

Dementia Reframed



DEMENTIA CARE:

WHAT WE WANT, WHAT IS GETTING IN THE WAY

**SUBMISSION TO THE
ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY**

by

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1. DEMENTIA AND CARE: CHANGING ATTITUDES AND APPROACHES

1.1 STATEMENT OF VALUE AND CONCERN

This submission is primarily focused on challenging the attitudes towards, and care of, people with one of the forms of neurodegeneration glossed as dementia.

Our submission is based on three core principles:

1. **A person with any form of brain degeneration is very much alive, through to the last stages of the diseases collectively glossed as dementia.** Their capacity to communicate their desires and needs is progressively compromised but that is not the same as saying that they do not want to engage with us. But they do require us to learn new ways of observing and responding.

If we listened carefully, what might a person experiencing brain degeneration want to say to us?

I have dementia and there are things I want you to learn so you can go on loving me, caring for me. Always assume I am doing things with meaning – there is a reason for what I am doing or saying – I just need you to try and work it out. I can't communicate in the old way and need you to learn the new way. I am alive and that means I need you to connect with me, right now - you can't help me if you are just regretting that the past is past – let's both live in today. This is a relationship, it is not about 'me', it is not about 'you' – it is about us. You can learn 'my perspective' by learning about the states of dementia and how that affects my ability to communicate with you.

People experiencing brain degeneration can be stigmatised to the extent of being written off, as barely human, and not worth effort. If we think this is changing, we are mistaken: there is a long way to go in Australia in reframing how people, including professionals, think about dementia. Our submissions points out impediments to achieving this.

2. **Those who care for loved ones with dementia do not choose this experience: they do what they can but the lack of support they receive amounts to abuse of carers.** Most family members take on this responsibility with goodwill, tinged with understandable apprehension. Dementia care is the most onerous of all care responsibilities. The lack of adequate information and support they receive often ruins their health, working life and family life. The majority will receive little of the right kind of assistance, and many will become ill through this most onerous form of care of our vulnerable fellow citizens. They continually share their stories but they are not being listened to adequately. This is one story, shared with us just this week:

Every day people ask me how I am doing. I almost wish nobody would ask. I hate the real answer so I make up a palpable response but truly – how can anyone answer that question? And how can they really understand my answer?

I have lost myself in caring for my mother. I am slowly watching pieces of her disappear every day. Every memory I have is saturated with the fear of never having the same feelings again.

Guilt strikes me as frustrations grow. Balancing work and home. I am losing myself and ageing faster than I can explain.

Trying to provide the best care for the person who gave everything to bring me into the world.

Any normal reasoning doesn't work. Explanations fall on deaf ears. Almost all of her is gone.

We are fighting against a monster with no cure. I am begging for a glimpse of a mom I have already lost.

A grandmother who sometimes in the back of the twinkle in her eye can see her grandchildren. That love seems to trump this disease although I wonder why she doesn't know me or the painstaking caregiving I am doing as it is almost meaningless to my mom.

It is like I am a new mother with a baby or toddler. No sleep, up every two hours. Feedings and cleanings and though I would never complain, I am exhausted and scared all the time. I am worried that the worst could happen in an instant all the while worrying about the division this disease is causing in my home-unintentionally.

I see the love and kindness in my husband and my boys, and I wonder how this will change all of our relationships. My husband has shown me a heart of gold. Something I may have missed without this experience.

But I also see disparity and loss. What do we do? What can we say to her? Classes have been taken, words from amazing people have been offered with well-meaning advice. But- how to live with it?

My sister is in pain. Dealing with sorrow. Unable to thrive in a hopeless situation. A woman who is usually a powerful force is now silenced.

... And then my mom whispers to me - 'I love you ' or 'thank you for taking care of me ' after hours of frustrating repetitions or tears.

She might even say something like 'Do you know my Jennie? She is wonderful! '

My love for her again clouds all the hard decisions ahead of me. The guilt of resentment returns often. I cry myself to sleep more often than I actually sleep at all.

How does anyone respond to that question? How are you?

The desire for a good quality of life – measured socially above all else – is not diminished by brain degeneration but ways in which care partners can adjust to achieve this is not taught well. They are often presented with a list of activities they can engage in – as if there is the ability and the time in the day to do so – and not to be able to do so becomes an additional pressure, exacerbating guilt.

We know how to train people to communicate well in dementia-relationships. We are just not doing it.

3. **Australians want to remain in their own homes, cared for by those they love, throughout their ageing years and through their increasing vulnerability, including with dementia.**

In the interests of saving 'taxpayer' money, we have medicalised and corporatized 'old age' to the extent that people fear their ageing years and the vulnerabilities this brings. From author, Gaynor Macdonald's experience of care:

When my husband, still very active at the time, was diagnosed with Alzheimer's, the geriatrician assumed – without discussion – that he would go into residential care. He assumed I would be incapable of caring for him – and I later realised this assumption was realistically based. The services available to me were either too expensive or very inadequate. And when I did access professional carers, they had no training in relating to a person with dementia. They ignored him, and I was treated as ignorant – because I didn't have medical or health qualifications. I encountered a

hierarchical world full of 'qualifications' but barely any understanding of care and relationship.

I did my own 'research', trained my own carers, and looked after my husband, at home, until he died. I did not do this with support from services – I did it despite their absence. The toll on our finances, my health, my work life, my relationships was enormous. Very few people could have done what I did – which made me angry because we should be enabling all people to do this.

I taught myself – I had the skills and health to do so. My husband was well cared for over six years, albeit gruelling ones for me. He was taken to hospital when he eventually collapsed. As he washed him, the male nurse commented, 'He is in remarkable condition – there is not a bruise or pressure sore on him! Where did he come in from?' Coming in from, I enquired. 'What nursing home?' I told him I had cared for him at home. It was one of the loveliest things anyone had said to me through all those years: it validated so many of my care decisions. Yet how disgraceful that he could even ask the question. My husband died a few days later: we were still on the waiting list for our home care package.

I remain angry with the society that made these years so difficult, so demeaning, and so expensive.

The attitudes of professionals in the aged care space - medical and non-medical - has to change. This negativity creates and perpetuates much of the stigma attached to dementia. We need to change these uncaring attitudes. We do not need to be told we are 'losing' a person we love – we need to learn how to help them remain in life even as they change.

Biomedical approaches must be confined to neurological research, and the treatment and care of people with dementia must come under practitioners with an explicit biopsychosocial commitment. The medical fraternity must be required to *generously* include the many insights from non-medical professionals and carers who understand what life is like with dementia, for all those affected.

The points above inform the rest of this submission. They also inform our own work in Dementia Reframed.

1.2 DEMENTIA REFRAMED

Dementia Reframed is a research and educational organisation committed to helping all people touched by dementia to live well. We challenge attitudes and stereotypes, and encourage positive and creative ways of thinking about dementia, and provide supportive information and training for those who care. We commenced the project in 2015. In 2019 we incorporated as a NFP charity in order to expand our work.

Our foundation: Dementia is a medically-defined condition but for those living with dementia, it is a *social* experience. It impacts on the lives of many, not just the person diagnosed. With good understanding from carers, family and community members it is possible to live well. Care is not an industry, a task or a skill: it is a relationship that enhances the life of another person.

Our vision: To support family and other carers, especially those who care at home, to think creatively, care positively, and deal more effectively with the demands that dementia makes. We are committed to reframing the negativity surrounding dementia, and to

working for just, humane and compassionate social policy that protects these most vulnerable people.

Dementia Reframed is staffed entirely by volunteers. It is headed by Associate Professor Jane Mears, Social Policy, Western Sydney University, a well-known expert in the care of the aged and elder abuse; and Dr Gaynor Macdonald, Anthropologist, University of Sydney, who brings her focus on relationality, personhood, and change to the understandings of the changes in the dementia relationship. Gaynor looked after husband at home throughout his six years with Alzheimer's, prompting her concern to do more for dementia care and carers. These scholars are joined by a small and well-qualified team of people, each of whom has first-hand experience in sharing the day-to-day life of someone with dementia, as well a range of qualifications (from highly experienced to committed students) across the medical and health sciences, social sciences, education and policy formation.

The work of Dementia Reframed:

Resources and activities for carers

Carer workshops: Informal and engaging, these are designed for familial carers, as well as staff and volunteers working across day, home and residential care. They focus on why behaviours change and how to respond rather than react, how to engage well, and how to de-escalate (currently online).

Carer website: Designed for carers by people with first-hand experience of dementia care. Includes carer stories and insights; and informative, supportive resources: www.dementiacarers-aust.com.au

Resources and activities to enhance community awareness

Seminars, research and consultancy: Our research, seminars and consultancies explore what it means to live well with dementia. We provide opportunities for those who want to enhance the value of quality care, and bring care to the forefront of social, political and economic agendas.

Community support: We assist local communities in their efforts to become dementia-aware and dementia-friendly.

1.3 DEMENTIA IS 'DIFFERENT'

Dementia as 'a relationship'

How people 'think' about dementia matters. The tragedy/loss/doom and gloom approach found in medical and health arenas as well as the popular press must be seen for what it is: stigmatising and life-denying. People with dementia are very much alive, and we can help people learn to communicate with them and hold them 'in life', throughout their entire life. We take the position that dementia is always a relationship, a partnership, and that all parties are of equal value and require equal if differing forms of support and assistance.

To speak of *dementia as a relationship* is to acknowledge that dementia is, first and foremost, a *social* experience, even if brought on by a medically-defined diagnosis. One person in a

social network (family, community) becomes increasingly vulnerable as a consequence of the way in which brain degeneration affects their executive functioning skills and sensory perceptions. To live well, they will increasingly need care-partners as well as family/community members who are properly *informed* and *supported*. Just as no single person can care for a small child without a social network (a 'village'), no single person can care for a person made vulnerable by dementia without a similar, viable, informed, and resourced social network. Lack of informed support cripples care partners and tears families apart.

We aim for a society in which all people are aware of the ways in which to recognise, communicate with, respond to, and support a person with dementia, regardless of whether they are understood as primary carers or people briefly encountered in the course of social life (including doctor/nurse, health professionals, police, staff in shops and cafes, etc). This is not an option, it is a necessity.

Human beings are inherently social beings. We come into being through a relationship, and we cannot survive our first day without a human relationship. Naturally, not all relationships are good, but we refer to good ones as 'connection' because connection is a wholesome recognition of our value as a fellow human being. This relational approach challenges the individualizing models of 'patient' and 'carers', as well as the overly biomedical ways in which both are understood. No form of brain degeneration is currently curable, and effective pharmacological treatments are limited; the best treatment is *quality care*.

A great deal is known about how to support dementia relationships – but very little of this knowledge is being accessed in Australia because biomedical models dominate our major research and public institutions. We do not follow – and are often unaware – of excellent 'best practice' elsewhere in the world. Our own research into alternative approaches informs our practice in *Dementia Reframed*.

Stigma is not due, as claimed by the 2019 World Alzheimer's Report **, to ignorance that dementia is a 'disease'. While it is the case that they documented health professions who thought it was a normal part of ageing, a significant source of stigma comes from medical and health professionals who know it is a disease but who do not value or want to care for a person with dementia. This impedes timely diagnosis, greatly affects quality of care, and exacerbates the burden placed on families. It also means that medical professionals, who have the power to help transform the lived experience of dementia, are not exerting enough pressure on governments to ensure this.

In saying this, we are very aware – and inspired – by those medical professionals (practitioners and researchers) who are working towards such change but they see themselves as a minority. In particular, we draw attention to a book by an Australian geriatrician that should be mandatory reading for Royal Commissioners, all doctors and any organisations offering support to people with dementia: Ludomyr Mykyta (2018) *Dementia is Different: Not Just Another Ordinary Illness*. Australian Scholarly Publishing.

Our value as persons as well as the quality of our social relationships are influenced by philosophical and social ideas, as well as economic and medical ones. Dementia challenges two ideas that are dominant in Australian society concerning human value: (1) that cognitive ability creates a hierarchy of social value, with those who have cognitive challenges being

stigmatised (including not only dementia but, for example, mental illnesses as well); and (2) that older people, especially those not employed, are of less worth. In addition to these two sources of stigma, there are other factors that increase the burden of societal worthlessness associated with dementia, including but not limited to sexism, racism, poverty and physical disability.

The medicalisation of both ageing and of dementia creates a negative space for both those experiencing cognitive decline as well as their family members. Disease and disability are overwhelmingly seen as deficits that ought to be amenable to cure. When these conditions are incurable or irreversible, people are consigned to live within the stigma of deficit. We are starting to make inroads into this with regard to physical disabilities but there is a long way to go with mental illness – and with dementia. While dementia may not be a ‘normal part of ageing’, it is most definitely a common experience of ageing. We need to challenge the mind-body split that permeates biomedical models and privileges cognition in the human experience.

1. The legacies of the philosophical mind-body split, which privileges cognition and individualism, has a major impact on medical modelling and research. This particularly affects those with mental illness and dementia. Efforts to convince people that dementia is a ‘disease’ and not mental illness do little to change the value placed on certain forms of cognition. Dementia is cognitive decline – and in medical terms this is a deficit. In social terms, it is increasing vulnerability and increasing need for care and compassion – not ignorance and hopelessness.
2. Neoliberal thinking exacerbates stigma through narrow understandings of the ‘normal’ person and the economic value of persons. Most human experiences are not being included as ‘normal’ or ‘economically valuable’.
3. Ageism is alive and well. This impacts not only on the aged who require care but also their carers, who remain barely acknowledged. Financial and social support remain negligible.
4. Central is the notion of ‘the caring society’. Dr Macdonald and Prof Mears aim to stimulate a big picture examination of these issues (ontological, philosophical, anthropological, social, medical) by bringing together an interdisciplinary group of people committed to challenging ageism, changing the negativity surrounding dementia, better supporting caregivers, and working towards a more caring society.

A common perception that death enters life through dementia should alarm us. This is evident in the negativity assumed in comments such as ‘we have lost our father’, ‘I don’t know him anymore’, ‘what a tragedy to see her like this’. The dementia space is governed by medical dispositions that constrain the options people have for thinking, not only about dementia but about the meaning of life. The contradictions are stark: we are living longer and a celebratory value is placed on the medical sciences that have made this possible. Implicitly, this is value placed on a death-defying life. There is clearly an issue in a society that assumes that not only can all illness be cured but that death itself can be resisted (cf. Macdonald 2018). Medicine limits our capacity to live well with dementia because it insists on a non-relational understanding of life. It also, again paradoxically, perpetuates the idea of the unhealthy society, even as it focuses on curing the individual. This fuels the fear of dementia.

Many terminal illnesses produce shock and grief in their diagnosis, require that someone receive care, and deny a person the prospect of living 'to a ripe old age.' Dementia is different, not because it is incurable, or might lead to an earlier death (in the case of younger-onset dementias), but because it is treated as a loss of life within life. A relational approach to dementia will counter this negativity.

A relational approach—to life not just dementia care—has as its central premise that to be human is to be a social, *relational being*. This is in opposition to individualism. 'Life' is not about whether an 'individual' is breathing, their heart is pumping or they can think and reason: the focus is on participation, shared experience, social connection. *To live is to be held in relationship*, regardless of the health of one's body (including one's brain). Connectedness and care are fundamental to human life, not just for infants, the sick, disabled, or the dying. It requires an acknowledgment that all life is inherently vulnerable and precarious. The liveable life of a person with dementia is the responsibility of everyone else in that person's environment.

A relational approach does not deny the reality and objectivity of dementia as a biomedical condition but proposes a different way of acting upon it, of shaping ways of living and dying. It thus counteracts or at least postpones the processes of disconnection that characterize dementia. It is not simply 'doing care' better. A relational approach is not merely an improvement on a person-centred approach (Macdonald 2018). It requires a moral response to seeking forms of engagement that hold people in connection. Some carers intuitively 'get this', others do not. Relationships are not techniques of interaction; a relational approach is not a strategy to include in a curriculum for health professionals.

As Rahn and colleagues (2020) note, 'Relationship-enhancing behaviours that contribute to older adults' well-being are scarcely considered in active ageing discourses despite relationship quality having been repeatedly linked to health outcomes'. While their focus is on the dyadic spouse-partnership, we argue that the relational needs of people with dementia, with any significant other in their life and especially their primary care partner, are also neglected in aged care policy.

The search for a cure for these forms of brain degeneration is clearly urgent. However, the need for financial support for this research is producing publicity campaigns that focus on the negatives of these diseases. That may attract funding but it also adds to the stigma and fear experienced by all those living within dementia partnerships. Public campaigns must focus on what we can bring to those living with dementia – and how this will contribute to a more aware and compassionate society.

'I didn't understand what we were being told – we both just went into shock. In fact, we lost a whole year being so depressed and not knowing who to talk to'.

There is a need for materials to be available to medical practitioners that assist people diagnosed with simple, accurate and *affirming* understandings of brain degeneration. The difficulties in giving this diagnosis is leading to simplifications that people are not understanding well and seeing only the negatives. While a diagnosis might understandably be met with shock and grief, no one should be led to believe there is 'nothing that can be done' or treated as if 'lost to life'. These materials should point people in the direction of post-

diagnostic supports that can assist people to live as well as is possible throughout the progression of the dementia.

RECOMMENDATION: That a relational approach to dementia and dementia care be promoted across all dementia care training.

RECOMMENDATION: That medical practitioners be provided with diagnostic material to give to people that contains a simple, accurate and affirming understanding of brain degeneration, and points to post-diagnosis support services.

RECOMMENDATION: That community education programs be introduced to present dementia in positive and affirming ways that do not fuel stigma, fear and negativity.

1.4 DEMENTIA CARE IS DIFFERENT

The understanding of 'care' that permeates the 'aged care industry' is skills and task-based. When dementia is put into the care equation, all that is added is the need to deal with 'behavioural challenges'.

- Care must be reframed back to its core meaning: care refers to a supportive, compassionate *relationship*. Care of employees, of family, of neighbours – care should reflect relationships within a caring society.
- It is essential that the very distinctive impacts on any relationship that are brought about when one person is experiencing brain degeneration are better understood and taught.
- What is required of a dementia care partner is no less than a reconceptualisation of one's understanding of oneself, of relationships, as well as of the person one is caring for.

Dementia care is different from any other form of care because one person in the relationship is constantly changing and, to care well and stay in relationship, the care partner must also change. This will challenge values, beliefs, conventional modes of relating, self-value and much more. Some carers manage this transition intuitively, a great many do not. It is the carer rather than the person cared for who is on the roller coaster ride, who is required to adjust, to challenge their own comfort zone. Currently, those around them rarely have the insight to assist and support them.

This care-demand is poorly understood by professionals and families alike, because they receive little information or training in what this entails. Our society provides many supports for young mothers with infants who cannot communicate their needs well – but almost none for those who care for adults who cannot communicate well. The results are frustration, agitation, guilt and anger on all sides.

The dementia-care relationship has to be learned. Much is known about how to do this but this is not being applied in Australia. Much of what passes for 'person-centred' care is noise when it is not conceptualised as a two-way *relationship* – the attitudes and relationship-skills of a carer are at the heart of quality in dementia care. A great deal of information needs to inform this relationship if it is to enhance rather than diminish life for all concerned.

It is common to read lists of ‘symptoms’, such as personality changes, withdrawal, memory loss, confusion, apathy. Some of these are symptoms of brain degeneration, but others are strategies of coping or avoidance, and some are reactions to the social or physical environment – such distinctions need sorting out if care is to proceed well. However, to expect a family member to deal with such changes is a huge challenge. At issue is not only the practicalities of dealing with changing modes of communication and relationship but the impact these have on the carer. This does not mean it is too much for them, but it does mean they need information and guidance. Some family members will not be able or willing to make the changes required of them. This should be acknowledged early so that alternative care strategies can be designed to help all parties to the relationship.

Although dementia care is moving to a ‘person-centred’ approach, what is meant by ‘the person’ is not well understood, and the training/support of carers (often locked into a biomedical model) in this respect is far from adequate, especially in RAC. The ‘person’ is still ‘the patient’ not a partner in a relationship which is increasingly dependent on the care-partner to enable *relationship*. This requires changed ‘care’ from its current task-orientation to a relational mode. Knowing a person’s history may help but it is the quality of relationship that is more important to holding people with dementia in connection.

RECOMMENDATION: That ‘care’ be reconceptualised so that it can move from an individualised medicalised model to a collective social and community responsibility.

RECOMMENDATION: That dementia care be conceptualised in relational terms to include all those who are part of the life of a person with dementia.

RECOMMENDATION: That accessible resources be made widely available about communicating and caring well with those with dementia, that engage with whole families (not just adults), and the wider community.

1.5 LISTENING

Research is a form of listening. As such, one might think that carers are well listened to. In this case, the vast numbers of studies into the experience of those who care at home for people with dementia, including into the ‘carer burden’ and the costs of care, should point to major improvements in the ways in which primary carers are informed and supported. Yet this huge amount of information is not translating into better practice. There are several reasons:

- There is no requirement built into the studies to turn the information gleaned into recommendations for practical outcomes, for policy or practice, nor attached funding to make this possible. Research that demonstrates engagement with organisations that can put findings into practice should be prioritized.
- Much research is done by people with no lived experience of dementia care. The research questions are researcher-based, not carer-informed. Putting ‘a carer’ on the planning committee is often tokenistic – it doesn’t necessarily result in *carer-driven research*, and does not conform to ‘*nothing about us without us*’ as best practice.

- Research questions, when concerned with dementia care, are often based on pre-existing assumptions/models about ‘dementia’ and ‘care’. This skews the outcomes and reinforces existing and unhelpfully negative paradigms.
- An ageist approach is evident in almost all dementia-related research in Australia, designed to target early career researchers. The evidence that this leads to long-term research commitment is sparse, and it negates the older voices of experience – in both research and dementia care.
- There is far too little financial investment in the experience of living within a dementia *partnership*. Carer-oriented research is often silent about the relationship with the person they care for, and vice versa.
- Compared to the amounts spent on medical research, the lived experience is allocated less than 10% of research funding. This alone makes a statement about skewed politics and social value, privileging medical research over hundreds of thousands of lived lives. The medical research is necessary – but the priorities must be reorganised.

People with a diagnosis of dementia are, and rightly so, given far more autonomy and respect than in the past. While this was an effort to move from a focus on carer to cared for, it has resulted in familial carers being sidelined. But these people are as essential to the welfare of those with the diagnosis as any medication – dementia demands that quality relationships be supported (and sometimes created) in every way possible.

People with a diagnosis of younger onset dementia (YOD) now have a significant and important public voice but the majority of people with dementia (over 90 percent) are in their ageing years and are rarely as articulate about their needs – and these needs are often very different. There must be a better balance in the public portrayal of these experiences. YOD speakers emphasise their capacities and demand to have these recognised. Their contributions have been exciting as well as influential. Older people with dementia are more often depicted as voiceless and hopeless – ageism kicks in. They can and should have a voice, even if only at times through their care partner.

RECOMMENDATION: That there be more qualitative research based on a fieldwork approach that is *relationship*-focussed.

RECOMMENDATION: That research funding opportunities be extended to local community-based initiatives, especially those that are program/outcome based; and that the social sciences in particular be encouraged to take up these themes so they are not medically-dominated.

RECOMMENDATION: That the principle of ‘nothing about us without us’ be extended to all dementia care research and that experienced and current carers lead care research.

RECOMMENDATION: That all research that involves people with dementia should also include significant care partners – such that this relationship is always valued.

RECOMMENDATION: That dementia care research opportunities be opened up to late career carers and researchers.

One outcome of apparent listening is the amount of 'advice' for carers. There is, in fact, plenty of this. It is usually generic to 'care' situations, idealistic and often impractical. This is more problematic than it might seem. Advice that people cannot translate into empowerment in their daily life can become oppressive. It leads to a great deal of the guilt that carers continually express.

This advice is usually task and activity-oriented, much of it designed to well-staffed RAC facilities not home carers. Tasks include safety, eating, avoiding falls, wiping bums, etc., but with little advice on what this means in one's own home. Activities include walks, using music, crafts – occupying a person – but without a sense of how to negotiate the washing, cleaning, bed-making, cooking and attending to visitors. This is overwhelming. What is practical is what is discussed by a support worker in a person's own home with some knowledge of what life in that home is like. Leaflets full of (helpful) advice do not work in this space. Rarely is there much about relationships, communication and dealing with constant change that is not also generic.

2. ENABLING THE DEMENTIA PARTNERSHIP AT HOME

2.1 CARING AT HOME

There is no cure for dementia at present. The best possible treatment is good care. Dementia care is not a medical issue, it is a social one.

We use the term familial carer in this submission to refer to the network of people who are involved in the care and support of a loved one with dementia. This includes primary carers (most usually a spouse/partner, daughter or son) and other family members, friends and neighbours, who assist in care or spend time with a loved one with dementia. Ideally, it requires a network of people to care for someone with dementia over time.

It is also important to recognise that we all exist within a web of relationships.. It is not just one person, with one relationship. We do not want to ignore and devalue the relationships involved by describing such carers through demeaning and sidelining terms such as informal, unpaid or substitute carers. We make a distinction only between familial carers (one of whom will usually be a primary carer) and professional carers (who receive an income for their work, and have at least some training for their role in home/day care or residential care).

Estimates of the numbers of people diagnosed with dementia who continue to live in their own homes vary from just over 70% to just over 90%. This is a significant number who want to, and manage to, remain at home. We know that people with dementia want to remain at home, among neighbours, family, and friends and at least 70 per cent currently live in their own homes. With support, most people with a diagnosis of dementia can have many years of productive life.

However, little attention is devoted to meeting the needs of those living at home and even less attention is focused on supporting familial carers. Lip service is paid to familial care as the most important and most highly valued form of dementia care but it is significantly under-resourced and undervalued. Reasons include:

- Most professionals assume that family members will not be able to cope with the challenges of dementia. This becomes a self-fulfilling prophecy, as little support or training is offered to familial carers, and home care services are inadequate and unavailable to most people (see Section 3);
- The relinquishing of social responsibility to care for our society's ageing and vulnerable people to private care providers, whether for-profit or not-for-profit, which puts a corporate focus on care, with older people being transformed into clients or consumers;
- Within an individualized, medical model, familial carers are not seen as playing an integral role in dementia care.
- Local communities are rarely seen as resources that can be effectively harnessed to support those caring at home.

Highly stressed families are expected to place their loved ones in residential care.. Research demonstrates, that once confined to residential care dementia invariably increases in severity. These institutions are understaffed, staff are inadequately trained, with little specialist training in dementia care, and have little time to spend with those they are caring for. This is normative violence: exposing a vulnerable person to erasure and exclusion, including to physical and emotional harm.

At the end of life, we all have a right to care that holds us in connection and keeps us safe— That we do not have homely, humane and welcoming places to live out our old age when we can no longer manage at home means a large number of Australians fear old age, and they especially fear old age with dementia.

There is no social investment in supporting those who care for us. Instead, carers become 'patients' themselves because the expectations placed on carers are so great. We need a very different social framework if we are to honour and care for our ageing families, friends and neighbours.

There is little commitment from governments to investing in or supporting familial carers or Home Care services Although There is much research on what is happening to dementia care partners, – there is a paucity of research focusing on listening to carers and asking what would really help them.. The knowledge is there, the carer voices are loud – but the political will to turn this into viable social strategies is lacking.

The following comment from a care partner echoes the experiences of many of a system that purports to care but does not.

My call to the Carer Gateway was referred to MyAgedCare and then to Carers NSW, who referred me to Dementia Australia. They (eventually) gave me the name of a local carer group (three suburbs away was the closest) but number didn't answer and messages weren't returned. That all took several hours over several days!

An ACAT assessor left me a pile of leaflets for home delivery of cooked meals. I didn't ask for these as I enjoy cooking but later, when I was getting so tired, I thought I would try them. But calls to three of them revealed that none of them could list the ingredients in their meals – so they were useless because of our allergy/intolerance issues.

So much time and absolutely no help. I began to think it was 'me' but I did hear similar stories from others which cheered me up.

2.2 INFORMATION AND SUPPORT

Carers with greater understanding of dementia and dementia care, as well as good support networks, are better enabled in their care roles and likely to have much reduced stress. We know that care partner training and skill-building is effective in both the provision of quality care at home and the alleviating of carer stress .

All familial carers need access to information and training that informs them about the changes that take place as dementia progresses, and they need opportunities to discuss the changing nature of relationships and share strategies to enable them to care and adapt over the long term

Dementia Reframed set up its carer website as one avenue through which carers could identify information, strategies, resources and services that they might find helpful.

Respite and counselling are currently seen as the main ways through which to provide carer support. Respite is important but it is only be one measure. Respite may be provided by day centres, residential homes or in-home. It is commonly defined as relieving the 'burden of care' – it is important to relieve this burden through continual ongoing information and support, rather than chunks of 'time out', which may only mean returning to the same burden of care or an even greater burden.

Respite can exacerbate the behaviour of people with dementia, leaving them – and their care partner – worse off. All models of respite require greater training of staff to respond well in a dementia relationship. Family cannot relax, and often have greater problems to deal with on their return from 'respite'.

For most carers, the most useful and appropriate respite services are those that support people in-home, and that respect the routines and values of that home environment.

A major issue with out-of-home respite continues to be the standard of care, and costs can also be prohibitive. There is an over-dependence on the ACAT package model, which leaves thousands of people on waiting lists with no support. Respite should be available and affordable for people without a home-care package.

Counselling may assist if it is part of a more general support strategy and does not turn the carer into the problem. Counselling will not change the stress of dementia care without information and training. One carer was offered a 'free' one-hour counselling session (by a person without dementia care experience) in response to a request for more information about how to work with behavioural changes. This is inadequate and borders on irresponsible. It does not recognise the enormous demands of dementia care, and simply contributes to the guilt that so many carers experience because they are not 'managing'.

To expect familial carers to manage with the often inappropriate support currently offered is an abuse of those who undertake this demanding form of care.

2.3 FINANCIAL AND LEGAL ISSUES

Care at home must be supported financially. Funding models need to change so that people are supported in their own homes. A for-profit nursing home can get a discount on a hi-lo adjustable bed with a pressure mattress – but not someone who needs one at home.

We need to change the language that discriminates against familial carers. It is outrageous to hear comments such as how much 'informal' or 'unpaid' care workers 'save' the government/tax payer. Familial care partners often lose employment, have to relocate to obtain services, and use all their own assets caring for a loved one – and little left to live on themselves when the partner dies. This is an unjust financial burden.

Provision for work flexibility and extended leave (similarly to parental leave) must be readily available to support primary familial carers, so they can keep working during and beyond their care responsibilities.

We need to acknowledge the physical and emotional stress of dementia care on spouse-partner in particular the experience of 'complex grief' which can persist for many months, even years, after their partner has died. This is rarely recognised, especially for people who are expected to return to work.

Professional care staff and managers of residential care, and family members, need more adequate understanding of what documents such as Power of Attorney and Guardianship papers actually empower a person to do on behalf of another. The rights of a person diagnosed with dementia cannot be taken away or ignored on the basis of a diagnosis, but only on grounds of incompetency – which must be demonstrated not assumed. A person with dementia may have good and bad times throughout a day, being very competent at times.

It is not right that a primary familial carer no longer has any say from the moment a person has died. They can be treated with disdain (e.g., by hospital staff) at this point because they no longer have rights to represented 'the deceased'.

RECOMMENDATION: That there be more community education about discussing and preparing legal (e.g., power of attorney/guardianship) and end-of-life documents so that people are aware of their advantages and limitations.

RECOMMENDATION: That families receive greater support to negotiate the legal and financial requirements that protect all parties, and helped to understand what rights these documents do and do not give them in practice.

RECOMMENDATION: That professional care staff and managers of RAC receive training in what documents such as Power of Attorney and Guardianship papers actually mean, and that the wishes and care of the person with dementia is always paramount.

RECOMMENDATION: That legal provision be made for a primary familial carer to continue to make decisions after a person has died.

The value of the person with brain degeneration, of whatever age, is diminished by the fear and stigma associated with cognitive decline and ageism, as well as the current emphasis on the economic value of citizens. Social value is measured only in terms of economic worth or cost. Australia must change this social imaginary. We must invest in *all* our people – *every* society has an approximate 50:50 mix of those who produce and those who care. This must be built into economic value and economic modelling.

RECOMMENDATION: That care - of the young, old, sick, incapacitated – not be conceptualised as a drain on the public purse and, rather, represented as an essential part of any healthy society.

RECOMMENDATION: That the national economic framework reflect the importance of care to a healthy society.

RECOMMENDATION: That the language of formal/informal or paid/unpaid care work be changed to ensure that familial carers are brought firmly into the dementia relationship and treated with respect by professionals.

Funding models need to change so that people are supported in their own homes. A for-profit nursing home can get a discount on a hi-lo adjustable bed with a pressure mattress – but not someone who needs one at home.

2.4 LOCAL, COMMUNITY-BASED INFORMATION AND SUPPORT CENTRES

The lack of information was extraordinary. Not only was it hard to identify and access services, the doctors had no idea how to assist, except for referring me to organisations that did not even operate in my (poorer) residential area. There was plenty of information about ‘the brain’ but nothing on care except generic and onerous lists of mostly patronizing and useless ‘advice’.

Communities need to be supported in building local initiatives. Knowledge about services, local knowledges, activity centres, respite, dementia-aware caf s and venues, and so on, is held locally. This is where support and resources need to be located. Local initiatives enliven local communities, and build up the broader community knowledge base essential to transforming attitudes. Local people form long-lasting networks which enable involvement with people in their communities who understand their circumstances.

RECOMMENDATION: That funding be diverted from national organisations to local community-based dementia-awareness initiatives. Local communities know what is needed and how to make this happen for their constituents.

A ‘one stop shop’ is desperately needed, with one designated social worker/case worker to navigate what is required throughout the duration of this ever changing illness. The needs of carers change in ways they cannot anticipate, and agencies are often staffed by people with no experience or specific training in dementia care, so they do not have the insight, foresight or compassion a carer requires. There is no one available with a big picture approach – and who also understands what is and is not available in one’s own locality.

I felt brutalised by the system . . . after struggling with work for a couple of years, going part time, taking leave, I had to completely suspend as I was rapidly becoming a wreck. I was grief-stricken, angry, guilty-for-being-angry, overwhelmed with the complexities of managing it all, and then totally bewildered as to how it was that I was left to be the ‘case manager’ for my husband. I stumbled around between Carers, Alzheimer’s, the gerontologist, GP, specialist GP (who misdiagnosed which meant things got worse); then there were emergency hospital admissions, delirium after an operation, wandering then escaping from hospital (after nursing staff ignored my assessment that he was in a delirium not ‘just’ expressing his dementia).

The emphasis on the 'rights' of the patient to the exclusion of consideration of my situation or opinion [as his wife] was difficult to manage.

Eventually, more or less by accident, a social worker after one of the hospital emergencies said I needed an ACAT assessment (what was that?) and booked one – and at least then there was some respite available.

Smaller, local centres staffed by case workers would solve a great many of the complexities that people find so difficult. Advice is inconsistent, information is sparse and most of it unhelpful. It is difficult to have conversations with providers who are competing for one's 'business' rather than concerned to find the best outcomes.

The hierarchical medical/health system contributes to this. Family members are often disregarded – perhaps, if the patient had cancer, they need not be involved in diagnostic and treatment advice, but in the case of dementia their knowledge is not only essential to the development of good care strategies – they are the ones who have to live with and act upon 'advice'.

Familial carers must be included in a partnership approach. They are providing most of the day to day care of all people with dementia. They should be as much a focus as the person diagnosed. Quality dementia care requires that this partnership be valued by all medical and health personnel, from day 1. Why is not possible for a spouse or daughter to speak to someone without having to fill out intrusive forms, to be signed by a solicitor, to be posted at a Post Office – all of which costs money and precious time outside the home (which means someone else has to be at home)? There is a reason why many carers do not access the meagre allowance – it is more demanding to apply for than it is worth.

Effective state-based dementia advocacy bodies have been amalgamated into an unwieldy national body that is dominating and competitive. This organisation explicitly markets itself as 'your dementia expert'. They are not dementia experts Dementia Australia should be an inclusive, cooperative and *enabling* organisation, supportive of independent initiatives and especially local ones.

The toll of caring at home care has been immense – socially, emotionally, financially. I don't regret it for a moment but I continue to resent the lack of support I received from what is simply an 'aged care industry' – divided into two camps, one which wants to avoid spending money, the other which wants to make money. I found the material from Dementia Australia unhelpful to say the least and their helpline just offered me 'counselling' as if I had 'a problem' that could be talked through – what I needed was helpful information!

Emphasis on the 'burden of care' represents, if unwittingly, a stressed carer as someone who is not coping – individualizing and medicalizing their problems, blaming carers (implicitly) rather than framing these experiences as a consequence of a lack of societal support. The carer who is 'not coping' is treated as if they have a mental illness – indeed many will develop depression, Carers become – in their own minds as well as that of others – the problem. This is also a form of societal abuse of carers.

We must invest in carers. Carers need practical information specific to dementia care, and they need continual and consistent support over time as the care relationship is continually changing. Carers need one support person to assist in accessing resources and information, and to navigate the financial and legal demands, respite and residential care options. Few

people who have not been through this experience understand how onerous even simple tasks can become.

A social worker/case worker would make all the difference. Dementia carers have a huge range of abilities, capacities for resilience, available support networks, educational and technological competence, physical and emotional health, and so on. A case worker approach is the only way to deal with them as unique individuals, building on varying strengths and needing a range of supports that will vary over time.

RECOMMENDATION: That a funding scheme be devised for each dementia partnership (person with dementia and primary care partner) that will allow for additional care support when required, respite, skills and behavioural training as and when needed, psychosocial support when needed, and that this be negotiated through a case worker and not through the current requirement to negotiate individually with competitive agencies or a range of professionals who can be hard to identify.

RECOMMENDATION: That a locally-based dementia-care trained social worker/case worker be assigned as soon after diagnosis as possible to every dementia relationship to ensure that all parties to the dementia partnership are well-informed and start putting a range of supports in place from the beginning, including negotiating the many agencies that will now fill their lives, identifying medical, financial and relationships issues, so flexible support and services can be provided before these become urgent crises.

3. EXISTING SERVICES: GREAT PEOPLE, BROKEN MODELS

3.1 HOME CARE SERVICES AND DAY CARE

The majority of care for older people is provided by informal carers, neighbours and local communities, yet the bulk of government funding is allocated to residential care. Residential aged care accounts for approximately 70 per cent, or \$12.1 billion of governments' aged care expenditure, with most of these funds being spent on compliance and buildings, not support and services. Home and community is mostly invisible, the poor relation that few care about, the Cinderella of aged care provision.

RECOMMENDATION: That 70 per cent of the governments' aged care expenditure be directed to home and community care.

How can risks inherent in home care be better managed? We need to turn this question around, to direct the majority of the funding to support those who need it most: informal carers, their families and communities. The major 'risk' those being cared for in the community are facing is neglect. Add to this the fact that most of us want to stay in our own homes for as long as possible – this is where the funding and support should go.

RECOMMENDATION: That tax relief be provided to familial carers for home adjustments, ramps, 'nursing' furniture (beds, chairs, wheelchairs, etc) for those in the workforce, and grants for those in poverty.

We know that most carers, particularly those caring for someone with dementia, live in poverty and often have major mental and physical health issues, exacerbated for those who are Indigenous, LGBTI+, CALD, those with disabilities and those living in rural areas. These disadvantages are exacerbated further if the older person has dementia - dementia care being the most difficult care of all, for the carer and the person with dementia.

The supports and services at present offered to carers, respite care, counselling, training programs are useful for only a small fraction of carers. What carer's need is support and assistance in caring day by day- helpful hints and conversations with each- those who are experiencing similar difficulties, stresses and strains.

RECOMMENDATION: That a proportion of all aged care expenditure be directed to community based support and services for those with dementia and familial carers

Both the carer and the person with dementia are in need of support – both are clients and consumers of services, not necessarily the same services but these are complementary to the needs of the dementia partnership.

RECOMMENDATION: That carers be eligible for support and services in their own right.

Exchanging information, stories, insights and hints with other carers is the most valuable support of all. We have had many people at our Dementia Reframed workshops, say, 'If I'd known that at the beginning, all our lives would have been enhanced'.

RECOMMENDATION: That community based initiatives to enable familial carers of those with dementia to exchange information and support each other, be built on and nurtured.

A social worker or care coordinator, from the local community, working out of community medical centres, should be assigned to every citizen over the age of 65 years. Many may never use or need this service but it should be there for all. A central contact person enables early identification of medical, financial and relationships issues, before it becomes an urgent crisis.

A caring society means better designed care packages, and – especially in the case of dementia - long-term planning for changing needs. This initiative should be trialled at the point of diagnosis of those dementia. GPs and Geriatricians should immediately be able to refer to just one person, who can then organise wraparound community support for the person with dementia and their prospective care partner(s).

Offer familial care partners a range of options for training and support. This training can then be extended all those who in the community who are seeking out knowledge and understanding to enable them to provide better care: GPs, care workers, all workers in allied health and social care.

How can we better achieve informed choices, reablement and relationally-centred care? This is everyone's responsibility. All of us in communities are already caring for those needing care – both as informal carers, paid care workers, GPs, pharmacists, hairdressers etc. Existing

community based initiatives need to be acknowledged, affirmed, built on encouraged and supported.

3.2 WORKFORCE ISSUES IN HOME CARE:

How can competency, continuity, attraction and retention be enhanced?

Home care workers are absolutely central, in working with and supporting those with dementia and familial carers. Care workers need to be acknowledged and fully appreciated as a crucial community support and connection to community. We need to make care a competitive and valued occupation. We all deserve this – workers and clients, and the society as a whole.

Homecare workers need paid sick leave. The recent decision not to pay the COVID supplement to home care workers is short-sighted. Care workers are putting themselves and those they are caring at great risk. The highest death rate amongst older people in Sweden, after those in care homes, was amongst care workers and older people in receipt of home care (Szebehely 2020).

RECOMMENDATION: Improve the employment and working conditions of home care workers by creating permanent positions (full time and part time), paying a living wage, with sick leave and recreation leave.

RECOMMENDATION: That opportunities be provided for further education, training and qualifications and creating career paths in the aged care sector for care workers.

Home care workers urgently want training and support to care well for those living in the community with dementia. An increasing proportion of their client groups are those with dementia who are living alone.

RECOMMENDATION: That opportunities be provided for senior care workers to become qualified and work as specialist dementia carers.

Home care workers are asking to be consistently allocated the same clients over time, so they can build relationships, know people well, and be able to monitor health and well being- and all in appropriate supports when needed. This is what those living at home, including familial carers want but providers are not responding.

RECOMMENDATION: That rosters be organised to match care workers and those receiving care to enable care workers to care for the same person over a period of time, so there is continuity of care, and care workers and older people can form productive relationships.

RECOMMENDATION: That care workers be trusted to implement agreed care plans, while enabling the care worker and the older person to vary the care plan when appropriate.

Care workers also want regular staff meetings, weekly, so they can share information and learn strategies and initiatives regarding what works and what doesn't. The opportunity to work collegially and collectively as part of a group, enables them to do a much better job.

RECOMMENDATION: That regular staff meetings be organized between care workers, to exchange ideas and solve problems.

Time to care adequately, to be able to sit and have a cup of tea and a chat with the client. Indeed, most care workers see *relationship building*, as both a central and important part of their work. When care workers are given these opportunities, they report high levels of work satisfaction. We believe this will be found to correlate highly with client satisfaction and enhanced wellbeing.

RECOMMENDATION: That time be provided for care workers to talk to and listen to older people regarding their needs, so they can tailor care accordingly

Priority should be given to a range of supports for home care workers, most of whom are women over 45, with familial caring responsibilities themselves that they juggle with their paid care work to survive (Mears and Garcia 2011).

RECOMMENDATION: Ensure care workers are supported and encouraged to deliver flexible, relationship based care, tailored to the needs of those with dementia and familial carers.

3.3 INNOVATION

What can we learn from other sectors, models and jurisdictions? Promising models include:

Support for families with autistic children (despite waiting lists) is much better than support for older people. Cancer support is also much improved – good support for carers as well as patients, community based, accessible drop-in centres, and provides models that can be used for a much greater range of care needs, including (and especially) dementia.

In these examples, this care and support builds on the increased understanding we have of autism and cancer, and attempts are made to tailor the care with an understanding of the needs of those already doing the lions share of the caring work

Can technical innovation, alternative accommodation models and workforce initiatives assist?

Technical innovation contributes to enhanced connectedness and relationship building by ensuring subsidised internet connections for all those with dementia and their carers.

This includes provision of mobile phones, tablets/IPads and so on to all those with dementia, their carers and care workers.

We need to enable easy access to Zoom and relevant social media platforms so all can participate in community from home. This is essential to deal with isolation in general as well as in situations such as the current pandemic. Access includes training.

RECOMMENDATION: That subsidised internet connections be ensured for all those with dementia, their carers and care workers, and that they be provided with mobile phones, tablets/IPads and training to facilitate use.

Alternative accommodation models include:

Increasing suitable public housing stock, particularly for those with dementia and their carers.

Alternative accommodation models are urgently needed. These must include real 'alternatives' – with priority given to small, homely and family-friendly residences which do not look like mini-hospitals, to enable people to stay in own communities.

We can look, for example to Norway, Denmark, Finland and Iceland, as countries investing in communities, building on already decent social care infrastructures.

RECOMMENDATION: That a proportion of aged care expenditure directed to home and community care be directed to local community-based support and services for those with dementia and familial carers.

4. WHAT WE LEARNT FROM COVID-19

This health crisis had revealed the world's fragility and laid bare risks we have ignored for decades: inadequate health systems; gaps in social protection; structural inequalities; environmental degradation; the climate crisis.

The pandemic has exposed fallacies and falsehoods everywhere: the lie that free markets can deliver healthcare for all, the fiction that unpaid care work is not work, the delusion that we live in a post-racist world, the myth that we are all in the same boat.

Antonio Guterres, Secretary General to the United Nations, delivering the 18th Nelson Mandela lecture, 18 July 2020

4.1 WHAT COVID-19 EXPOSED

The COVID-19 pandemic, whilst rife with tragedy, has provided many lessons that we as a society should not ignore. These issues have been placed more prominently in the spotlight over the course of the pandemic, and their adverse effects have been significantly exacerbated throughout this period. It is important to understand that:

- Whilst COVID-19 has certainly unveiled and brought more attention to problems faced by ageing Australians, it is vital that the pandemic is not seen as the cause of these issues. The many problems that COVID-19 has exacerbated have long existed within aged care, which has over time been allowed to become increasingly vulnerable to a health and economic crisis.

That crisis has been thrust upon us in the form of the coronavirus and the subsequent recession. There is no doubt that aged care's many years of decline have facilitated the extent of the problems that we have witnessed. It must also be noted that across European countries, roughly half of all COVID-19 deaths are occurring in care homes according to early figures gathered by UK-based academics (Booth 2020), highlighting just how universally susceptible aged care is to this particular crisis. Furthermore, the UK has the highest death rate of older people in care homes and home care; at least 10 times higher than any other European country. Services in the UK, as in Australia, have been brutally cut in all areas, consistent with the neoliberal

agenda. The countries that have fared the worst (in percentage of population terms not raw figures) are the most unequal (such as Australia, the UK and the US) and those that have pursued a strong neoliberal agenda, and agenda that put the economy (i.e., business interests) before people and their quality of life, throughout life. The countries that are faring far better are the more egalitarian countries, such as Norway, Finland, Iceland, Sweden, and Denmark. These are also the countries that have more quickly acted on what has been learnt, both within and beyond their borders.

Therefore:

- We must not detract from the fact that the consequences of this crisis are being predominantly experienced by those who rely upon aged care, in particular familial carers and people living with dementia.
- It is imperative that we do not allow our attention to be overly preoccupied with the plights and fears of shareholders, but instead, with the fears and concerns of the very people that we as a society have allowed to become increasingly vulnerable over the years.

The RCACQS, and COVID-19 specifically, have provided a significant opportunity to fully understand the misdirections that we as a society have taken when it comes to aged care and how we support people with dementia and their carers. **This is an opportunity that we must boldly grasp and transform into progression towards a more egalitarian and compassionate Australia.**

4.2 FAMILIAL (INFORMAL) CARERS

COVID-19 has highlighted just how vital familial carers are in our society, and how unrecognised they were prior to the pandemic. Whilst familial care was often required in residential facilities prior to COVID-19, due to extremely inadequate staffing levels and poor practices across aged care, the pandemic has put more onus upon familial carers to provide support to their loved ones, but strain in relation to how to do so.

- The increased reliance and pressure on familial carers has been especially exacerbated by the outbreaks in residential facilities, local lockdown measures which have increased isolation and limited caregiving, and virus-related fears leading to recipients of home care cancelling services.
- Furthermore, Skatssoon (2020) reported that according to a national survey, forty-one per cent of Commonwealth Health Support Program (CHSP) providers reported a reduction in inquiries and 75 per cent reported service cancellations, while 47 per cent of Home Care Package (HCP) providers reported a reduction in inquiries and 73 per cent reported service cancellations.

Due to the precarious state of aged care's staffing, and the over reliance on familial carers to fill in the gaps, there have been increasingly levels of tension over the ways that residents have been treated, particularly when visitation restrictions limit the amount of care that they can receive. This dynamic has led to an unfortunate level of tension between familial carers and aged care staff, which mitigates the capacity for proper collaboration that prioritises the needs of the residents, as well as their immediate familial carers.

Furthermore, over an eight week period from 1 March, the RCACQS received several hundred complaints about visitor restrictions and lockdowns (Egan 2020). This highlights the prominence of this issue, and provides some insight into the depth of stress that these evolving circumstances were creating amongst familial carers. However, it is important to note that we have a very limited understanding of what has been happening to older people being cared for in their own homes by familial carers and home care services during this period.

4.3 STAFFING

Over the course of the COVID-19 pandemic, the inadequate state of the aged care staffing system was exposed, as the majority of the labour force is filled by underpaid and undertrained workers, volunteers, and family members. Furthermore, 62 per cent of workers surveyed stated that they had been working unpaid hours to ensure that clients received more appropriate levels of care (Meagher, Cortis, Charlesworth and Taylor 2019). These are inadequate arrangements that the pandemic makes more precarious as infection levels rise. In the COVID-19 pandemic, the consequences of attempting to sustain an underpaid and understaffed aged care workforce has had especially noticeable consequences:

- Whilst workers across all industries are encouraged to self-isolate as soon as any symptoms emerge, aged care workers are less inclined to comply. This is due to the significant economic hardship, and precarious employment standards faced by our aged care workers, which has been exacerbated by the current state of our economy;
- Though it is imperative that we combat the spread of the virus, aged care workers may be disinclined to self-isolate due the fragility of the staffing system, and the reduced level of care that those in residential care, and in receipt of home care services, may experience as a consequence. It must be further noted that it is not uncommon for aged care staff to work across multiple facilities to sustain a living and sometimes between residential care and home care. Therefore, governments that are not committed to paying proper compensation for self-isolating workers, and to ensuring that aged care is staffed appropriately, further exacerbate the issue of workers otherwise feeling compelled to continue going to work.

The errors of not addressing these staffing issues, which have been of long-standing concern, have been a major contributor to the various outbreaks in residential facilities that we have witnessed in both New South Wales and, more recently, in Victoria. The unfortunate circumstances concerning the Anglicare Newmarch House in Western Sydney is a prominent example of these staff-origin outbreaks, where a staff member who tested positive for coronavirus had worked six shifts whilst displaying symptoms (Nguyen & Raper 2020). The pandemic has also demonstrated the consequences of over-reliance on family members to fill in labour gaps. These very gaps are susceptible to growing more unmanageable as clusters emerge, and visitation restrictions are implemented. These restrictions make it difficult for families to continue providing the care that their loved ones rely on, at the same time that, in the current climate, existing staff members, whose numbers may even be further depleted, are unable to provide the adequate support needed. This leaves older people subject to neglectful practices, such as being locked in rooms, left without a bed, provided with inadequate nutrition, and continence pads often go unchanged.

Such conditions are particularly deleterious for those with dementia. They are highly likely to both exacerbate high levels of anxiety that produce undesirable behaviours that cannot be properly addressed, as well as accelerate the progress of irreversible degeneration. This has been a major concern for both resident well-being as well as increasing family concern – and the sense of helplessness and guilt many family members already have to deal with.

The significant reliance on family members to fill in staffing gaps should not be ignored, and we should build in support for carers in a safer and more appropriate manner, as families continue to play a prominent role in providing care for their loved ones even after admission to a facility.

4.4 HYGIENE

The devastating consequences of COVID-19 across aged care has also highlighted the need for improved hygiene standards:

- The spread of the coronavirus throughout New South Wales earlier in 2020, especially in Newmarch house, reinforced the significance of having aged care facilities that are not only employing strict hygiene protocols, but that also possess a workforce that is appropriately trained to correctly use Personal Protective Equipment (PPE). By extension, this level of training and expertise, particularly in regard to use correct usage of PPE, must also be expanded to home care.

Whilst it was reported in early March that residential homes were preparing themselves for a potential outbreak (Scott, Sas and Sadler 2020), the enormous outbreaks at facilities such as Newmarch house, and many others, has highlighted the inadequacy and lack of uniformity of the approaches that were taken to ensure that all facilities were properly prepared. Furthermore, this occurred after the RCACQS issued a letter to all providers to crack down on known poor performers, further demonstrating that inadequate hygiene and infection control practices were known to exist within aged care (Egan 2020).

This lack of preparation has been observed across the Australian workforce more broadly. A UComms poll found that aside from physical distancing practice, hygiene measures and a plan to respond to positive cases were quite rare (Karp 2020). Despite the clusters that were emerging throughout aged care facilities, the Federal government did not initially implement a plan for daily testing of aged care workers (Visontay 2020), instead encouraging workers to do so if symptoms occurred. This does not address the instances where care workers may be asymptomatic and further highlights the lack of preparation and foresight that was being deployed to protect the most vulnerable people in aged care.

- It was further realised throughout this period, that many residential facilities did not have adequate outbreak protocols regarding hospital transfers (Cheu 2020). Aged and Community Services CEO Patricia Sparrow discussed not only the extremely problematic nature of expecting aged care facilities to convert themselves into Intensive Care Units, but also the underlying ageism that this suggests. Upon being tested positive, older Australians were not being provided with the necessary arrangements for appropriate healthcare.

- Leading Age Care Services Australia CEO Sean Rooney called for a more uniformed approach from the Federal government, that would ensure that all positive cases pertaining to aged care would have coordinated transfers to hospitals for safer care.

The tragic consequences of these coronavirus clusters have highlighted just how important it is that aged care facilities and home care providers have the proper capacity to respond to a health crisis. The pandemic has provided further insight into the ways that these providers' standards have been declining over the years.

4.5 ISOLATION

The lockdowns and physical distancing measures that were implemented in residential facilities, due to the extent of the COVID-19 clusters, not only perpetuated and exacerbated experiences of isolation, they also had adverse effects on the health and wellbeing of older Australians:

- The measures in question made it extremely difficult for familial carers to visit their loved ones who lived in residential facilities, which increased experiences of fear and anxiety. Furthermore, as many familial carers actively continue supporting their loved ones after admission to a facility, the isolation measures and visitor restrictions mitigated the level of care that residents were receiving. There is little doubt that, especially in the case of dementia, this will have exacerbated the rate of deterioration in their health and well-being throughout this period.
- As we have pointed out above, social interaction and meaningful relationship is of particular importance in dementia care.

The negative effects of social isolation were not only felt by residents in aged care facilities, but also by older Australians who still live at home, where they may have been recipients of home-based care. Due to the fears that the coronavirus was perpetuating, many older Australians ceased the use of home-based supports. While this may have granted a reaffirmed sense of safety, these individuals become susceptible to the negative effects of isolation.

Many older people in self isolation at home stopped home care services, and indeed, sought no outside help. Their lives were miserable. In one UK case, an older woman simply died alone: her body was not found until services resumed, a fortnight later. Many Australians have given voice to the distress this has produced for themselves as well as family members.

The impact for families of restrictions on attending funerals due to deaths in residential care has also increased the impact of grief, with little care being extended to the bereaved in such cases.

- The necessity for creative and innovative strategies to address this increasing isolation led to the utilisation of technology, which has been used to maintain some form of social engagement with older Australians, and to ensure that health monitoring could continue.

COVID-19 has solidified the need for all older people to have reliable internet connections and devices, and for services to assist them in utilising telehealth and embrace technology, in order to fill cracks in our capacity to support our most vulnerable residents (Hospital and

Health 2020). However, it must be noted that a Cochrane Rapid Review indicated that there is currently very uncertain evidence on the effectiveness of video call interventions to reduce loneliness, arguing for more rigorous studies moving forward (Noone et al 2020). Our own experience indicates that many older people were dependent on having family members available to assist them, which lockdowns often prevented.

- COVID-19 has not only reinforced the necessity of maintaining social relations in order to sustain good health, it has unveiled that we as a society must properly invest in ways to ensure that older Australians are not disproportionately affected by social isolation in such ways again. We must also remain vigilant of increasing instances of neglect and mistreatment of older persons that have emerged since isolation measures were enforced (Guterres 2020).

This notion goes to the heart of what we as a society need to do in terms of redefining our approach to aged care and dementia care more broadly, which is to recognise the true value and importance of social relations, and by extension, the necessity of care for older Australians to be based on a model of relational care.

RECOMMENDATION: That a minimum percentage of government revenue (GDP) be mandated for the provision of various models of compassionate care for all ageing Australians, in all parts of the country.

RECOMMENDATION: That lessons from this pandemic experience be taken on board as part of all facets of the provision of services to ageing Australians, including health and safety protocols; the construction of residential facilities; staffing levels and training; hospital transfers, and so on.

RECOMMENDATION: That standards of out-of-home care, that meet the concerns about staffing, hygiene and isolation, be established and mandated for all agencies and organisation taking on the responsibility to provide services for ageing Australians, and that there be an efficient means by which government both takes responsibility and is able to be called to account in monitoring these standards.

4.6 HOME CARE PREFERENCE

In the post-COVID era, it is imperative that we as a society put more onus on community expectations regarding the kinds of environments within which ageing Australians will be cared for.

- Both Research Paper 4 and Research Paper 5 released by the RCACQS have addressed such expectations, revealing that 80 per cent of 10,000 older Australians surveyed want to remain in their current home; 62 per cent want to receive care services in their own home; and only 25 per cent would prefer to live in a facility (Elgood & Phan 2020; Roy Morgan 2020).
- The effects of the COVID-19 crisis on the aged care should further encourage us to act upon what are very clear desires among older Australians, to be supported to live in their own homes where they can receive home-based care if necessary, and avoid entering residential care.

- Furthermore, these findings and the effects of the crisis have demonstrated a significant disconnect between the priorities of our policy makers, and the expectations of older Australians.
- In 2018-19, the Australian government spend nearly 66 per cent of aged care expenditure on residential aged care, with the remaining 34 per cent going towards home care and home supports (Department of Health 2019). This is already disproportionate to the number of ageing Australians living in their own homes compared with residential care.
- Thus, despite the fact that remaining at home has always been, and is becoming an even more prominent desire, this is not being reflected in government policy, which is allocating two-thirds of aged care expenditure to residential care.

In the post-COVID Australia, supporting the desire to remain at home must be at the centre of aged care policy, and by extension be reflected in levels of expenditure. The disaster pertaining to the implementation of Home Care Packages (HCP) further demonstrates that the Federal government needs to be far more dedicated to supporting people to remain at home. At the present time, more than 100,000 older Australians are waiting for their at-home care packages to be implemented. Occasional announcements of small increases in the number of packages inadequately address the enormity of this issue: each package represents a recipient as well as a family network under great stress: in other words, many thousands of people. It is significant and alarming that such a stagnating waiting list could prematurely force some into residential facilities (Visontay 2020). Furthermore, the demand for Home Care Packages could rise significantly over time: COVID-19 and the impacts felt by residential care providers are likely to compel older Australians to remain at home if at all possible.

Furthermore:

- Whilst an additional 6,100 HCPs were announced recently, this trickle makes little more than a dent in addressing this increasingly problematic situation.
- Discussions regarding HCPs cannot ignore the horrendous level of deaths that have occurred whilst people have been on the waiting list: recorded at 16,000 in the year 2017-18 (CPSA 2019). This clearly demonstrates the severe impact that our current approach is having on the lives of older Australians, and how vital it is that we alter course.

If such an abhorrent death rate had not made it explicitly clear that the deliverance of HCPs requires drastic reform, then the coronavirus pandemic and its associated consequences should be the final straw. Without urgent action, the HCP disaster may only worsen over time, particularly as the consequences of COVID-19 become more and more prominent.

RECOMMENDATION: That home care be recognised as the preference of a majority of Australians and that the current funding model be completely restructured so that it prioritises home care and makes it affordable and viable for all.

RECOMMENDATION: That home care professionals be trained and paid at rates commensurable with the high value that must be placed on their important social role.

4.7 MARKETISATION

The effects of COVID-19 on ageing Australians has further reinforced the argument against the marketisation of aged care, as well as the increased reliance on competition between providers. The coronavirus has had devastating consequences on the capacity of markets to function and to return increased profits, due to measures that have been put in place to ensure community health and safety. By allowing aged care to operate as a market, the system has become increasingly fragile over the years, and consequently severely unprepared for a health crisis, such as COVID-19. This fragility was apparent before the pandemic, but the pandemic has further exposed the fact that a system such as aged care requires strong and consistent support and investment from the state, instead of the fierce competition and marketisation that has degraded the capacity of providers to adequately care for ageing Australians, and effectively respond to the coronavirus.

Governments cannot be allowed to condone this exploitation of ageing Australians. These citizens should not be a focus for profiteering at the expense of their own well-being. Nor should government be condoning the tax avoidance of major providers or the massive shareholder wealth being generated at the expense of adequate investment in staff quality and numbers.

RECOMMENDATION: That the government fulfil its obligation to oversee all services provided by all agencies and ensure that they meet minimum standards.

RECOMMENDATION: That there be more transparency about the companies (for profit and not for profit) offering services to ageing Australians, including their Boards, their financial backing, their staffing levels, their commitment to on-going staff training, and the distribution of their profits.

RECOMMENDATION: That the government encourage and incentivise the provision of small-scale, home-like residential options for people who are unable to stay in their own homes, and that these be available in all areas, and be affordable for all.

4.8 REPEATED MISTAKES

The issues that have long existed within aged care have been exacerbated significantly over the past few months. Moving forward, we as a society must learn from the many lessons that this pandemic has presented, so that we may alter course, and make the necessary changes to ensure that ageing Australians are treated as humanely and as compassionately as possible. However, the very recent developments regarding the spread of COVID-19, especially in Victoria, demonstrate the magnitude of the change that we must commit to, and the reality that it will take quite some time to adequately learn from our mistakes, which we seem to be repeating. In Victoria, we are once again seeing more community transmissions predominantly occurring throughout aged care facilities.

- Despite the Federal government committing to providing all nursing homes across Victoria with face masks, there was still a lack of PPE provided to both home care and residential care workers. There was also an initial reluctance to move all positive cases to a hospital environment and instead opting for a case-by-case basis.

- Financial barriers are once again making workers feel disinclined to avoid work (Egan 2020), which are patterns that we initially observed in the first wave of the virus. The evolving circumstances have led to over 450 coronavirus cases in aged care across some 35 sites, a disaster which has been described as absolutely foreseeable, due to aged care's dependence on a workforce that is inadequately trained, underpaid, and highly casualised. We learnt nothing from the overwhelming international evidence regarding the vulnerability this creates for residents of aged care facilities (Alcorn & Boseley 2020).

The consequences of the second COVID-19 wave that we are observing, especially its disproportionate effects on older Australians, reinforce just how important it is that we learn from what that pandemic has demonstrated about the overall instability, and inadequacy of aged care, and how we regard older Australians.

COVID-19 has ultimately demonstrated just how urgent and vital it is that Australia commits to implementing, and sustaining, a model of care for older Australians and people with dementia that is genuinely compassionate, humane, and relational.

This submission started with our concerns about attitudes towards dementia and its care. We recognise this is unlikely to improve significantly, except at the level of tinkering, unless the entire edifice crafted as 'aged care' is radically changed. This requires radical changes regarding shared social responsibility, compassion for the vulnerable and aged, a high value placed on the social significance of care, and economic values that are socially-engaged rather than shareholder-driven. People with dementia, in particular, require a caring society – but we all deserve this in a nation that can well afford to reposition itself in this way.

Dementia is the canary in a society's coalmine: like COVID-19, it also shows how far we are from being that caring society.

5. LIST OF RECOMMENDATIONS

Recommendations made in the body of this submission are listed here under relevant headings rather than in the order in which they appear above.

5.1 FOCUS ON RELATIONALLY-BASED CARE

5.1.1 RECOMMENDATION: That 'care' be reconceptualised so that it can move from an individualised, task-oriented and medicalised model to a collective social and community responsibility.

5.1.2 RECOMMENDATION: That dementia care be conceptualised in relational terms to include all those who are part of the life of a person with dementia.

5.1.3 RECOMMENDATION: That a relational approach to dementia and dementia care be promoted across all dementia care training.

5.2 SUPPORT FOR PEOPLE DIAGNOSED AND THEIR PRIMARY CARERS

5.2.1 RECOMMENDATION: That medical practitioners be provided with diagnostic material to give to people that contains a simple, accurate and affirming understanding of brain degeneration, and points to post-diagnosis support services.

5.2.2 RECOMMENDATION: That accessible resources be made widely available about communicating and caring well with those with dementia, that engage with whole families (not just adults), and the wider community.

5.2.3 RECOMMENDATION: That a locally-based dementia-care trained social worker/case worker be assigned as soon after diagnosis as possible to every dementia relationship to ensure that all parties to the dementia partnership are well-informed and start putting a range of supports in place from the beginning, including negotiating the many agencies that will now fill their lives, and helping with family dynamics that may arise.

5.2.4 RECOMMENDATION: That families receive greater support to negotiate the legal and financial requirements that protect all parties, and helped to understand what rights these documents do and do not give them in practice.

5.2.5 RECOMMENDATION: That professional care staff and managers of RAC receive training in what documents such as Power of Attorney and Guardianship papers actually mean, and that the wishes and care of the person with dementia is always paramount.

5.2.6 RECOMMENDATION: That legal provision be made for a primary familial carer to continue to make decisions after a person has died.

5.2.7 RECOMMENDATION: That a funding scheme be devised for each dementia partnership (person with dementia and primary care partner) that will allow for additional care support when required, respite, skills and behavioural training as and when needed, psychosocial support when needed, and that this be negotiated through a case worker and

not through the current requirement to negotiate individually with competitive agencies or a range of professionals who can be hard to identify.

5.2.8 RECOMMENDATION: That tax relief be provided to familial carers for home adjustments, ramps, 'nursing' furniture (beds, chairs, wheelchairs, etc) for those in the workforce, and grants for those in poverty.

5.2.9 RECOMMENDATION: That carers be eligible for support and services in their own right.

5.2.10 RECOMMENDATION: That subsidised internet connections be ensured for all those with dementia, their carers and care workers, and that they be provided with mobile phones, tablets/IPads and training to facilitate use.

5.3 CARE WORKERS SUPPORTING PEOPLE TO AGE WELL IN THEIR OWN HOMES

5.3.1 RECOMMENDATION: That home care be recognised as the preference of a majority of Australians and that the current funding model be completely restructured so that it prioritises home care and makes it affordable and viable for all.

5.3.2 RECOMMENDATION: That home care professionals be trained and paid at rates commensurable with the high value that must be placed on their important social role.

5.3.3 RECOMMENDATION: That rosters be organised to match care workers and those receiving care to enable care workers to care for the same person over a period of time, so there is continuity of care, and care workers and older people can form productive relationships.

5.3.4 RECOMMENDATION: Ensure home care workers are supported and encouraged to deliver flexible, relationship based care, tailored to the needs of those with dementia and familial carers.

5.3.5 RECOMMENDATION: That care workers be trusted to implement agreed care plans, while enabling the care worker and the older person to vary the care plan when appropriate.

5.3.6 RECOMMENDATION: Improve the employment and working conditions of home care workers by creating permanent positions (full time and part time), paying a living wage, with sick leave and recreation leave.

5.3.7 RECOMMENDATION: That opportunities be provided for further education, training and qualifications and creating career paths in the aged care sector for care workers.

5.3.8 RECOMMENDATION: That opportunities be provided for senior care workers to become qualified and work as specialist dementia carers.

5.3.9 RECOMMENDATION: That regular staff meetings be organised between all care workers, to exchange ideas and solve problems.

5.3.10 RECOMMENDATION: That time be provided for care workers to talk to and listen to older people regarding their needs, so they can tailor care accordingly.

5.4 SUPPORT OF LOCAL, COMMUNITY-BASED INITIATIVES

5.4.1 RECOMMENDATION: That funding be diverted from national organisations to local community-based dementia-awareness initiatives. Local communities know what is needed and how to make this happen for their constituents.

5.4.2 RECOMMENDATION: That a locally-based dementia-care trained social worker/case worker be assigned as soon after diagnosis as possible to every dementia relationship to ensure that all parties to the dementia partnership are well-informed and start putting a range of supports in place from the beginning, including negotiating the many agencies that will now fill their lives, identifying medical, financial and relationships issues, so flexible support and services can be provided before these become urgent crises.

5.4.3 RECOMMENDATION: That a proportion of aged care expenditure directed to home and community care be directed to local community-based support and services for those with dementia and familial carers.

5.4.4 RECOMMENDATION: That community based initiatives to enable familial carers of those with dementia to exchange information and support each other, be built on and nurtured.

5.5 FUNDING OF RESEARCH

5.5.1 RECOMMENDATION: That there be more qualitative research based on a fieldwork approach that is *relationship*-focussed.

5.5.2 RECOMMENDATION: That research funding opportunities be extended to local community-based initiatives, especially those that are program/outcome based; and that the social sciences in particular be encouraged to take up these themes so they are not medically-dominated.

5.5.3 RECOMMENDATION: That the principle of ‘nothing about us without us’ be extended to all dementia care research and that experienced and current carers lead care research.

5.5.4 RECOMMENDATION: That all research that involves people with dementia should also include significant care partners – such that this relationship is always valued.

5.5.5 RECOMMENDATION: That dementia care research opportunities be opened up to late career carers and researchers.

5.6 POLICY AND FUNDING CHANGES REQUIRED TO SUPPORT AGEING AUSTRALIANS

5.6.1 RECOMMENDATION: That care - of the young, old, sick, incapacitated – not be conceptualised as a drain on the public purse and, rather, represented as an essential part of any healthy society.

5.6.2 RECOMMENDATION: That the national economic framework reflect the importance of care to a healthy society.

5.6.3 RECOMMENDATION: That the language of formal/informal or paid/unpaid care work be changed to ensure that familial carers are brought firmly into the dementia relationship and treated with respect by professionals.

5.6.4 RECOMMENDATION: That carers be eligible for support and services in their own right.

5.6.5 RECOMMENDATION: That tax relief be provided for home adjustments, ramps, 'nursing' furniture (beds, chairs, wheelchairs, etc) for those in the workforce, and grants for those in poverty so as to allow people to remain in their own homes.

5.6.6 RECOMMENDATION: That 70 per cent of Government aged care expenditure be directed to home and community care.

5.6.7 RECOMMENDATION: That a proportion of aged care expenditure directed to home and community care be directed to local community-based support and services for those with dementia and familial carers.

5.6.8 RECOMMENDATION: That lessons from this pandemic experience be taken on board as part of all facets of the provision of services to ageing Australians, including health and safety protocols; the construction of residential facilities; staffing levels and training; hospital transfers, and so on.

5.6.9 RECOMMENDATION: That the government encourage and incentivise the provision of small-scale, home-like residential options for people who are unable to stay in their own homes, and that these be available in all areas, and be affordable for all.

5.6.10 RECOMMENDATION: That the government fulfil its obligation to oversee all services provided by all agencies and ensure that they meet minimum standards.

5.6.11 RECOMMENDATION: That standards of out-of-home care that meet the concerns about staffing, hygiene and isolation be established and mandated for all agencies and organisation taking on the responsibility to provide services for ageing Australians, and that there be an efficient means by which government both takes responsibility and is able to be called to account in monitoring these standards.

5.6.12 RECOMMENDATION: That 70 per cent of the governments' aged care expenditure be directed to home and community care.

5.6.13 RECOMMENDATION: That a proportion of all aged care expenditure be directed to community based support and services for those with dementia and familial carers

5.6.14 RECOMMENDATION: That a minimum percentage of government revenue (GDP) be mandated for the provision of various models of compassionate care for all ageing Australians, in all parts of the country.

5.6.15 RECOMMENDATION: That there be more transparency about the companies (for profit and not for profit) offering services to ageing Australians, including their Boards, their financial backing, their staffing levels, their commitment to on-going staff training, and the distribution of their profits.

5.7 SOCIAL CHANGE TO SUPPORT CHANGE IN THE EXPERIENCE OF DEMENTIA AND DEMENTIA CARE

5.7.1 RECOMMENDATION: That community education programs be introduced to present dementia in positive and affirming ways that do not fuel stigma, fear and negativity.

5.7.2 RECOMMENDATION: That there be more community education about discussing and preparing legal (e.g., power of attorney/guardianship) and end-of-life documents so that people are aware of their advantages and limitations.

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