Naming the demon of dementia

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Background

- Most common forms of dementia are Alzheimer's Disease, Vascular and Lewy-Body dementia
- Global, Incurable, Progressive
- Arguably the major public health challenge of the 21st century - around 900,000 people living with dementia in UK and 50 million across the world – prevalence will double in 30 years
- Strong narrative that people living with dementia lack insight into their own world

Frau Auguste Deter (1901)

“Oh God”
“I as good as lost myself”
“I have lost myself”
“I am lost”

Terry Pratchett, (The Observer, 15.03.15)

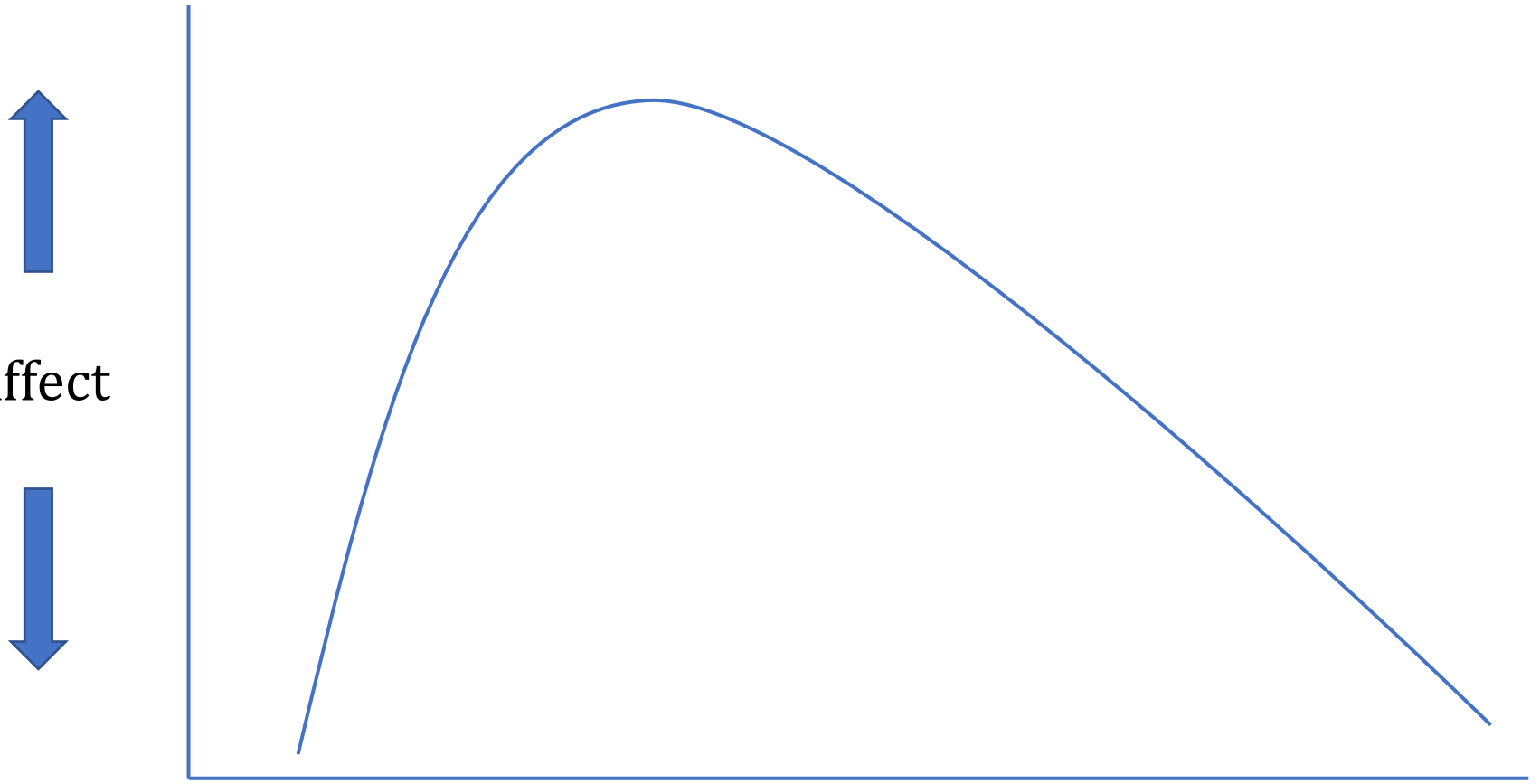
- *It occurred to me that at one point it was like I had two diseases – one was Alzheimer's and the other was knowing that I had Alzheimer's.*
- *There were times when I thought I'd have been much happier not knowing, just accepting that I'd lost brain cells and one day they'd probably grow back or whatever. It is better to know, though, and better for it to be known*
- *The first step is to talk openly about dementia because it's a fact, well enshrined in folklore, that if we are to kill the demon, then first we have to speak its name.*
- ***Once we have recognised the demon, without secrecy or shame, we can find its weaknesses.***

Assimilation of Dementia

- Bill Stiles – Assimilation Model of Problematic Experiences/Voices
- In general, experiences are assimilated into the self-concept but some experiences are so threatening or problematic that assimilation is difficult
- At any one time, the extent to which a problematic experience is integrated into the self can be thought of as lying along a continuum – from warding off, to the emergence of awareness, and working through so that the knowledge is fully integrated into the self
- An alternative model of ‘awareness’ for dementia

The awareness continuum

- At one extreme – information about dementia that is problematic for the self is pushed away – "*warded off*" - not recognised, and the person will avoid contact with reminders or cues that may trigger unwanted thoughts.
- At the other extreme dementia is recognised, the most problematic aspects of it are understood and possible adaptations are tried out. Dementia is integrated into the person's identity
- Movement along the continuum associated with changes in affect
- Psychotherapy may help people to move along this continuum and to address changes in affect



Assimilation stages	Warding off	Unwanted thoughts	Vague Awareness	Problem clarification	Insight	Working through	Noticing change	Mastery
Therapeutic tasks	Naming dementia without being overwhelmed			Finding distance and mastery			Integration	

Research and clinical work

- Identifying markers of assimilation - indicative of different stages in the process
- Psychotherapy groups including *Dementia Voice* and *Living Well with Dementia* projects
- How couples talk together about their diagnosis
- Psychotherapy with couples and individuals

First stage of adjustment - emergence: Putting a name to dementia (without being overwhelmed)

Unwanted thoughts marker

- The "*thing*" that is wrong is referred to this indirectly – e.g., as "*the problem*" or "*it*" – it is recognised but not named. Markers include phrases like "*toughing it out*" or to "*soldier on*".
- Henry: *It [memory loss] has been in my mind yes, erm, because in a way it's almost writing you off and I don't think that is right at all but you are suddenly becoming somebody totally different to what you used to be and mentally you don't want that mentally you don't want to accept that and I think that's a good thing. Because once you start waving the white flag, you pack up and I don't want that (...) Well I think, you have got to have a positive attitude in life if you don't you just wave the white flag and you pack it all in, and I don't want that, no (...) I mean once you have reached the age of 80, it's ever so easy to wave the white flag and say oh I can't do this I can't do that but you have got to have a positive attitude, which I think I have got*

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Fear of loss of control marker

- Fear of loss of **internal** control **over emotional equilibrium** - concern that continuing to talk/think/explore their dementia will threaten their sense of identity and self-esteem or compromise important social relationships
- Mr E: *I find what we're doing now, it brings all memories to me, so and being around listening to you all, talking. I find I just want to be [pause] .... not normal no. I don't think a memory loss and I don't. Talking, and being around each other. I'm not being funny about that, I'm trying to make a point that I'd rather be at home doing what I need to do and want to do and this is why I really don't want to talk about that you know, I mean I'm sure it's being selfish but, it's just the way I feel about it, I don't really want to be here .... Well, I just don't want to be here. I just want to be. I've got lots of things I'd like to do, and er. Well, I can't think about coming here, it just brings it all back.*

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Key therapeutic tasks

- Create a safe place for the person with dementia to begin to explore their experiences of living with dementia
- Hold onto both problematic and dominant voices
- Help client to place some form on their expressions of problematic material, whilst containing associated anxiety
  - Metaphors
  - Story-telling

Second stage of adjustment – finding distance and perspective

Clarification and stuckness markers

- A problem (of dementia) is acknowledged, and the client begins to explore its problematic aspects
- “Yes… *but*…” – markers of internal conflict
- Val: *I went into the local shop, around the corner from ours and I got to the front of the queue, and they asked me for my money, and I couldn't find it. I didn't know what I wanted or where I was, so I ran out, and my husband was there. He said, "what are you making such a fuss about?" he always treats me as if I'm a little girl, it's embarrassing, but he's right - I need to try harder and to do things, but I'm scared to do them, so I don't know what to do.*

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Making links between past and present

- A client may start to make links between aspects of their dementia and the wider context of their life
- Mr B: *You see I think the essential difference is that I was brought up as a boy to learn to stand on your own two feet. In the navy the whole basis of the navy training is that every man jack on board should stand up on his own two feet. So fundamentally, you develop this idea that other people are around and are very useful and helpful, particularly if they are doing things that you want them to do, but the idea that you can actually begin to rely on other people to do things that you don't want to or you can't remember how or you didn't have any intention to do anyway, is something I've begun to learn in the last 4 or 5 years. I've been a very independent soul all my life.*

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Key therapeutic tasks

- Explore the problematic aspects of dementia-related experiences
- Establish distance from these feelings by stepping back
- Support the client in addressing problematic experiences across their life – e.g.,
  - Disclosure tasks
  - Anxiety
  - Separation distress

Third stage of adjustment – integration and identifying strategies

Noticing change and Problem solutions markers

Yes. Well, it's an illness. It's something of the body not working properly and if your appendix isn't working properly, you go and have it seen to, don't you? Anything that isn't working properly, you get it put right. And you may not do it easily, and some things you can't get put right, but I think we've come a long way to cope with the problems we've got. And I'm personally very grateful. I feel much better about things than I did when I first started .... You have to develop techniques to help you to remember. Even if it means writing notes down on a pad or ... recording it on a machine or pinning it on a board, or something. We all have to do those things and that is what I think is the only solution. You can't bring this memory back; the brain is gone in that respect.

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Looking forward marker

Mrs. A: *Is it hope that's got something to do with your present outlook?*

Mr. B: *Hope for what?*

Mrs. A*: Hope for anything that's in Pandora's box*

Mr. B: *Yes, but you, hope has got to be attached to something. When you say hope left, you've got to say ... hope for what? Now, have I got hope that this problem will go away? No. Have I got hope that there will be a, that we will evolve a way of living with it? Yes, I have, high hope that we can do that.*

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Key therapeutic tasks

- Help the client to address any choices they need to make about their life (e.g., driving)
- Identify strategies they can adopt to improve quality of life
- Prepare for the future (e.g., advance directives)
- Continued support and checking in

Dear Alzheimer's,

We know you have now recruited a new, insidious ally into your invisible army of mayhem and grief - the Coronavirus.

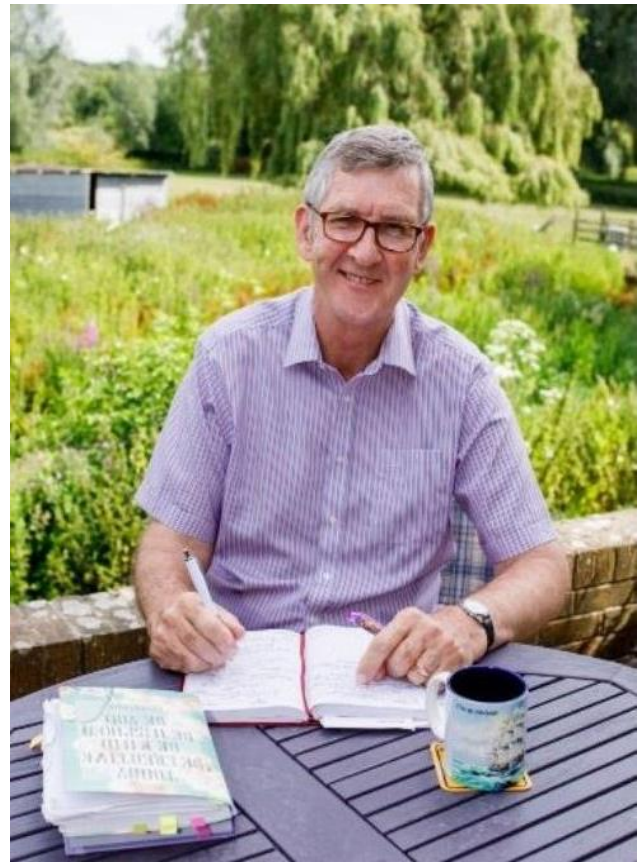
But we have many more allies than you and ours are united to ensure that we stay as safe as possible so neither you nor your wicked partner gain the ascendancy.

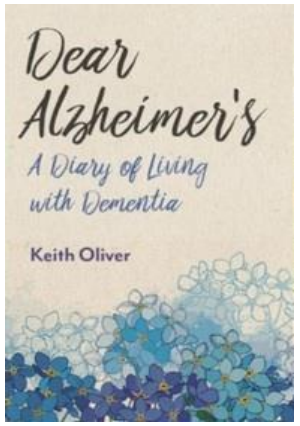
You have worked hard to cause me and others to be worried, scared and anxious.

We stand united with our true friends and caring communities, assisted by technology.

Humanity is resilient and we will emerge stronger than you.

Keith Oliver, Alzheimer's Society Ambassador





Keith Oliver: author, advocate, Alzheimer Society ambassador, blogger

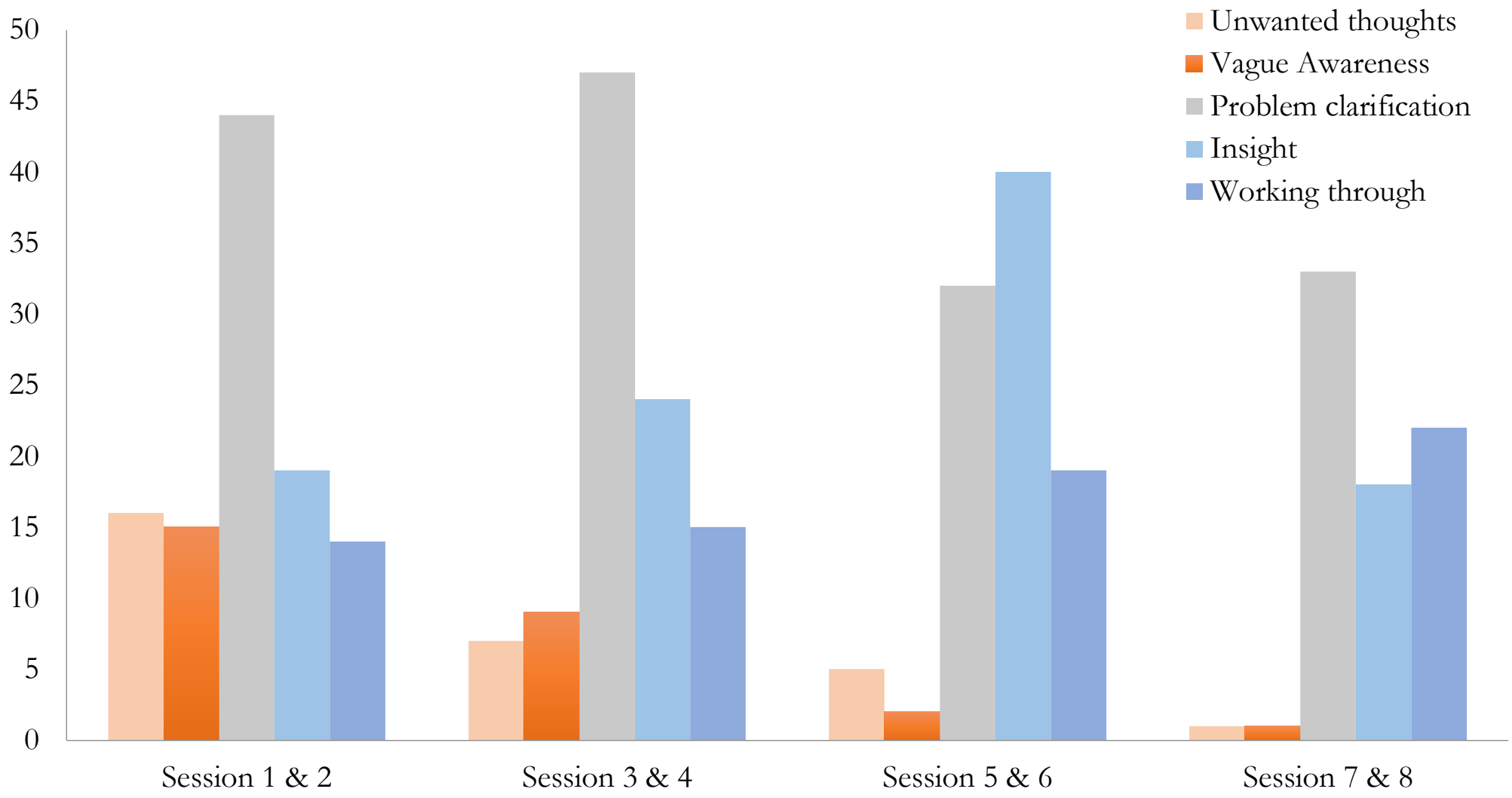
Psychotherapeutic possibilities

- An 8-week course specifically for people who have a diagnosis of dementia
- Slow pace encouraging people to talk more openly - sharing feelings with others in the same position
- Online training course for non-psychologists – supervision provided by CPs
- LivDem in 40 sites across UK + Ireland, Italy & Oman
- Around 250 facilitators in “research community”
- www.livdem.co.uk

Reported benefits of LivDem

- Less afraid of dementia
  - *"I now feel that the best thing to do is to tell friends that you have dementia and not be afraid of it"*
- Greater self-esteem and confidence
  - *"I didn't realise there were others in the same situation as me. I felt quite alone before the group"*
- More able to talk about their dementia
  - *"Before attending the group, I did not accept I had this condition. Since attending I have accepted and come to terms with it"*

Changes in dementia talk



Coming soon ….

Dementia and Psychotherapy Reconsidered

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