments of unexpected memory ability.)

The diagrams in **Box 5** show how the factual memory bookcase develops a micro-wobble, then a more serious wobble, and gradually collapses. This process makes it increasingly more difficult to retrieve old factual memories that are stored chronologically, but sometimes they emerge with the help of prompts or triggers.

After the factual memory bookcase has collapsed, it is no longer possible to store new factual memories according to time. (This implies that **there is little point in trying to argue about, or teach 'facts' to a person who has no top bookshelf on which to put them anymore, and, who cannot re-learn old facts.)** Emotional memory and sensory memory bookcases become dominant. The types of information they store are very different from 'facts stored according to time'. When a person with dementia uses these other memory bookcases, they will make **predictable errors** about facts. (This is 'their best ability' with the brain damage they now have.)





Practical consequences of knowing about the bookcase model

This memory bookcase model can explain how, even though a person cannot know the facts of a person or event, they can still know other emotional and sensory details. It explains how:

. cognitive abilities can be so intermittent while a person has a wobbly bookcase ^{10, 11}

. you may have a symbolic identity for a person with dementia – and not be present as 'yourself'; family carers and caregivers can be mistaken for other family members, work colleagues, previous acquaintances who 'feel' the same¹²

. the identity a person 'gives you' can vary – even during one day. (Variations seem to be related to - which name a person with dementia can retrieve for you - from all the names on the emotional bookshelf of 'people that you feel like to them'. Your identity can also vary with factors like time-of-day, lighting, fatigue, and expectation.) [During one day, I was called 'sister', 'mother' and 'gran', by a lady I caring for.]

. likewise, if a person with dementia is in a care home setting, they may mistake other residents for other people also – depending on who they 'feel like or seem like' $^{\rm 13}$

. sometimes, through no fault of your own, nothing you have done, you may remind a person with dementia of someone who is on their shelf for 'negative authority figures'. If you know this, you won't take it personally. You will understand that it is an accidental association based on some attribute you have in common with the person in their memory. You will realize that you cannot correct this mistake, or teach the person factual details about your real identity (name, age, role) if the person has a *collapsed factual memory bookcase*. You will try to find someone who feels 'safe' to the person to be with or work with them.

. there is a time to stop expecting that a person can 'take in' and remember 'facts', and that is when their bookcase starts to develop a noticeable wobble. When a person has difficulty with 'facts', switch to talking about feelings, and, what you both observe and experience in present time ¹⁴.

For a summary of how the Memory Bookcase model throughout the course of dementia illness, see **Appendix 2.**

Conclusion:

Since it is impossible for anyone to have lost ALL their memory, we can replace inaccurate idioms like 'She's got no memory', with 'She has poor factual memory, but still has good memory abilities for the emotional flavour of things, and sensory memory'... or whatever descriptor is fitting.)

The value of good models is that they are explanatory, and even predictive.

A husband (carer) said that, as a result of knowing about this model, he was now better able to understand how his wife with dementia 'thought', and therefore didn't correct her so much anymore. This helped him to prevent the atmosphere from turning sour and/or quiet, and it gave him new ideas for conversation and activities based on that. The example he gave was this.

He took his wife do their weekly shop in the supermarket. As they entered, they saw ambulance workers checking out an elderly man lying on the floor, seemingly unconscious and with some blood on his head. There were lots of people around, all looking anxious. Soon thereafter, the injured gentleman was placed on a stretcher and moved into the ambulance. The wife seemed to take in what was happening, and made the comment "I hope they'll be OK." Thereafter, she seemed anxious to return home as soon as possible, and repeatedly asked when they could leave. He had struggled to complete the shopping.

That evening a neighbour came over for a chat. The lady told her neighbour they'd seen a TV programme about accidents in stores. She continued to say that she had found it really upsetting, and didn't want to go out today. Rather than correct her, the husband asked questions about what had upset her most, and about what she remembered about what she'd seen. Had she seen how competent and helpful people were?

He explained to the neighbour, in a moment alone, what had really happened, and that, seemingly, what his wife had been relating, is what it had felt like to her... something she was watching (like on TV), and something upsetting that made her want to stay-in - safely at home.

Best Regards, Gemma

P.S. One fond memory I have of the value of this model, came from a couple who attended the Alzheimer Café (AC) for several years. The lady, wife of a gentleman with dementia, had been skeptical about whether her husband was getting much value out of the AC talks. They returned, a month after I gave the AC talk about the 'bookcases and blackboards'. The wife was eager to tell me that, just that very morning, her husband had proven her so wrong. She had been rushing him during breakfast, washing and dressing. They had an appointment to keep and he seemed deliberately slow and uncooperative. Suddenly, he turned to her and said, "Back-off – I'm having trouble with my bookcase today". She was caught off guard, speechless for a while, and then laughed and apologized to him. She hadn't noticed that the effect of her rushing and chiding him was that it was making it more difficult for him function and remember why he needed to hurry. She was elated that he had remembered *something about the talk* a whole month later, and more so - that he was able to put it into use to come to his own defense.

Appendix 1 Communication tips related to attentional mode, blackboard capacity, and its use

1 In conversation, **wait to speak until you have a person's visual attention** (you can notice head movements, and when someone makes and breaks eye contact.) Try to keep the person's attention by staying in their field of view (suitable positioning).

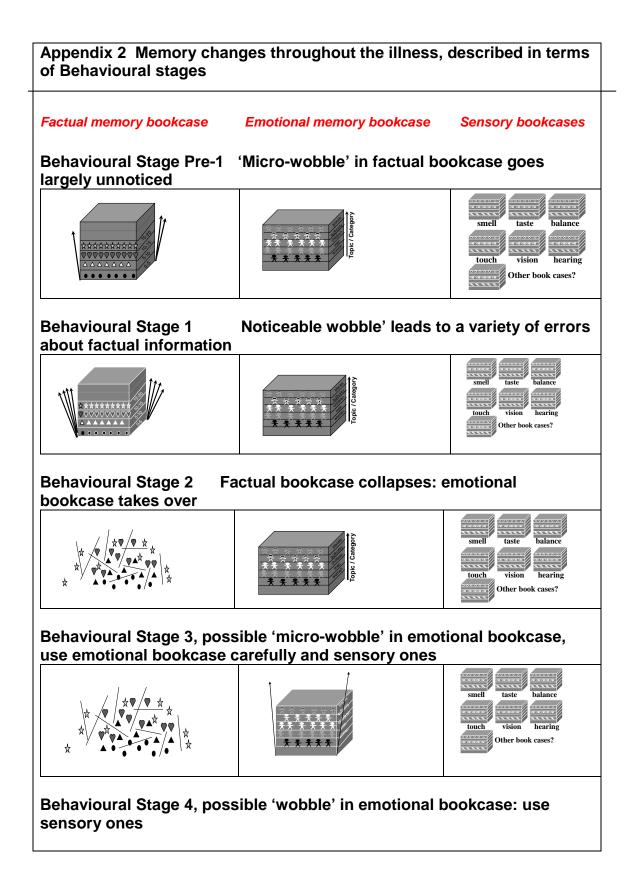
2 Try to match your sentence length to what fits onto a person's blackboard;

i.e., a story, a paragraph, a sentence, a phrase. (Notice when a person is no longer able to take in more information.)

3 Notice and try to match the mode of attention a person is using.

When trying to communicate with a person with dementia, it is usually more successful to try to match, rather than change it. I.e. a person who is sitting still and concentrating (*undivided attention*), will likely find it easiest to speak to someone who sits with them, without expecting them to get up and converse while walking. Conversely, if a person is walking or pacing, and looking around a lot (*divided attention*), the best way to get their attention will likely by walking with them whilst talking. (When it is necessary or desirable to change a person's attentional mode, several steps may be required to do so, as well as the continued presence of another person.)

4 Most of us function best when we have a bit of free space on our blackboard each day, on which to put new items. Having our blackboard constantly full-to-overflowing is tiring and restricts our functioning. (One way of defining *personal stress* would be that stress is our physical and emotional response to the on-going futility of trying to fit more things onto our blackboard than it can hold.)



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