

Dr Gaynor Macdonald

Anthropology, University of Sydney

Assoc Prof Jane Mears

Social Policy, Western Sydney University



Who is abusing whom?

Elder abuse in the context of structural violence

Elder abuse is a huge concern

We are concerned here with the **abuse of family/unpaid carers**

Our focus is on those caring for people with dementia

- Expectations of the home care situation
- Structural violence in the wider society
- Cultural attitudes reproducing this violence



Turn the lens around

Identify structures, processes, attitudes that subject carers to abuse



Conceptualising carer abuse:

The grinding down and potential destruction of a person prepared to take on one of the most important tasks in our whole society: the care of a person who has the incurable condition of dementia



Dementia: a form of bone pointing

Dementia is represented as loss, deficit, tragedy, an end – for everyone involved in the ‘dementia experience’

The person receiving the diagnosis AND those around them are counselled to expect their ‘being in relationship’ will start collapsing, being challenged

For loved ones the overriding message is that they will ‘lose’ the person they knew

This advice alone is shocking and traumatising, and often causes family and friends to withdraw, having been told they will be unable to connect to ‘the person they once knew’




Dementia care is DIFFERENT

The dementia difference lies not in tasks or time
but in the changing relationships that the carer is engaged in

'It is difficult to understand the behaviour of a loved one acting so out of character. In addition, this behaviour is constantly changing, requiring constant adjustment from the carer – for which they are seldom adequately prepared'

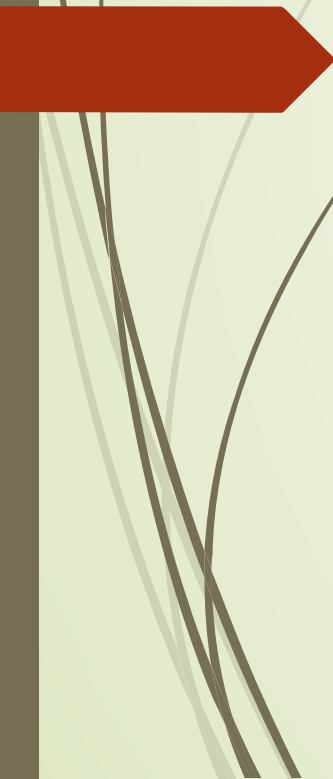
A dementia carer is not an onlooker: she or he is ENVELOPED IN THE DEMENTIA SPACE and is compelled to change themselves accordingly, with no acknowledgement, warning, support or advice.



'Dementia not only affects the minds of its victims; it also creates a world so fragmented, so skewed and redundant – so indifferent to normal rules of behaviour – that caregivers unwittingly become part of the madness'.

Kiper 2015

Much is said about valuing the personhood of the person with dementia, even as this changes over time



It is little appreciated that, as the personhood of the person with dementia changes, *the personhood of the carer is also challenged and must also change*

Requires intensive adaptation of the carer's self – often never fully realised, and even resisted, to the detriment of both

'The despair of comprehending the implications of dementia is too great, so carers never fully come to terms with it, and shock still exists even when the behaviour of the patient becomes habitual and mechanical'


Paid carer observing unpaid family members

This is what doctors, guidebooks, professionals offering counsel to family caregivers often fail to notice – or even understand

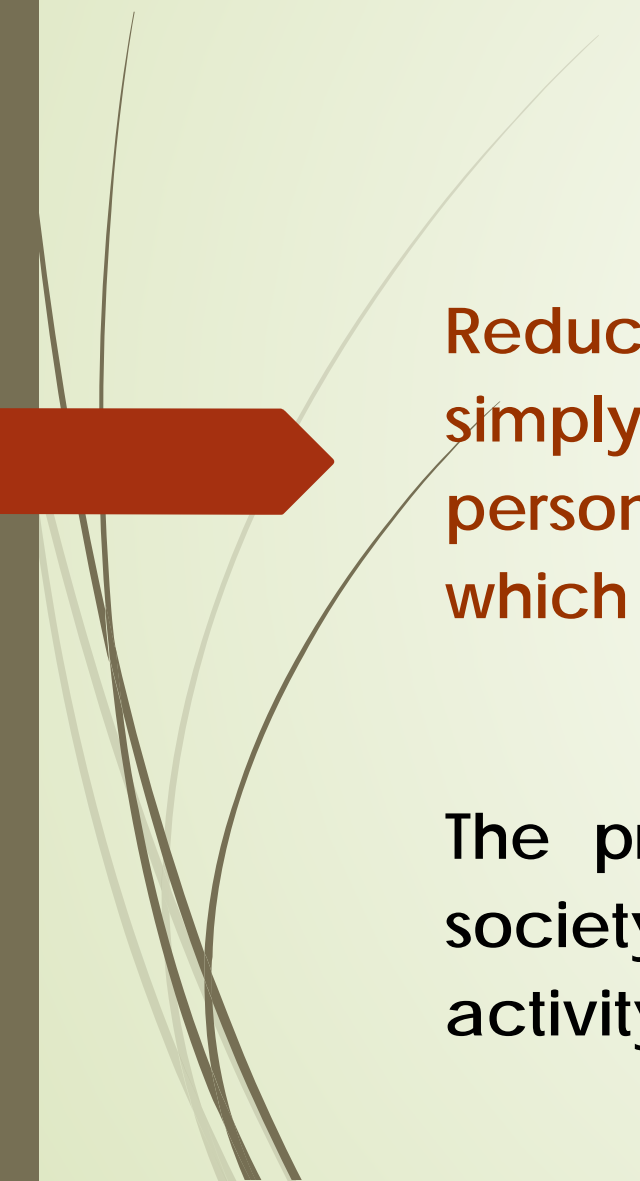
We automatically posit a clear distinction between caregiver/patient, between normal/abnormal

We don't see that the true burden for carers is the absence of such a divide.

'When a loved one loses cognitive purchase, it's not only his or her world that begins to unravel, but the caregiver's as well' (Kiper 2015)



Not to be aware of this, not to support a CARER through this – to be task oriented or person-with-dementia oriented – is a denial of what is involved in dementia caring, and this denial is a violation, an abuse of a carer



Reducing a healthy and engaged person to a depressed wreck simply because they want to, or are expected to, care for a person with dementia and are not given adequate support by which to do so is **ABUSIVE**

The presence of social and economic structures within our society that prevent such support make caring a high risk activity.

This sets up a **self-fulfilling prophecy** for dementia carers. We know that dementia carers are commonly (and unsurprisingly) reported as experiencing:

- Foreboding about challenges/difficulties of caring
- Impending lack of social value and isolation
- Resentment, anger, confusion, bewilderment, guilt, grief
- Desire to lash out, often at person they care for, physically or in other ways abusing them (stop caring, disrespectful of rights)
- Adopt dysfunctional strategies (self-criticism, substance abuse)
- Have higher levels of stress than caregivers of people with other illnesses, increasing over time
- High functional rates of depression
- Suicidal and homicidal thoughts
- Increased mortality risk



How would you feel about being told this is likely to be your future?

How are carers supposed to recognise and respond to these pressures BEFORE they have to be medicated for not responding well enough?

Simple answer: they can't

Well-meaning advice often comes as

- an explicit set of demanding expectations and
- an implicit set of warnings about what lies ahead

Too many expectations placed on carers – by too many people

Constantly reminded of the challenge – they will need respite

Automatic assumption that caring is a burden

Too much 'good advice', from people who 'don't get it' –

'empathy' is often shallow if well-intended

Inadequate training/information – too generalised, too abstract

Own health and financial security are at risk

Medicalised and impoverished instead of supported



Dementia care

NEEDS of a person with dementia include:

- Progressive assistance with daily tasks: bathe, dress, ...
- Meaningful activities, tailored to interests and abilities
- Treatment/management of symptoms, including co-existing illnesses and general health; supervision of medication
- Provision of safe physical environment, transport and mobility assistance, physical exercise
- Provision of environment in which quality of life is maximised
- Supportive and affirming social engagements
- Trust in those caring for them



This translates into the following **EXPECTATIONS** of a carer:

- Capacity to deal with activities of the day to day (ADLs)
- Banking and financial management
- Functional tasks (managing personal safety, behaviours)
- Improving quality of daily life through activities, social engagement
- Computer literacy - access/navigational skills assumed
- Medical/health awareness, communication and management
- Social, legal and financial advocacy
- Mediate with family members, provide support/training, be accountable, deal with end of life issues


Responsibilities are multidimensional, demanding, assumed gradually - **no matter how competent you are, this is impossible for one person to do alone**



Nothing unusual in these lists

But the lists should continually **SHOCK US** with the realisation that carers are being subjected to so much **ABUSE**

MANY good people are working to turn this around –
SO WHY IS THIS NOT HAPPENING?



It is not within the context of carer support that this answer can be found

Need to examine the 'big picture' of the society within which this abuse is occurring





Structural violence

Lack of attention paid to the well-being of dementia carers is evidence of structural violence produced by an uncaring society

It is an indictment of this society that we expect unpaid family carers to carry a burden so intolerable burden that it produces two sick people instead of one

Structural violence = social, economic and political policies, attitudes and practices which prevent or impede wellbeing for certain categories of citizen. Impacts negatively and often severely upon the quality of life of certain categories people

Structural violence stemming from fiscal/policy decisions:

View of the aged as an economic burden

- Financial burdens carried by carers
- View of the aged as an economic burden
- Unpaid carers save us money - WRONG headed thinking – transfer the money into better support for them

Ways forward

- There must be generously based needs-assessed
- Couples should not be financially penalised
- Tax relief for family members (home adjustments, paid care, etc)
- Rich and poor are (reasonably) catered for – bad luck if you are a middle/average income person caught between the poles




Structural violence as lack of social/educational investment

Inadequate training and education

Strategies for combatting ageism in general and attitudes towards dementia in particular need to be an ongoing priority

- The quality of training and information must improve for ALL paid and unpaid carers
- Every household in Australia should receive educative information regularly
- Investment must be made in high quality training
- All unpaid/family carers should be able to access ongoing education in the community, at home and online
- Strategies for combatting ageism in general and attitudes towards dementia in particular need to be an ongoing priority



Urgent need to rethink the culture and economics of care to break the nexus between violence and care

Cultural violence underpins structural violence

Cultural violence = values and practices in the wider society that create the negativity associated with dementia and the negative space occupied by family carers

Violent ideas and practices that influence social structures

1. Neoliberalism – valuing the ‘economic subject’

Economic and political philosophy – the ‘normal’ person is economically-valued (productive, independent, cost-neutral); the ‘abnormal’ = cost, burden, ‘spent’ lives.

Exacerbates ageism – posits ‘old age’ as a negative, a part of our life cycle is devalued because no ‘use value’

Wealthy seniors retain some economic/social value as consumers (of travel, retirement housing, pharmaceuticals)

Those with inadequate wealth/health = burden on a society

Pensioners = failed ‘self-funded retiree’, drain on the taxpayer purse

2. Medicalisation

Medically-dominated models turn ageing people into patients

Exacerbates individualism: the individual-society split

Individualise and problematise (abnormal, deficit, pathology)

Removes social and fiscal responsibilities onto medical/health professionals



3. Fiscal and social responsibility vs individualism

If caring were valued, one would expect it to be well paid, recognised positively.

In a 'caring society', one would expect as much attention, support and research to be given to those who care for the aged (and sick and disabled, etc) as those for care for children (parents).

4. Denial of our mortality

Secular world is preoccupied with extending mortality, to the point of denying it.

Ageing - and dementia in particular - confront us with our mortality

In modern secular societies the value placed on our lives diminishes -

The person with 'life' ahead of them vs 'life' behind them

What does 'life' mean here?

'Usefulness' model vs wasted space

Compounds fear of exclusion and ill-treatment (nursing home)

5. The 'abnormal' starting point for thinking about dementia is a big part of the problem


Just as easy to argue that what is abnormal is trying to extend our life span despite our 'mortal coil'



Normal? Does this mean Perfect? Capable? Happy?

'Dementia is not a normal part of ageing'. Really?

Well, it is until the 'cure' is found!



These cultural ideas and values act in concert
to create structures that both subtly and overtly
violate rights, personhood and dignity for CARERS

This creates a violating habitus
normalised as 'the carer burden'



6. Understanding of human beings as mind + body

(Descartes: I think therefore I am)

Dementia as a 'loss' of personhood rests on the privileging of cognitive rationality in understanding the 'normal person'

Lies behind demeaning and stigmatising of all 'mental illness' as well as dementia

Therefore, fear of dementia because of fear of 'unbecoming'

BUT we are NOT just mind + body

A person is
a social human being
in relationship

What is this experience of 'being'?



Dimensions of 'being a person'

Creative

Emotional

Speech/sound/language

Relational

Symbolic

Somatic (touch, pain)

Mirth

Smells

Music/Rhythm

Taste

Tactile

Sight/aesthetics

Cognitive (thought, memory, imagination, etc)

Dementia is seen a loss of 'personhood'

All persons change through their life

Knowledge, wisdom, physical abilities,

Sick one moment, unfit the next

Competent in some situations, incompetent in others

Love being with some people but not others

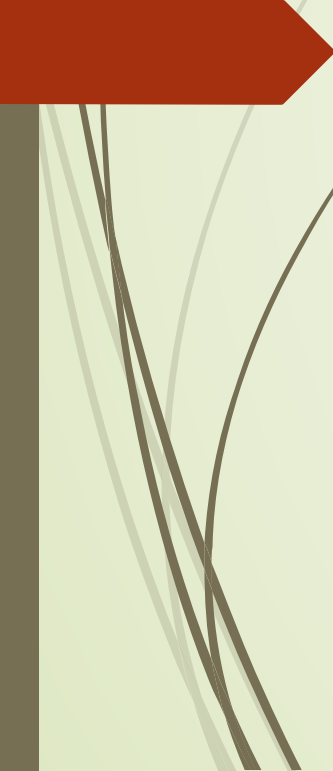
Remember some things and forget others

You could think of life as continual 'loss' (if you wanted to). We lose our childhood innocence, our teenage energy, our virginity, our independence when we marry, our kids when they leave home, we lose on the stock exchange, we lose our jobs, our mobility, our hearing . . .

I am no less a person because I am continually experiencing my life in different ways

'Dementia is a thief who steals the memory of a loved one. Insidiously, slowly the person we once knew becomes a shell of who they once were. The frustration at forgetting a name, a place, a time is palpable. The struggle as I witness the inner turmoil . . .

This statement by a daughter is a denial of being



**If you can't cope with my changing cognitive ability, it is YOU who are choosing to 'lose' me because YOU don't want to adjust to me
- I am not lost**



The caring society should be the normal society

What is 'care'? Who 'cares' for whom?

In ANY society – in human history – across the world –
approx 50% of people 'produce' in order to support the other 50%

This is NORMAL – one 50% are NOT 'a burden' on the other 50%

'It takes a village to raise a child'

It also takes a village to tend to one ageing person

WE are the village and we all need the village



Change the society!

Re-situate 'caring' – it is a social value and necessity not a burden or option

Care is not a sector, an industry: it is an orientation to life, to others

We should ALL be carers of each other

Those who can produce must produce for those who do not/cannot – we are SOCIAL BEINGS

Change the 'use by' date applied to our lives

Education about the human social life cycle should begin in school

Get rid of ageist, negative, defeatist, deficit language

Re-value human mortality – cognitive decline is just one of the declines of the ageing process

Change our understandings of personhood: no one is lost, ever
Challenge Cartesian models 'I think therefore I am' that represent dementia as a deficit of personhood

My eyes light up when I see you therefore I AM!

I sing (badly) when I hear music therefore I AM!

A journey of a thousand ri (km) starts with the first step



Single-handedly carers are trying to be the village we all need

Hug – and thank – a dementia carer today

**She/he is caring for someone you may not know
but that person is a part of YOUR social world**