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'There's lots of support!'
So why did I feel I was on my own?



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 told to expect their 'being in relationship' will start collapsing, being challenged

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: activities, social engagement
- Computer literacy - access/navigational skills assumed
- Medical/health awareness, communication, 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**



Well-meaning supportive advice often comes as

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



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

How can we support the family carer?

Carers are essential to the well-being of all of us

Their toughest task is **DEMENTIA CARE**

Let's change the negativity surrounding dementia care

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CARERS ARE PLUNGED INTO A NEGATIVE, AGEIST SPACE

- Expected to cope, told they are burdened, medicated for depression
- Socially devalued, even though they perform essential tasks
- Advice is hard to access (education, computer literacy, too much to navigate) – and harder to put into effect
- Expectations increase guilt – 'respite' doesn't change things
- Financial remuneration grossly inadequate, makes the negative space darker

CREATE a space for CARERS to feel RECOGNISED, SUPPORTED

- ASK what they need, don't assume
- FUND integrated care plans that target support
- Provide ACCESSIBLE information and education
- Provide proper FINANCIAL SUPPORT including tax relief
- POSITIVE and APPRECIATIVE attitudes – thank a carer today

Carers need us to:

CREATE a CARING SOCIETY – Caring is an attitude that continues across the life cycle – the core of all social life and cannot be reduced to a 'profession' or an 'industry'

CHALLENGE AGEISM – Value ALL persons regardless of age and ability: Neoliberalism exacerbates ageism – the 'normal' person is valued (economically-productive, independent); the 'abnormal' are a cost burden. Medically-dominated models of ageing view people as abnormal, a deficit; remove social/fiscal responsibility to medical profession

CHALLENGE the SUPREMACY OF 'THE MIND' – Value the totality of human experience – our minds, emotions, senses, embodied experience. Cognitive decline is just one of the declines of the ageing process


MOVE AWAY from NEGATIVITY – Dementia as 'loss' of personhood creates a negative space of demeaning, stigmatising ideas, practices, attitudes

Dementia care *is* DIFFERENT

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

A dementia carer is not an onlooker: she or he is **ENVELOPED IN THE DEMENTIA SPACE** and is **compelled to change themselves accordingly**

Often with little acknowledgement, warning, support or advice



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, constant adaptation of the carer's 'self'




Turn the dementia lens around

It is focussed on an individual 'patient' (consumer)

It is a RELATIONSHIP

**between a person diagnosed
and all those around them**

*I, the 'family carer', am the one 'living with
dementia'*



The geriatrician, and the next geriatrician
The GP

The guy who did the ACAT assessment
The awful local aged community centre
The trained paid carer

And dozens of phone conversations with people
running services to make money out of my distress
– (who occasionally sounded as if they care – but
it's hard to know with 'professionals'!)

They don't 'get it' unless they have experienced it

The doctors, guidebooks, professionals offering counsel to
family caregivers *often fail to notice – or even understand
what is involve in dementia care*

They posit a clear distinction
between caregiver/patient
between normal/abnormal



The true burden for carers is the *absence* of such a divide.

The prospect for dementia carers

Commonly (unsurprisingly) reported as experiencing:

- Foreboding about challenges/difficulties
- Impending lack of social value and isolation
- Resentment, anger, confusion, bewilderment, guilt, grief
- A desire to lash out, often at person they care for, physically or in other ways abusing them (stop caring, disrespectful of rights)
- Adopting dysfunctional strategies (self-criticism/substance abuse)
- 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

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**

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

Abuse stemming from fiscal/policy decisions:

View of the aged as an ECONOMIC BURDEN

- Financial burdens carried by carers not costed
- Unpaid carers are not there to save the government money

WRONG headed thinking – CARERS must be bettered supported

Ways forward

- There must be generously based needs-assessment
- Couples should not be financially penalised
- Tax relief (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

Abuse as lack of social/educational investment

Inadequate training and education

Ways forward

- The quality of training/information must improve for ALL carers
- Investment must be made in high quality training – and remunerated accordingly
- All unpaid/family carers should be able to access ongoing education in the community and at home – not just online
- Strategies to combat ageism in general and attitudes towards dementia in particular need to be an ongoing priority
- Every household and school in Australia should receive educative information regularly (not glossy pictures!)

Violent ideas and practices that promote this

1. In the neoliberal economic system in which we live the individual entrepreneurial subject is the *valued norm*

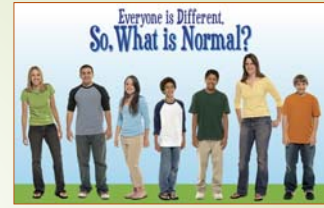
- The 'normal' person is economically-productive, independent, cost-neutral;
- The 'abnormal' person is a cost, a burden
- Exacerbates ageism – posits 'old age' as a negative, a part of our life cycle is **devalued** because no 'economic value'
- Wealthy healthy seniors retain value as consumers (of travel, retirement housing, pharmaceuticals)
- Those with inadequate wealth/health = burden on a society
- Pensioner = failed 'self-funded retiree', drain on the taxpayer purse

2. Medicalisation

Medically-dominated models turn the 'non-normal' (e.g., ageing) person into a **patient** (sorry, 'consumer'!)

- Individualise and problematise (abnormal, deficit, pathology)
- Removes social and fiscal responsibilities onto medical/health professionals
- Isolates people deemed abnormal
- Does not include those around the 'patient' in the 'treatment approach'

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



Normal? Does this mean Perfect? Capable? Happy?

"Dementia is not a normal part of ageing"

Really?

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

Such cultural ideas and values act in concert -
to create structures that (subtly and overtly)
violate rights, personhood and dignity
for CARERS

The CARER is cast into the 'abnormal'

Normalised as 'the carer burden'

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 what is NORMAL

50% are NOT 'a burden' on the other 50%

**THIS IS WHAT IT MEANS TO BE A SOCIAL HUMAN BEING – 'TO BE'
 – IN ANY AND EVERY SOCIETY throughout the entire world,
 throughout history**

Total Australian population			24, 511, 800
0-14 yrs	Children below working age =18.5%	4,534,683	
65-84 yrs	Post-retirement = 15.6%	3,823,841	
		50% = 1911921	
85+ yrs	Aged = 2.1%	514,748	
15-64 yrs	Potential labour force = 65.8%	16,159,825	
	Actual labour force (employed + unemployed, looking for work, including underemployed)		12,996,500
	Not in labour market	3,132,264	
% WHO WORK FULL/PART-TIME TO SUPPORT THE WHOLE = 53%			
Pay your tax! Redistribute! Be caring!			

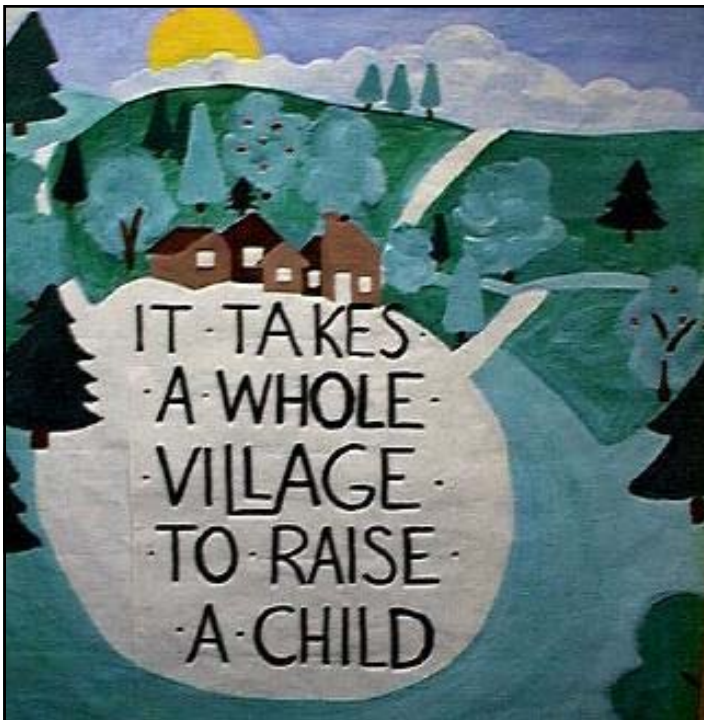
Re-situate 'caring' – as a social value and necessity
NOT an economic burden

Care is not 'a sector', 'an industry' – relegated to the
'outside'

It is an orientation to life, to all others who share our
world

Care is necessary to EVERY society


Those who CAN produce MUST produce for those who
do not/cannot – we are **SOCIAL BEINGS** not 'individuals'



Dementia makes intense
social demands, as great
as those involved in
parenting

As the old African saying
goes, 'it takes a whole
village to raise a child'

It also takes a whole
village to tend a single
person to a worthy and
respectful death



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



The paradigm shift

Valuing the whole of the life course in every person – the vulnerable (we all are at times), sick, poor, disabled at ANY age, any stage of life

**Re-situate 'caring' –
as social value and necessity
not a burden or an option**

The caring 'industry' idea needs to go – care is not an industry, it is what all social life is about

What do I want?

I want to live in a caring society

In which people are mindful of each other

In which people ask me how I am, and not just how my husband is

In which people accept that the normal is not the perfect and the wealthy and the healthy

I want people to stop telling me dementia is tragic (casting us into their black hole) and feeling sorry for us (waste of emotion)

That is simply a denial of who I am, who my husband is

All I often want is a hug and a cup of coffee . . . to know there is, here and there, someone who 'gets it'

What would
it mean to
live each
day
as if every
one of us will
experience
cognitive
decline?