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Reducing Traumatic Stress.

Understanding attachment and a feeling based approach to dementia care

For 20 years Dementia Care Matters has emphasised that feelings matter most in dementia care. This principle remains at the core of our whole model of care. To some people this principle can sound more like a fluffy sentiment than a philosophical stance. However it is based upon a belief in the central role feelings play in human life. We take feelings so seriously that we evaluate how carers do dementia care, (serving lunch, giving medication, assisting in personal care etc) in terms of how it makes someone feel. Consequentially we believe that emotional intelligence is the key competency in dementia care. This is not simply because we are particularly emotional and sen-

timental people but because people with a dementia are extremely vulnerable to traumatic levels of stress if their feelings are not taken into account. It is universally recognised that a dementia undermines memory, logic and reasoning ("higher" cognitive processes). However a dementia also functions to undermine the "primitive" processes that regulates someones feelings and emotions. Psychologists refer to these processes as "*affect regulation*" and "*self regulation*" as the process by which an individual influences their felt states. In this article, I explain why an impaired capacity to self regulate makes people with a dementia vulnerable to traumatic levels of stress and describe the ways a feelings based approach compensates for this disability.

Understanding Stress and the Role of Affect Regulation

'Stress' is a word used so often in our society that it may have begun to lose some of its impact. People refer to all manner of stresses; the stress of an exam, of moving house, of public talking. When referring to the stresses of life we often talk more about what 'stresses us' out than we do about how we experience and respond to it. However we can learn more about stress if we focus less on the external events and more on the felt states and coping strategies that shape our experience of stress. Consider for a moment a time in your life when you felt stressed. How did you know you were stressed, what do you tend to do when stressed? You may have felt hot, sweaty, noticed that your heart rate increases, your breathing becomes shallower your mind races. Such sensations may have alerted you to your levels of stress. You may have also noticed that you tend to rush around, have difficulties focusing your attention, become irritable, short tempered or aggressive. These behaviours also alert you to your own level of stress. You may

have found yourself being more 'emotional' when stressed, anxious, upset, tearful, fearful, or enraged. These heightened negative emotions may have also helped you to realise that you are stressed. Perhaps, under the sway of these feelings and behaviours, you lost your own self-awareness and only realised how stressed you were when someone else pointed out your behaviour. You may have become visibly agitated, aggressive, withdrawn, emotional, and anxious. In this case you depended upon someone close to you and brave enough to help you recognise your own feelings and needs. Reflecting upon this experience of stress helps us recognise that specific sensations, feelings, behaviours and emotions enable us to identify when we are experiencing a level of stress that is beyond comfortable. Psychologists refer to stress as '*arousal*', and acute level of stress that is beyond tolerable is referred to as '*hyper-arousal*'. In states of hyper-arousal we are likely to experience escalated negative emotions such as fear, panic, anger or anxiety. These heightened emotions increasingly determine our behaviour and even our perception of reality.

The sensations, feelings, emotions and behaviours we experience during times of stress are the result of a multitude of biochemical and physiological changes that function to prepare us for 'fight or flight' responses to a perceived threat. This response is so basic to our survival that it is largely coordinated by the sub cortical or "lower" areas of the brain, such as the brain stem, limbic system and hypothalamus. Perceiving a potential threat the hypothalamus activates the pituitary adrenal glands to engage the *sympathetic nervous system* (a branch of the Autonomic Nervous System) to super-charge the body and mind in preparation for vigorous action, (fight or flight). The biochemical changes that underlie this process create a dispersed response that influences our entire

body-and-mind, alert us to a perceived threat and prepare us to take some form of action. Whilst these basic changes are involuntary and unconscious, the coping strategies we consciously employ to resolve the situation rely upon the "higher" cortical systems of the cerebral cortex. These systems enable us to inhibit some of the aforementioned impulsive behaviours and coordinate our attention, emotion, behaviours and cognition with our conscious intentions and actions. They enable us to organise our actions as well as reason and reflect upon them. Effective responses to stress rely upon the optimum functioning of upper and lower neural systems and the effective interaction between them.

The more differentiated and adaptable our coping mechanisms the more developed our capacity to self regulate. We need not avoid stressful situations for fear of being overwhelmed nor fear that our responses to stress might make a bad situation worse. Normally effective responses to stress involve the body and mind lapsing into rest and relaxation once the threat has past. A complementary branch of the autonomic nervous system, the *para-sympathetic nervous system*, helps to restore us to this resting state by inhibiting sympathetic activity. In healthy functioning the activation of the parasympathetic nervous system follows sympathetic activity to enable us to cope with the stresses and challenges of life without being overwhelmed. Some coping strategies might be more effective than others and depending upon our repertoire of coping mechanisms we are likely to have different strategies for different situations. For example not all acts of self regulation involve reducing stress, sometimes it involves seeking it out and even thriving from it; after all, most people find it uncomfortable to be unoccupied for long periods of time. During such a time you may have noticed that you felt restless, lost in thought, prone to day

dream, lethargic and sleepy. You might have found yourself fidgeting, wandering about, distracted or unmotivated. You may have felt bored, frustrated, flat, sad or low. Sustained periods without sufficient stimulation may have resulted in feelings of depression, low self-worth, even shame. Once again specific sensations, feelings, behaviours and emotions help us to recognise when our internal levels of arousal have fallen beyond what is comfortable to us. 'Hypo-arousal' refers to a state when levels of arousal are chronically low. Having fallen below our threshold of comfort we are normally motivated to take some kind of restorative action. Coping strategies generally involve some kind of work, leisure or domestic activity, anything that keeps us active, occupied and in some way stimulated.

All of the various strategies we might habitually or consciously employ to self regulate, in one way or another, help keep our levels of stress at a comfortable optimum level (see fig.1).

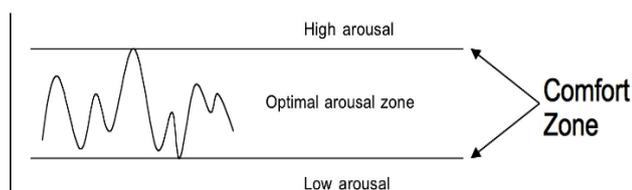


Fig.1

By staying in our comfort zone we avoid difficult feelings and escalated negative emotions. When we are within this comfort zone we tend to feel most relaxed, safe and secure. Our capacity to *self-regulate* therefore provides us with our basic sense of security and well-being. This means that we tend to feel most at home in our comfort zones. Our sense of belonging is often tied to those places within which we enjoy most readily this experience of feeling at home in ourselves. "Homely" environments afford us the opportunities for both comfort/relaxation

and occupation/stimulation that we need to self regulate.

Coping with Stress and the Experience of Dementia

Consider your own response to stress and the degree to which this may be compromised with the onset of a cognitive impairment. A milder cognitive impairment would undermine your ability to effectively employ coping mechanisms, i.e. planning a course of action, adapt it to novel/changing situations and reflecting upon its efficacy. A moderate level of dementia may undermine the cortical functions critical to inhibiting your more impulsive behavioural responses to stress. A more severe cognitive impairment may undermine your ability to identify and interpret your own feelings and needs (insight) and effectively communicate them to others. In the later stages of a dementia, there are very few resources available to either interpret or express affective states. Having a cognitive impairment, however, does not undermine your actual ability to feel the stress or negative emotions. The cognitive impairment associated with a dementia therefore actually impairs someone's capacity to self-regulate. People with a dementia struggle to adopt and adapt new coping strategies to novel situations; they are often reliant on strategies acquired earlier in life that are not fit for present purposes (see fig.2). Sometimes people experiencing uncomfortably low levels of arousal seek out places, activities or people that were a source of stimulation in the past such as their children, school or work. Alternatively someone experiencing higher levels of stress may seek out parental or attachment figures that were a source of comfort in early life.

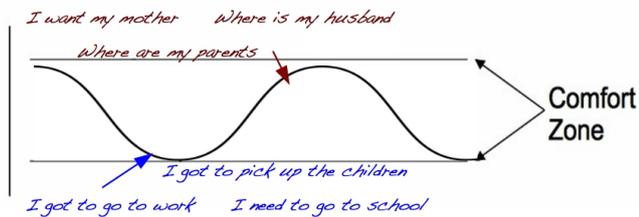


Fig.2

In the latter case psychologists call these “attachment behaviours”, because they are the more primitive coping strategies that we acquire in our early childhood. During these early years the primary means of regulating levels of stress was through interactions with caregivers who offered comfort during times of distress. Infants do not come with ready-made coping strategies that enable them to deal with stress independently of their caregivers. They are however equipped with basic behavioural responses that function to alert a care giver to their distress. Affect regulation in infancy therefore happens in and through care giving interactions that respond to such behaviours. These early experiences of attachment are internalised, (imprinted upon the limbic system) to become attachment styles. These attachment styles are often unconscious patterns of behaviour that are most active during times of stress. Many of the anti-social, aggressive, agitated and repetitive behaviours listed amongst the behavioural and psychological symptoms are identical to the behaviours outlined in the extensive literature on insecure attachment styles (Ainsworth, 1979). For many people with a dementia these impulsive behavioural responses to stress are the only ones available to them. Unfortunately many of these behaviours often alienate carers and relatives because they can be difficult, confusing, shocking and upsetting particularly when observed in adults. However the fact remains that many people with a dementia are just as dependent upon attachment figures for interactive regulation as they were in their infancy and childhood. Consequently if at-

tachment needs are not met in and through care giving interactions people with a dementia are vulnerable to heightened negative emotion and traumatic levels of stress (see fig 3).



Fig.3

Identifying Symptoms of Traumatic Stress

When stress is prolonged and or acute the very mechanisms that are supposed to enable people to cope with the challenges of life can be potentially debilitating. Prolonged stress sustains sympathetic activation suspending the body and mind in a state of readiness for a fight or flight responses. This primes the limbic system to become more sensitive to mild or novel stressors. This means that people are likely to react more strongly to subsequent stressors that are milder in nature. Sustained levels of high stress therefore reduce the threshold of arousal that is tolerable thus functioning to narrow our comfort zone (see fig.4).

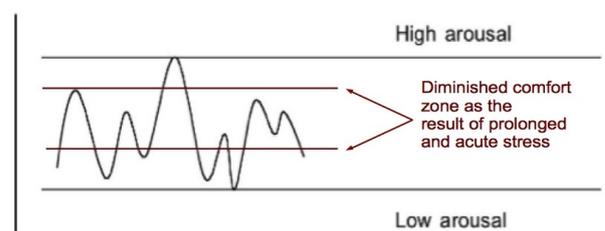


Fig.4

Sustained exposure to acute stress have profound behavioural and psychological implications; irritability, anxiety, aggression, withdrawal, paranoia, delusions, obsessive compulsive behaviours, psychosis, post- traumatic stress and even self harm have all been linked to pro-

longed exposure to this biochemical state (Cozolino, 2002). Furthermore because this state forges a neural highway to the fear circuitry of the brain it limits the participation of cortical regions crucial for memory, reality testing, language and the integration of sensations, emotion, cognition and behaviour (Cozolino, 2002). Experiences of hypo-arousal or hyper-arousal therefore limit someone's capacity to store information, learn, reflect, and develop new coping strategies for novel situations and to make use of these abilities in relationships. The bio-chemicals released in the case of acute stress can inhibit hippocampal functioning to the extent that sensations, emotions, behaviours, images and meaning become dissociated. This means that sensory, motor and emotional aspects of past-traumatic experiences can actually intrude upon the present resulting in traumatic flashbacks. A last resort coping strategy to traumatic levels of stress is dissociation. Dissociation can be characterised as a (hyper??)hypo-aroused state that deals with heightened arousal and emotions by not feeling them. Overwhelmed by stress the body and mind shuts down, numbed by high levels of the biochemical endorphins. Physiologically, endorphins are released when we are injured or stressed. Endorphins act similarly to morphine and reduce the amount of pain we experience when we are hurt. In high levels they have an analgesic effect, dulling emotions, dampening down experience to produce an altered state.

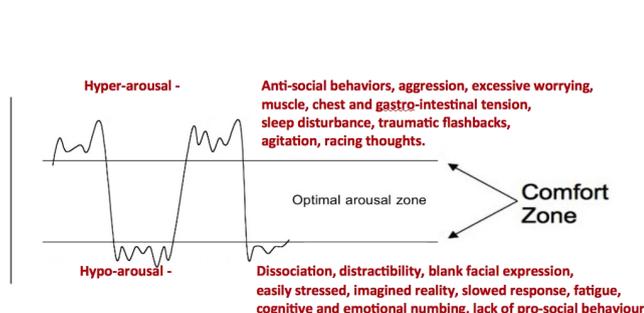


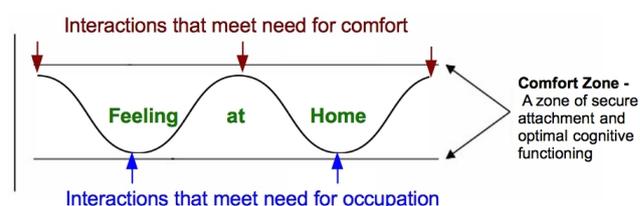
Fig.5

The symptoms of traumatic stress are as diverse as they are profound (See fig.5). These

symptoms are also strikingly similar to many of the most distressing behavioural and psychological symptoms of a dementia. Like symptoms of trauma they arise from physiological states of hyper or hypo-arousal. These behavioural and psychological symptoms therefore indicate a profound need for interactive regulation. They are not an inevitable feature of cognitive impairment but rather a consequence of a care provider's failure to meet someone's basic attachment needs. More often than not they are the result of leaving people with a profound need for interactive regulation isolated and unoccupied for long periods of time throughout the day. This makes someone with a dementia extremely vulnerable to traumatic stress and more reliant on the very behaviours that care givers find most distressing and disruptive.

Enabling Feeling Based Carers

Contemporary attachment theory suggests that to meet attachment needs caregivers must provide adequate experiences of "interactive affect regulation" (Stern: 2000, Schore:2012). Interactive regulation refers to care giving interactions directed towards someone's affective states. Experiences of comforting and stimulating interactions/activities matched to an individual's changing affective state help someone remain in their comfort zone (see fig.6).



These interactions need to be spontaneous responses to individual signals of distress rather than scheduled interventions or activities at set times of the day. These interactions also need to be matched to an individual's level of a dementia. Someone experiencing the earlier

stages of a dementia may be comforted in and through a meaningful conversation or stimulated through participation in a domestic activity such as laying the table or doing the laundry. In contrast someone experiencing the late stages of a dementia may be comforted by gentle touch and physical closeness and stimulated by enlivening sounds such as birdsong or uplifting music i.e. a more sensory intervention. Someone experiencing more moderate stages of a dementia may require a degree of “emotional coaching”. Simply asking someone with moderate stages of a dementia “what’s the matter?” is not enough since they may not have sufficient insight to know what the matter is. In such cases someone’s basic behaviours need to not only be acknowledged, but also elaborated into specific feelings, needs and actions. This helps someone not only become aware of their feelings and needs but also understand them. In identifying and naming a range of feelings someone feeling “bad” may be able to differentiate this basic state into a range of feelings like “irritation”, “disappointment”, “anger”, “annoyance” or “hurt”. This feeling based language is an important element of effective interactive regulation (Gerhard: 2008). Care givers can also help someone to identify their feelings and needs non-verbally by mirroring their facial expressions. This provides an opportunity for someone to see how they feel because it is written on the carer’s face. Exaggerated mirroring of words and gestures can therefore help someone to discover how they feel themselves. Without this “emotional lending a hand” the person is totally lost in a sea of difficult feelings they can neither avoid nor make sense of. In each case an emotionally attuned interaction fosters a sense of togetherness on the basis of a mutual recognition of someone’s feelings, “I know that you know how I feel”. This feeling of being understood is profoundly comforting, in meeting our basic attachment needs. Experiences of feeling understood are profoundly

comforting - in basic attachment needs it functions to reduce stress levels (Stern: 2000). This kind of understanding is not a rational categorical understanding but rather an empathic understanding which shows that we know what “IT” feels like. It has nothing to do with knowing, naming or identifying a symptom of dementia. It is an empathic understanding conveyed by the experience of someone's touch, the look in their eyes, the tone of their voice, the pace of their speech and look on their face. There is immediacy to this bodily form of communication, that is to say, we feel rather than interpret the message it conveys. It hits us in a similar way a lively song may excite us and a slow song may calm us down.

Creating Feeling Based Organisations

Staff need emotional support to do emotional work. Emotionally intelligent feeling based carers can only flourish within emotionally intelligent, feeling based, organisations. Feeling based interactions rely upon someone’s capacity to feel, reflect upon and cope with difficult feelings and emotions, their own and others. This kind of capacity is often referred to as emotional intelligence. Carers must learn to feel comfortable and at home with a range of emotions to do this emotional work. Imagine a care giver that cannot cope with the feelings of anger that are triggered by the “difficult” attachment behaviour of someone in their care. The difficult feelings that the person triggers in them overwhelms their capacity to attune to the other. They may be compelled to avoid this person or suppress their behaviour rather than engage with them. Furthermore if someone struggles to identify, name and reflect on their own feelings and emotional needs they will struggle to identify, name and reflect upon someone else. In such cases care givers are likely to rely on terms, such as “attention seeker”, “wanderer”, “aggressive”, that reduce all behav-

iours to pathological labels or symptoms of a dementia, both of which obscure the underlying feelings and needs. Feeling based organisations develop person centred practice by both recognising and nurturing staff's emotional intelligence (Sheard: 2009). This is why dementia care matters begins every Being a Star training programme with an opportunity for staff to reflect upon their own feelings and needs, and consider the key ingredients to their own emotional well being (Sheard:2008). Feeling based care also requires a relaxed, go with the flow culture of care that subordinates care tasks and routines to people's changing emotional needs. Task oriented interactions that overlook people's affective states and focus exclusively on physical care needs fail to meet attachment needs. Attachment needs are not met in care giving interactions directed exclusively on someone's basic physical needs unless they have this essential feeling based component. Feeling based cultures of care therefore recognise every care giving interaction as a therapeutic intervention that provides an essential opportunity for interactive regulation. In helping to regulate levels of arousal and affect regular experiences of emotionally attuned relationships reduce people with a dementia's reliance on more primitive and often distressing coping mechanism.

Developing Feeling Based Environments

Feeling based environments provide people with a dementia adequate opportunities to self regulate in and through their interactions with their environment. Engagement in activities and occupation tends to be higher when those activities are self-initiated. This means shifting the focus from scheduled large group activities to brief and regular interactions that are spontaneous responses to individual changing needs. Filling a dementia care setting up with stuff enables people to occupy themselves independ-

ently of caregivers. Clutter often compensates for the disability because people with a dementia can lack the capacity to seek out the means to occupy themselves. Tidy care homes with objects and items out of reach, in boxes on shelves deny people the opportunity to occupy themselves when they need it most. To safely and effectively achieve this level of independent well being care providers need to create care giving environments matched specifically to people's functional capacities and emotional needs. For example:

A small scale living environment for people experiencing the earlier stages of a dementia provides easy access to functional household items and facilities. These environments enable plenty of opportunity for independent domestic activities, household tasks and partnerships in daily living activities.

A small scale living environment for people experiencing a moderate level of dementia (or different reality) needs to be full of visual cues that prompt people to engage in self initiated activities. An environment full of stuff to rummage through and plenty of "half done" domestic tasks (an unsorted basket of laundry to sort, pile of ironing to fold etc) set up around the room all invite opportunities for self regulation.

A care giving environment matched to the needs of people experiencing the late stage of a dementia includes easy access to comfort objects and other items that provide opportunities for sensory stimulating and sensory soothing experiences throughout the day. Care givers working in a specialist later stage of dementia draw upon these environmental features to create a sensory journey; balancing times of sensory stimulation with sensory soothing to help people feel at home in themselves.

In compensating for an impaired capacity to

self regulate, matching the environment with someone's stage of a dementia provides the maximum chance for someone with a dementia to remain in their comfort zone. In these enriched environments all a person needs to do to self regulate is have the freedom to follow their feelings. It matters less whether the activity makes logical sense or is completed and more how it makes that person feel inside. The items, activities and features of the environment are, however, always more meaningful when they are related to an individual's identity and previous life experiences. Matching the features of the environment to both someone's stage of a dementia and individual life history therefore enhances the quality of interactions.

Feeling at Home in your Comfort Zone

The loss of a capacity to self regulate is a very significant disability that has profound emotional, psychological, behavioural and cognitive implications. In a culture that tends to value thinking over and above feeling we tend to emphasise how a dementia undermines, "higher cognitive processes" and ignore how it undermines the "primitive" processes that regulates feelings and emotions. Furthermore in a culture that tends to separate mind and body, thoughts and feelings, cognition and affect, it is easy to overlook how connected these two processes are. To adequately compensate for this disability care providers need to:

- Believe that feelings matter most in dementia care
- Recruit feeling based carers
- Recognise that the quality of EVERY care giving interaction matters
- Nurture staff's emotional capacities
- Create a relaxed 'go with the flow' culture of care
- Develop enriched and "matched" care giving environments

This feeling based approach enables people to relax into the experience of a cognitive impairment, feel at home in their comfort zone and, in doing so, also optimises people's cognitive functioning.

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