



Carers Extrinsic Disorder: Dementia & Alzheimers

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ABSTRACT

This article makes the case for a new diagnosis: Carers Extrinsic Disorder, caused by the extrinsic determinants of carers of patients with dementia & Alzheimers. It argues that the causal symptoms are beyond the control of the carer. It further attempts to high light the role of the carer as the disease in the patient escalates - from imperceptible signs and symptoms to full blown diagnosed dementia. The carer becomes the lone interface between the deteriorating patient, society, and the provision of the often-disunited welfare systems. A biopsychophysical role undertaken often by a spouse without any previous medical, therapeutic training or experience.

Keywords: Dementia Alzheimer's, loss, identity, familiarity, coping, biopschosocial - physical deterioration, extrinsic factors, isolation, disorder, fatigue.

INTRODUCTION

Dementia and Alzheimer's are both progressive neurological diseases which affects cognition, insight, memory, the inability to solve problems and to cope with day to day living. Behaviour can become inappropriate. The estimated size of the problem is that there are approximately 900,000 patients who are living with these conditions in the UK.

However, along side the actual patients there are the carers the spouses, families, who are intimately caught up in adjusting to these very debilitating diseases in their family members. Who unwittingly due to the toll of the caring demands consequently are in danger of become patients themselves.

Trying to navigate and untangle the world of dementia is difficult for both the patient and the carer because it is progressive. Dementia demands continual adjustment : involving the physical, medical, social, the emotional, and not forgetting the financial. However, both dementia and Alzheimer's are insidious. The initial changes may be imperceptible because they can just be exaggerations of previous behaviour and personality characteristics and therefore can be attributed to ageing or stress related. Unlike an acute illness / disease which can most usually be pinpointed to a certain causal symptom or an event which galvanises the recipient into taking steps that something is wrong and treatment should be implemented.

There are different levels of carers some are carers:

1. In word only, who do very little other than just popping in — they don't live in.
2. Paid carers provided by the welfare system. Both these have respite in so far as they are not on duty 24 hours.
3. Then there are the real 24/7 carers such as spouse's family members who are unpaid and live in often with no respite.

This paper is concerned with number three. The lone carer who can become so caught up in the ups and downs of navigating day to day necessities alongside the emotional turmoil that they fail to realise that they too are changing and not for the better. The caring is taking its toll.

These carers are most usually attempting to bridge the loss on different levels. Loss of sharing roles and responsibilities, loss of shared humour, loss of the familiar and identity. Unlike the death of a spouse when the grieving process has a definitive beginning the spouse of a patient suffering dementia has no definitive beginning or end. The patient, their loved one, with dementia still physically exists!

The loss is insidious. Even on a day to day or an hourly basis the patient can alter. One minute they can appear coherent and insightful, the next irrational. Similarly, the patient can appear benevolent but quickly followed by aggression, sometimes physical.

The carer usually has to cope on different levels:

- Daily domestic essentials such as shopping, cooking, cleaning, washing.
- Appointments
- Finances and administration
- As a therapist - reasoning, relating, administering prescriptions.
- Social connections communication, coordination and subsequent contractions.

This often-lonely trajectory of the carer is not a recipe for their own health. The usual stabilising rituals of daily living has to be abandoned for the spasmodic. Such as the onset of insomnia due to being woken during the night to find the patient wanting breakfast at 11 pm fully dressed and ready to start the day.

Socially too the world can contract — the carers energy is sapped they need to not only at the same time cover up inappropriate behaviour, but to also anticipate and prevent problems and find the right solutions.

Outings instead of being pleasurable can become onerous. The best laid plans have to be amended. Such as the patient can't be left alone in a car while errands are run risking the patient turning knobs and altering the technical aspects of the car.

Mobility issues can escalate, the constant medical appointments become a burden, such as: preparation and dressing appropriately, getting to appointments on time, parking, even navigating to clinics: for optical, audiology, memory, orthopaedics, etc. Which eventually raises the questions whether the enormity of effort outweighs the benefits?

As the situation becomes more accumulative the 24/7 carer becomes more socially isolated. On the surface intervention can be provided but it is often counterproductive. The carer finds themselves the pivot between cursory assistance from therapists who just provide lists of exercises and instructions which the carers is supposed to implement. They are in fact doing what the therapists should be doing. Additional help can be awarded by paid assistants but who have to be worked with alongside their needs and fluctuating schedules. This can also prove to be counterproductive.

Advice is a plenty but it can also be accusatory. Such as “I called but I was cut off?” When the phone has been answered by the patient pressing the wrong button resulting in communication chaos. Or advice such as have you done this or why don’t you do that? Or words like “I understand” when in fact unless they have endured the hands-on unrelenting process for years they have absolutely no idea of the enormity of the problem - they don’t understand.

The faces of the carers so often tells the story: worn tired and fragile. Caught up in a world of loneliness despair and of a drudgery demanded by duty. Always in limbo. Quite often their lives are worse than the quality experienced by the unreality of the patient with dementia? The carers guiltily inevitably wonder when will it end? On the back of such debilitating circumstances is there a case for a new diagnosis: carers extrinsic disorder. Importantly it is argued that the causation is extrinsic - it is a situational decline as opposed to a reactive illness. (Thomson 1996). In so far as the carer is in a situation not of his or hers own making. Furthermore, it can be perfectly conceptualised as a complex adaptive system of disorder. Thomson (2022)

It is brought on by a specific situation: The diagnosis dementia, Alzheimer’s in a spouse or family member amounting to consequential:

1. The loss of a soul mate and the end of a relationship.
2. Financial problems
3. People can be more susceptible to extrinsic dementia if they already have a physical health condition themselves.
4. Social isolation
5. Physical drudgery

The symptoms of carers extrinsic disorder are gradual:

- Emotional depletion, loss, pessimism, tearfulness, anxiety, lack of humour.
- Fatigue insomnia
- Heightened physical difficulties.
- Low self-esteem, lack of confidence, loss of identity.
- Lacking the energy to fuel motivation.
- Problems with decision making.
- Social isolation inability to pursue hobbies

CONCLUSION

The carer of a patient with dementia becomes a victim of circumstances often perpetuated by their own kindness and diligence. But more seriously the caring role can become unsustainable and they risk becoming incapacitated, mentally, physically, and socially themselves. It is recommended that their situation needs to be recognised in its entirety as opposed to being treated as consequential symptoms.

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