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## Review

# Adopting a trauma-informed approach to managing behaviour that challenges in dementia

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**Causes of behaviour that challenges in dementia are often thought to be due to reversible factors, such as a urine infection or disrupted sleep-wake cycle. In this review, the authors consider a definition of behaviour that challenges, commonly cited causes and management models. Finally, recommendations for an alternative view and subsequent approach to managing behaviour that challenges are suggested.**

It is estimated that 90% of people living with dementia display behavioural and psychological symptoms of dementia, more recently referred to as behaviour that challenges<sup>1-4</sup> or neuropsychiatric symptoms.<sup>5</sup> These symptoms form the umbrella term for behaviour that challenges and may be observed in isolation or combination and include: walking with purpose; verbal and physical aggression in general and to others; repetitive speech or questioning; 'physically aggressive agitation; physically nonaggressive agitation and verbal or vocal agitation';<sup>6</sup> destruction of property; irregular sleep patterns;<sup>7</sup> irritability; disinhibition; delusions and hallucinations;<sup>8-10</sup> agitation; depression; anxiety, and hallucinations.<sup>8</sup> It is often found that behaviour that challenges is characterised by the high levels of distress it causes to people living with dementia and their family, negatively impacting care settings, and is complex and costly to support.<sup>11</sup>

### How is behaviour that challenges managed?

Management of these behaviours that can vary in type, frequency and severity may include exploring for possible reversible factors as a cause (Table 1).<sup>12</sup>

In addition to exploring reversible factors formulation models such as the Newcastle model,<sup>13</sup> unmet needs model<sup>14</sup> and Kitwood's flower of emotional needs (Figure 1),<sup>2,14,15</sup> also serve to manage behaviour that challenges by exploring why an individual may be expressing particular behaviours and adjustments that may ameliorate them.<sup>16</sup>

Where reversible factors have been eliminated, NICE guidelines<sup>10</sup> recommend antipsychotic medication for the treatment of 'agitation'. However, this is only recommended for use with people living with dementia where:

- i. They are deemed to be at risk of harm to themselves or others.
- ii. Behaviour that challenges is deemed inappropriate or disruptive in the context of their usual place of residence, or
- iii. Behaviour that challenges is instigating acute distress.

However, a link within the NICE guidance does acknowledge the increasing concerns surrounding the use of antipsychotics in treating behaviour that challenges. Further, not only were antipsychotics associated with adverse cerebrovascular events but also with increased mortality rates when specifically used in this population.<sup>17,18</sup> Risperidone and haloperidol are the only antipsychotics licensed for use to treat behaviour that challenges in the UK. However, antipsychotics continue to be

used off label for the treatment of behaviour that challenges despite evidence to the contrary regarding their efficacy and suitability in people living with dementia.<sup>19</sup> Further, current guidelines do not acknowledge the multiple complexities that influence how behaviour that challenges is viewed, understood and ultimately managed.

### **An alternative view to behaviour that challenges**

Within a growing body of research, behaviour that challenges has been suggested as possibly arising from trauma or delayed expression post-traumatic stress disorder (PTSD).<sup>20</sup> Significantly, it has also been suggested that trauma experienced in earlier life, more specifically, the resulting delayed expression PTSD, increases the probability of an individual developing dementia and conversely, that dementia increases the risk of delayed expression PTSD.<sup>21,22</sup>

Trauma is inextricably linked with PTSD,<sup>23</sup> whether PTSD is experienced immediately after the traumatic event or some time, or even years later as an older adult.<sup>24,25</sup> By extension, it has also been proposed that trauma can be viewed as an experience that overwhelms an individual's ability to cope, is response-led and can occur vicariously from witnessing a traumatic event as well as experiencing it.<sup>26</sup> Trauma may subsequently result in mental and physical health concerns and with the onset of cognitive impairment and possible disinhibition experienced in ageing, so behaviour that challenges may arise.<sup>27</sup>

### **Trauma-informed practice**

Trauma-informed care – taking trauma into account when working with patients – is defined by the UK Government as: ‘...an approach to health and care interventions which is grounded in the understanding that trauma exposure can impact an individual's neurological, biological, psychological and social development’.<sup>28</sup>

The aim of trauma-informed practice is to increase awareness among practitioners of the long-term negative impact that trauma can have, particularly in services that require human interaction. We know from extensive work<sup>29,30</sup> that trauma is pervasive and woven into society. The impact of trauma is wide and varied, significantly increasing risks of multiple vulnerabilities such as PTSD, disproportionate hostility, eating disorders, mental and physical health concerns, substance misuse and abuse. Often these presentations are unconnected with the original traumatic experience(s), and therefore strongly linked to the suggestion that trauma-informed services are established to support problems other than trauma.<sup>31</sup>

The extent of the neurological, biological and psychological impact of trauma is immeasurable and idiographic and permanently shapes our experiences and views of the world around us. Significantly, individuals have often experienced complex relational trauma within a service context or an apparent place of safety, for example, a parent or guardian, teacher, head of an orphanage or a health care professional. All of this and the trauma alone severely impacts how an individual may view and approach the help that a health care professional or service may be offering. Likewise, it may increase the likelihood that an individual may be retraumatised either due to previous abuses of power or due to the highly personal nature of a consultation, examination or support with activities of daily living (ADL).<sup>32</sup>

Consider alongside this, the impact of trauma on an individual diagnosed with dementia whose coping mechanisms have deteriorated by virtue of the atrophy observed in key structures of the limbic system.<sup>33</sup> The deterioration of the hippocampus, largely responsible for memories, particularly episodic memories and their long-term storage and also the amygdala, the brain structure well known for our flight, fight, freeze or fawn response to situations we find ourselves in. The amygdala is also responsible for the strength and content of the emotional responses that are attached to

those memories. The impact that trauma can have on our explicit and implicit memory is described in strangely similar terms to some of the descriptions of dementia. For example, trauma can prevent words, images and associated sounds from creating a semantic memory meaning you cannot remember what a particular object is. Likewise, trauma can impact the hippocampus and prevent recall or create fragmented versions of memory. The amygdala may be impacted resulting in an individual being triggered, experiencing painful memories that may seemingly be unrelated to the current context. For people living with dementia this may be seen in behaviour that challenges during, for example, personal care. Bathing or showering is often discussed as a time when people living with dementia who are being supported become verbally and physically aggressive. This is an unwanted intrusion of very intimate parts for an individual. When viewed in the context of a trauma-informed approach, we can perhaps begin to understand why people living with dementia respond in such a way and we can begin to collaboratively formulate a better way of supporting an individual's hygiene. Finally, trauma can negatively impact how we create new ways of doing things and may even result in not being able to remember how to do a previously automatic task such as driving a car.<sup>34</sup>

### **Clinical implication of adopting trauma-informed practice**

If we were to assume that every individual living with a diagnosis of dementia has experienced a traumatic event in their life, might they also have comorbid PTSD? How might that change our approach to them as individuals when supporting them in health care practice? Would we, for example, be more understanding of missed or cancelled appointments or a rude or defensive presentation on first meeting them? Could we be creative enough to build contingencies into our systems and processes to support these individuals as we figuratively 'hold their hand' through their contact with services?

The purpose of adopting the six principles of trauma-informed care when working with people living with dementia is to create the feeling of safety; trust, choice, collaboration and empowerment through being cognisant of the language we use, paying attention to boundaries and embodying a 'do no harm' philosophy, to avoid retraumatisation<sup>35,36</sup> (Figure 2). It may be suggested that adopting these principles when working with any individual forms the basis of a trusting, caring, collaborative and transparent environment that nurtures individuals and fosters psychological safety.

Treatment is not the purpose of adopting a trauma-informed approach, but rather supporting individuals with the barriers that their experience of trauma may have created. This approach may facilitate support of people living with dementia where treatments for those who have experienced a traumatic event are unsuitable due to the physiological impact that trauma processing may have on older patients, particularly those living with dementia. Equally, where non-pharmacological interventions such as dementia cafes, psychoeducation and self-management techniques become less effective as cognitive ability declines, adopting a trauma-informed approach may provide an alternative to managing behaviour that challenges.

The efficacy of carers adopting a trauma-informed approach to support people living with dementia in the community is currently being explored as part of a PhD study.

### **Declaration of interests**

No conflicts of interest were declared.

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Table 1. Reversible factors that may cause or exacerbate behaviour that challenges<sup>13</sup>

Factor	Behaviour	Intervention
Medication	Reaction to medication or polypharmacy	Medication review and dose reduction or discontinuation
Physical health concerns	Constipation, urinary tract infection, dehydration, pain	Testing where possible and treatment of the condition
Sleep hygiene	Insomnia, irregular sleep-wake cycle	Improve sleep hygiene
Mental health concerns (pre-existing)	Depression, PTSD, schizophrenia, bipolar disorder	Treatment of the condition
Environment	Noise, lighting, under- or over-stimulation, lack of social interaction, space to wander, lack of recognised routine	Correction of the environmental issue for example, too much noise: create a quieter environment, under stimulation: explore appropriate activities
Unmet needs	Hunger, pain, needing the toilet, to have a purpose, exercise	To meet basic needs, make exercise activities accessible

Figure 1. Kitwood's flower of emotional needs that evolved into person-centred care



<Figure 1 text>

Attachment

Comfort

Inclusion

Identity

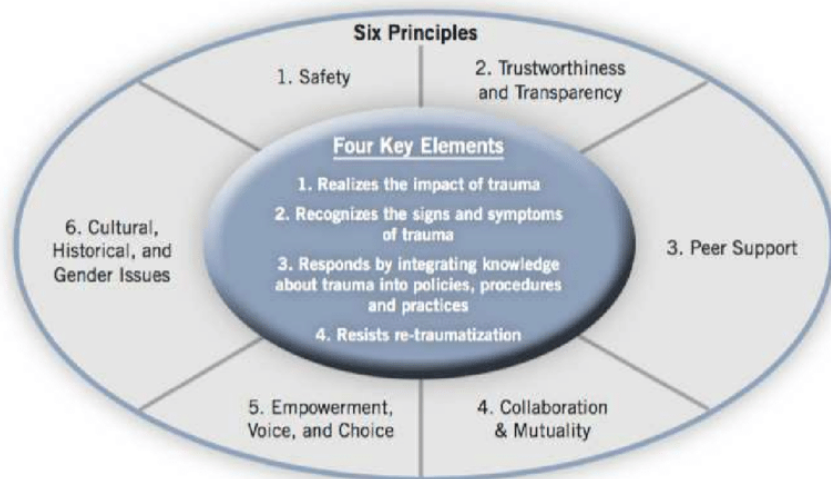
Occupation

Love

<Figure 1 text ends>

Figure 2. SAMHSA's (Substance Abuse and Mental Health Services Administration) trauma-informed approach

(Reproduced from Lang J, Campbell K, Vanderploeg JJ. Advancing Trauma-Informed Systems for Children. Farmington, CT: Child Health and Development Institute of Connecticut, 2015)



<Figure 2 text>

Six principles

1. Safety
2. Trustworthiness and transparency
3. Peer support
4. Collaboration and mutuality
5. Empowerment, voice and choice
6. Cultural, historical, and gender Issues

Four key elements

1. Realises the impact of trauma
2. Recognises the signs and symptoms of trauma
3. Responds by integrating knowledge about trauma into policies, procedures and practices
4. Resists re-traumatisation

<Figure 2 text ends>