
Psychological therapy: trial of a new intervention

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Dementia – the post diagnostic gap

- An early diagnosis - may help people to
 - adjust to the illness
 - prepare for the future
 - reduce stress
 - But it's not clear ...
 - What post-diagnostic support should be available?
 - Who should provide it?
 - Where this should take place – primary care, memory clinics, third sector?
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Preliminary work

- Cheston, Jones and Gilliard (2003) - Ten week group intervention - task of group “*to think about what it’s like when your memory isn’t as good as it used to be*”. Predominantly exploratory approach
 - 19 research participants from 6 groups. Data collected at 4 different points.
 - Unpublished data from 8 additional participants
 - Measures of depression collected independently – baseline, intervention and follow-up measures
 - Cheston and Jones (2008) – compared with psycho-educational model
 - Logsdon et al (2010) Early Stage Memory Support groups – 96 people in intervention arm and 46 in control. Significant improvement in quality of life, depression and family communication
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Living Well with Dementia Groups

- Two year pilot RCT funded by NIHR – led by Ann Marshall
 - 60 people randomised to receive
 - Eight week plus two intervention (8+2); or
 - Treatment as Usual (Waiting list control)
 - Trained memory clinic nurses to use manual
 - Seven groups set up in Hampshire and Wiltshire
 - Measured Quality of Life, self-esteem and depression
 - Data collection at baseline, end of group and 10 week follow-up by researcher blind to group allocation
 - Main aim is to test for future larger trial
 - Follow-up interviews with 17 participants – acceptability
 - Sessions were recorded – fidelity measure and process research
 - Also small study in Primary Care
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Participants

- Participants are
 - referred from memory clinics
 - have a recent diagnosis of either Alzheimer's disease, Vascular Dementia or Lewy Body dementia with an MMSE of at least 18
 - acknowledge, at least occasionally, that they have a memory problem;
 - do **NOT** have significant mental health problems
 - Six to eight participants in each group
 - Joint sessions with family at start and at end
 - Primary care project has a parallel group for carers
 - Session length is 75 minutes
 - Can include playing a DVD
 - Handouts at end of every session
 - Closed group
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Structure of Living Well with Dementia group sessions

Pre-group: setting the scene (with families)

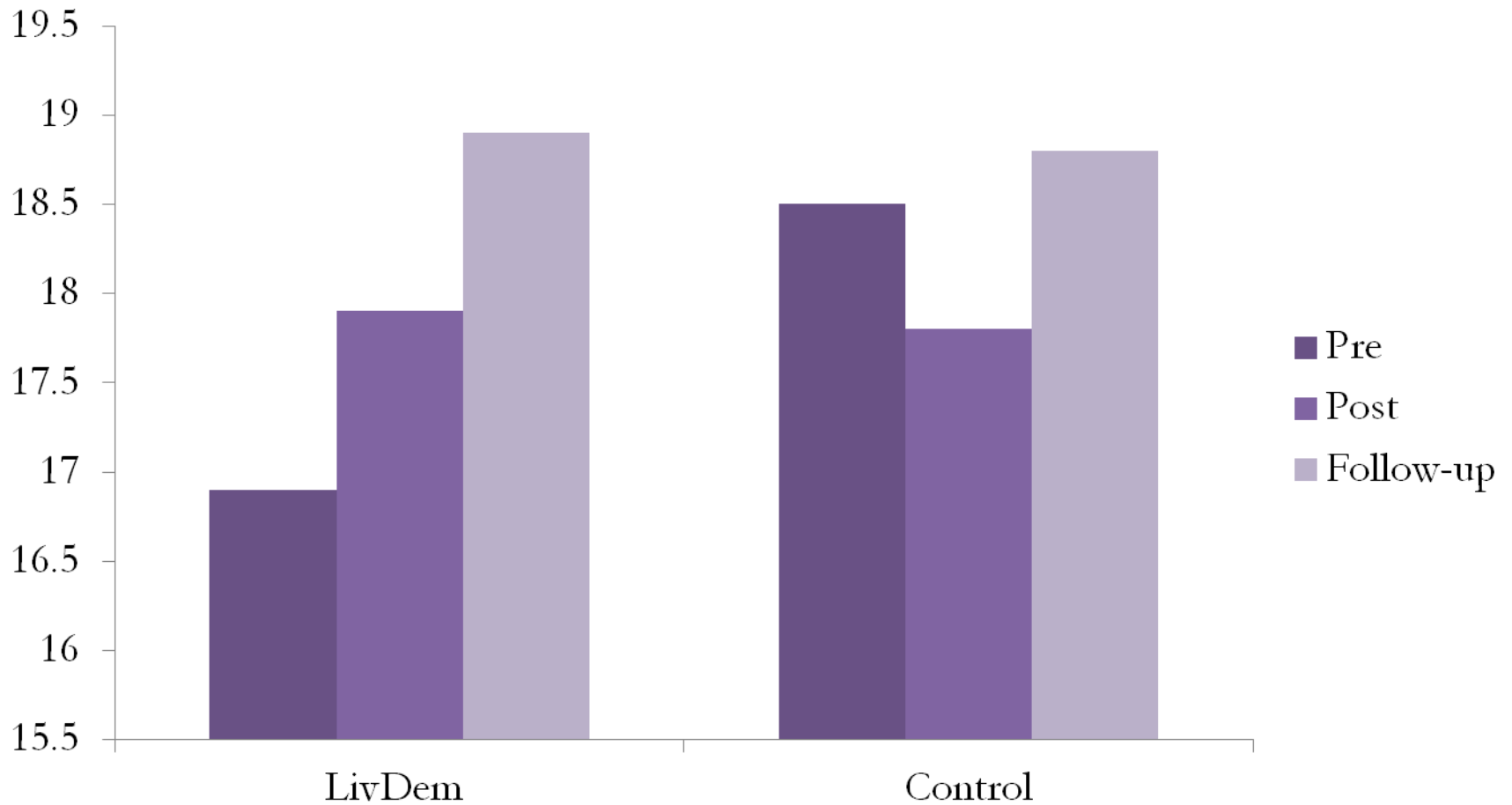
Session one and two: identifying memory problems and strategies

Session three, four and five: finding a way through feelings, coping with stress, relationships and social situations

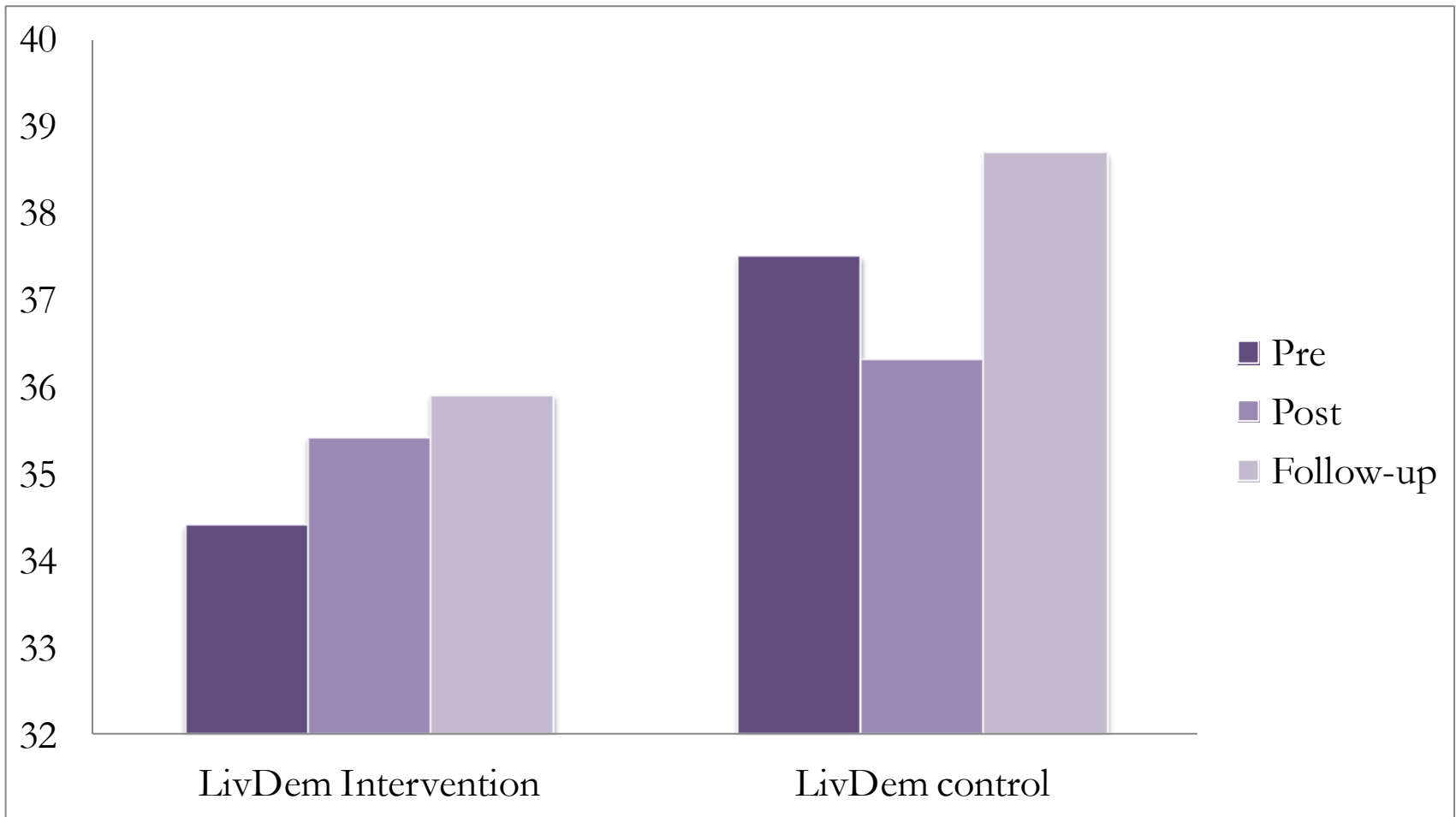
Session six, seven and eight: information about dementia, living as well as you can, staying active

Post-group: Bringing it all back together (with families)

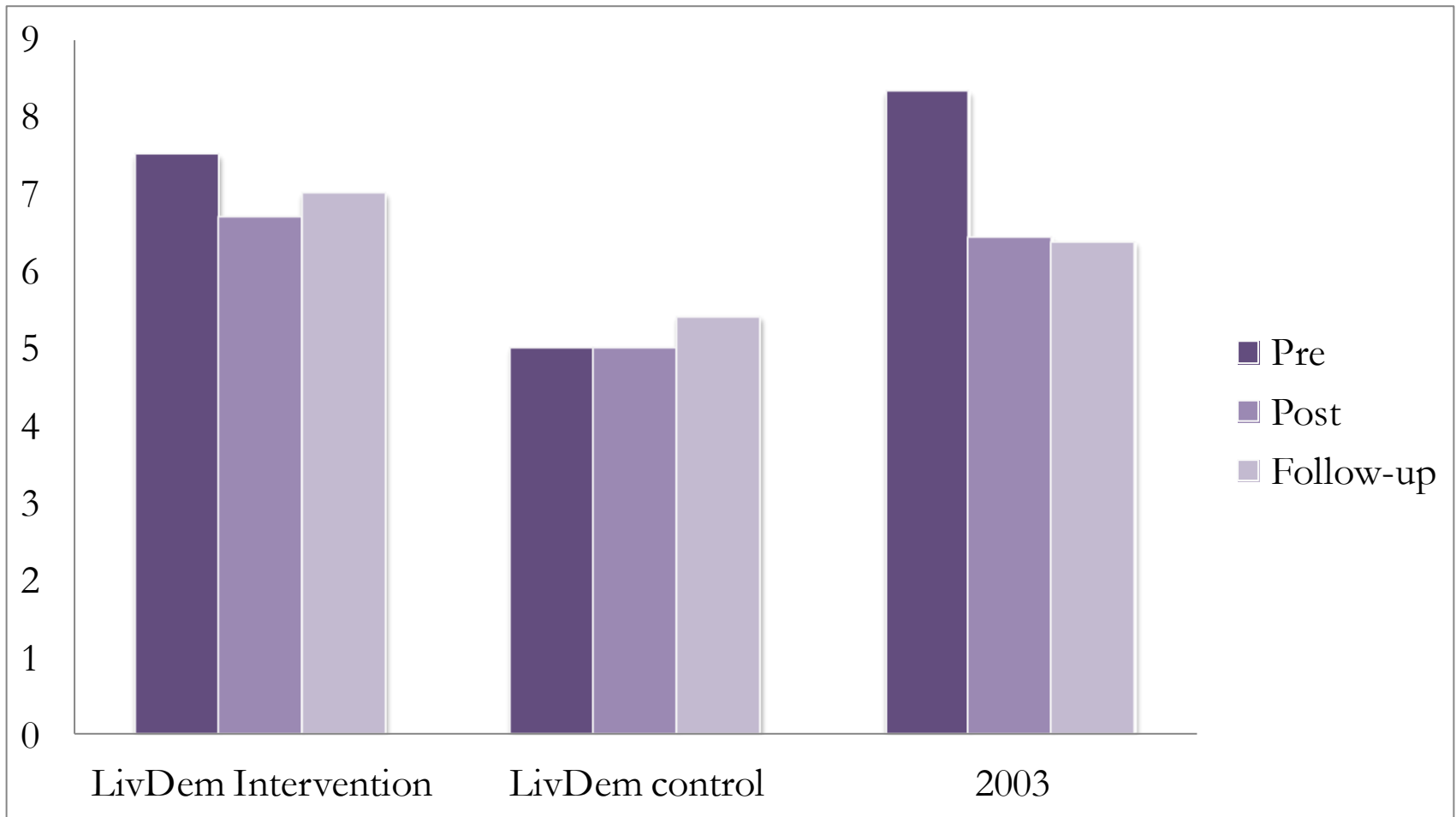
Self-esteem



Participant rated Quality of Life



Depression



Feedback and acceptability

- Participants
 - Generally felt positive about the groups
 - Some felt that they had benefitted
 - Carers felt
 - Positively about the groups
 - Generally felt that they were beneficial for people with dementia
 - Therapists
 - All felt the groups were worthwhile
 - Generally patients benefit
 - Also felt they benefitted - learnt new skills and enjoyed doing the groups
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People with dementia

- *“We talked about dementia and the problem with dementia, you know, the memory problem, but if you asking me whether the memory is still there I would say well no, it’s gone, it’s in the background there.”*
 - *Well I suppose the biggest thing is you realise that there’s a lot of people with dementia, you know, that you’re, you know, it’s not just a very small thing, it’s a big thing. And I suppose that makes you feel a wee bit better doesn’t it? [laughing] You know, that you’re not the only one.”*
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Carers – learning about dementia

- *I thought they were very good. Definitely. And well it gave us more insight on what Alzheimer's is. Because, you know, in our little world we don't know, you just hear about it. But there's been so much of it lately in the papers that, you know, since R's been diagnosed, that, you know, you can learn about it. But up until then there wasn't a lot. So going there definitely enlightened us on what Alzheimer's*
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Carer – noticing change

- *There's two important things about that group as far as you're concerned. One you've already mentioned it makes you realise that you're not alone but the other, probably the most important thing, is it encouraged you in front of other people to stand up and say "I have dementia"... I think up until that hospital session S was in denial that she had it but after that she wasn't in denial and that helped a hell of a lot I think."*

Therapists

- *“I think it’s a good investment those ten sessions ... I think that can change the whole pathway of someone’s illness. I really do. Because I think far too much now somebody has struggled and struggled and struggled and we’re thinking ‘Why did we not know about this?’”*
 - *You know, you’re often looking for little things, you’re not, you know with dementia you’re not looking for huge great leaps and changes and you often have to put a lot of work in to get something back from people but when you see that I think that really makes you feel like you’ve done something.”*
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Concerns

- Participants had different cognitive levels
 - some benefits, but also drawbacks
 - Did people retain anything?
 - Not everyone wanted to continue
 - People with sensory loss sometimes struggled
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Process of change

- Dementia involves both emotional as well as cognitive challenges
 - *“Oh God”, I as good as lost myself”, “I have lost myself”, “I am lost”*
Frau Auguste D, (1901)
- Important to understand the process of “coming to terms” with dementia. This will enable us to
 - support people more effectively
 - identify people for whom confronting dementia directly may be risky

Work to date

- Series of small scale studies looking at the process of change within psychotherapy groups.
- Recently extended this to non-therapy settings – looking at changes before and after having a diagnosis, and in how couples discuss the diagnosis
- Qualitative research methods – analysing recordings
- Consistent findings is that one of the most distressing aspects of dementia is people's fears about losing control

The Voldermort problem (naming dementia means losing the battle)

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 its 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”.

Losing my faculties

Mrs H: *And I just wonder where it's going to end, that's my fear you know where am I going to end up, just before the end you know*

Rik: *So what is the frightening, when you say about the future?*

Mrs H: *Being, being useless, you know. Not having all my faculties, I dread that, I dread that, it's as if I'm going to sort of come to it one morning, perhaps, you know and think 'oh my godfathers, what's left?', you know I really worry about that.*

Losing control: being dependent

Mike: *I mean at the moment I can drive, I've been driving for around 50-60 years or something like that and then all of a sudden I'm going to have to rely on someone. (Laughs)*

Mike: *And before long they'll be giving you toilet paper and wiping your bum for you ... it's total and absolute control.*

Losing control: fears about madness

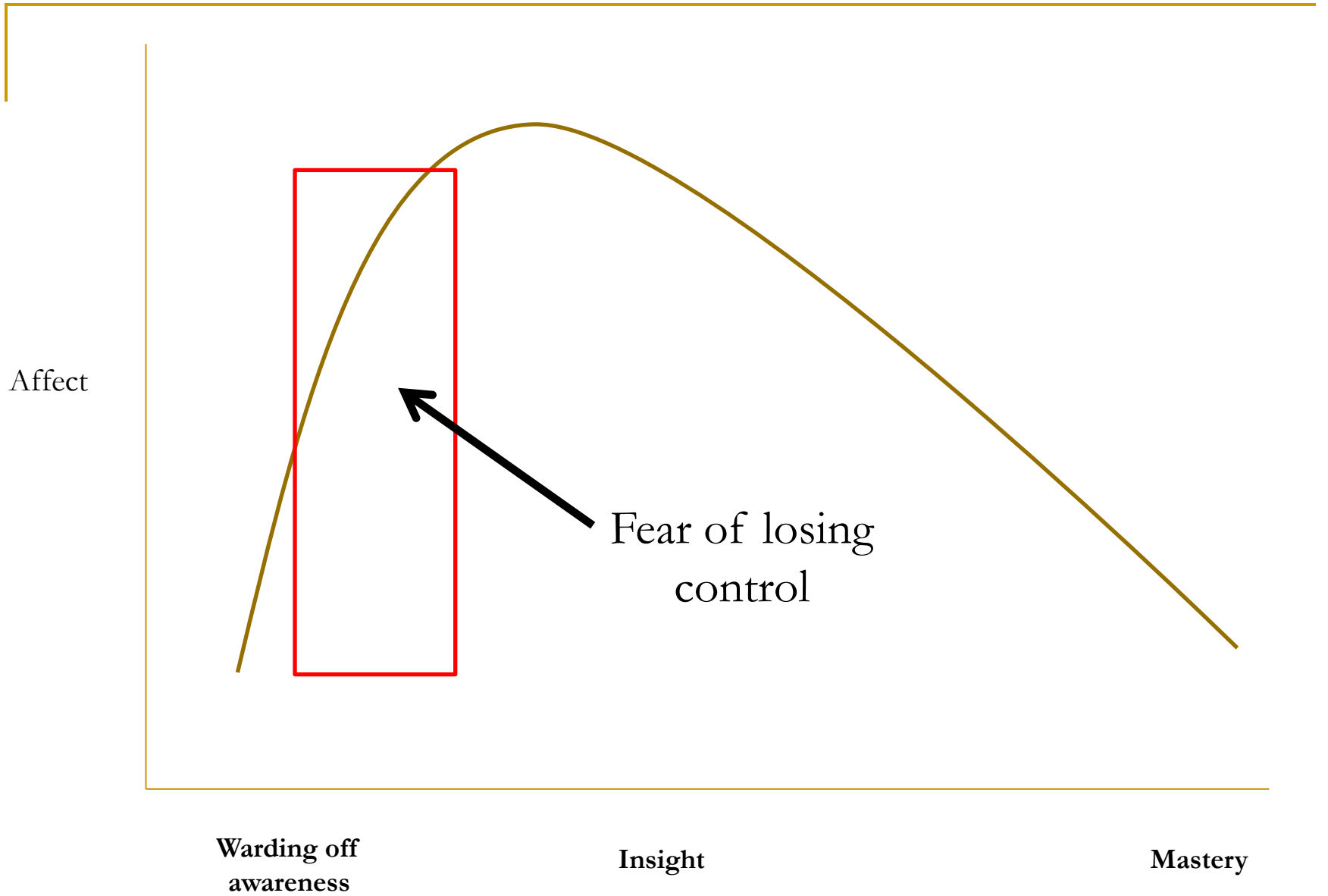
D: *Well you already know this, but the biggest thing was to me was that I was going to go down and be a loony, and they were all going to go “yer, yer, yer” [gestures with index finger of hand, pointing and rotating it against his head and signing that he is being thought to be "screwy"]*

J: *it's a horrible word ... dementia, makes you think that you're barmy... , yeah the word , cause then you think that you're nutty (laughs)*

Len: *“I think that if people know, they understand, but if you hide it as I did, first going, they get frustrated with you, so if I was advising someone, if they found themselves in the situation I found myself in, I think you've got to be open with people and they may understand instead of thinking ‘oh that silly old fool is losing his marbles’”*

Looking back

Mr B:... *I find I've, I've got a great deal of moral uplift by coming here. Meeting you, listening to the way you do it. And I don't see the problem now, it frightened me, the problem of declining memory, until I came here, and now I'm not frightened ... it frightened me. Because I thought, well, I'm going mad, I'm going crazy. What am I going to be like in another five years? But now I realize that everybody is getting this problem*



Affect

Warding off
awareness

Insight

Mastery

Fear of losing
control

Conclusions

- A group intervention can be taught and delivered by:
 - Memory nurses with little experience of therapy groups; and
 - IAPT therapists with little experience of dementia
 - Some preliminary evidence that groups can
 - Reduce depression and increase self-esteem
 - Help (some) people to be more able to talk more openly about their illness, and to adjust to it
 - Intervention seems acceptable to participants, families and therapists
 - Some elements of research process (e.g. blinding) work better than others (e.g. randomisation)
 - To work towards application for larger, national, trial
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 - Disclaimer
 - The views expressed here are not necessarily those of the MHF, the NHS, the NIHR or the Department of Health.
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