PUTTING OLDER PEOPLE FIRST WITHOUT PUTTING FAMILY CARERS SECOND

The building blocks of support for older Australians and their caring families

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1 INTRODUCTION

1.1 About Carers Victoria

Carers Victoria is the state-wide peak organisation representing those who provide care. We represent more than 700,000 family carers across Victoria – people caring for ageing parents, children with disabilities, and spouses with mental illness or chronic health issues.

Carers Victoria is a member of the National Network of Carers Associations, as well as the Victorian Carer Services Network. Carers Victoria is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of family carers.

Carers Victoria is a membership based organisation. Our members primarily consist of family carers, who play an important role in informing our work, contributing to advocacy and strategic aims, and distributing information more widely.

Carers Victoria has worked over many years to draw attention to the needs of family carers in both community and residential aged care and to promote the need for aged care service providers to work in a more family inclusive way. This has included:

- Developing frameworks for the assessment of family carer needs and for the practice of carer support work
- Developing resources for residential aged care facilities on family carer friendly practice
- Studying the experiences of relatives and friends of older people who live in residential aged care facilities
- Making a range of recommendations to the Department of Health and Ageing on family inclusive changes to the Aged Care Act, Principles, Standards, Guidelines for packaged care and the Charter of Resident Rights and Responsibilities
- Delivering accredited and professional development training for the aged care workforce on working effectively with family carers
- Consultations with family carers of older people about their experiences of and preferences in consumer directed care.

1.2 Summary views about the draft report on caring for older Australians

Carers Victoria supports the overall direction and many of the recommendations in the draft report particularly:

- Recognition that the majority of support and assistance for older Australians is provided by families and friends
- Acknowledgement of some of the supports needed by caring families such as counselling, information, respite, education/ capacity building, mutual support and advocacy
- Recognition that supporting family carers is central to delivering a more person centred approach
- The intention to increase the choice and control held by older people and their families.
- The proposed service continuum with no barriers to the types of services which can be accessed within the funding level
- Aged care needs assessment including separate assessment of needs of carers for dedicated services through the Australian Seniors Gateway Agency (ASGA).

However the draft report raises many questions:

- How will a market driven system respond to diverse needs of individuals and families?
- Will the proposed new aged care system develop and provide the kinds of support caring families want and need?
- How can we ensure there is a range of providers to meet the needs of all communities?
- How can a single entry point ensure that information regarding services and entitlements reaches the most isolated caring families?
- How can the new aged care system support and sustain family members or friends who do not identify themselves as carers?
- How can we help more families take up support to sustain them in the caring role?
- What level of entitlement to funding and services would ensure that an older person would not have to rely a great deal on care provided by their family?
- How can we ensure that family carers have real choices, including the choice to reduce caring tasks or stop altogether?

Carers Victoria believes:

- Relationships with friends and family are the most enduring supports for many people.
- The redevelopment of aged care services should include a focus on ongoing and preventive support and assistance to individual care situations
- The aged care system should sustain the health, well being and quality of life of both the older person and those who support and assist them
- Person centred care can be applied to families and communities, as well as to individuals
- Giving and receiving support and assistance are dynamic and developmental processes - a person centred and family focused system is required
- Person centred care can establish partnerships between the person receiving care, their families, service providers and professionals
- It is important to individualise information to people, alongside the provision of nationally consistent information
- Information provision needs to be targeted to the changing needs of individual care situations
- Person centred, family focused care should be seen as the core business of aged care service delivery both in community and residential care
- Acknowledging interdependence and reciprocity between individuals, their families and friends recognises the reality of most people's lives. It is preferable to viewing independence as "positive" and dependence as "negative"
- The support needs of family carers cannot and should not be reduced to services that resource their capacity to continue to provide care.
- The needs of family carers are as diverse and unique as the needs of older people
- Aged care and support should be matched to individual family needs and circumstances
- Combining formal and informal care should aim to ensure a good life for all

Our submission proposes a way forward in thinking about the interrelated needs of older people and their carers. It presents:

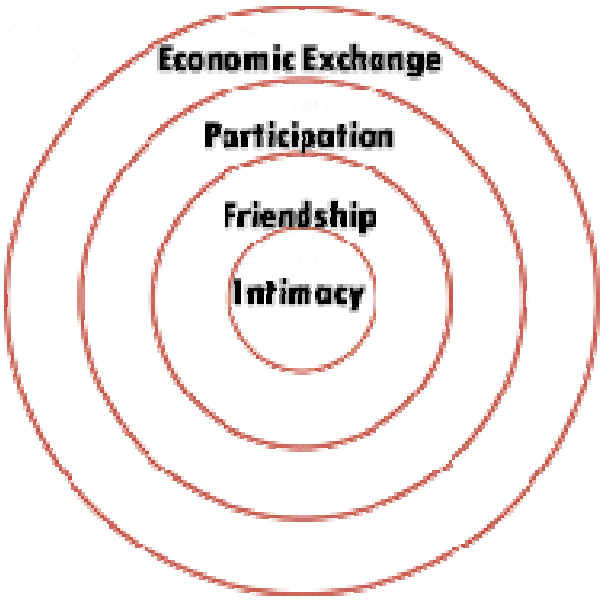
- A rationale for the need to focus on older people and their caring families
- Issues in access to the Gateway
- A framework for assessing the needs of caring families
- Building blocks of support for caring families of older people at home and in residential aged care.
- Questions about reliance on the market
- Questions about the role of peak bodies.

2 A FOCUS ON OLDER PEOPLE AND THEIR CARING FAMILIES

Caring families have the person with care needs at their centre and include all those family members and friends who care about the person and who may provide support and assistance for them. A focus on caring families recognises the interdependence of needs, particularly between the person with care needs and any primary carer. Importantly, it also recognises other family members who provide direct support for both the person with care needs and for the primary carer (if any)

2.1 Circles of support

Circles of support are a useful concept for understanding the different relationships and connections between a person with support needs and others in their life:



Source: www.capacitythinking.org.uk

Circle of intimacy
This is the innermost circle and includes the people closest to the older person.
This may include a spouse/partner, other close family members and/or very close friends.

Circle of friendship
The second circle includes others with whom the older person has a relationship of trust but who are not within first circle.

Circle of participation
The third circle includes people with whom the older person commonly interacts such as people met through work, social clubs, volunteering etc and “friends of friends”.

Circle of exchange
The outer circle includes all the people who are paid to be in the life of the older person - either directly or because they provide a service. This includes doctors, hairdressers and plumbers. Most paid support workers fit within this circle.

2.2 Interdependence in caring relationships

The reality of the lived experience of older people with a disability or chronic illness is that most are both cared for and cared about by family and friends. Most of the support and assistance they receive (80 %) is from unpaid carers. Rich and long term relationships, mutual support and interdependence are common.

A focus on older people as being “independent” or “dependent” ignores the realties of many people’s lives and does not adequately capture reciprocity and dynamic changes in caring journeys within families.

Carer needs have become narrowly defined and there is frequently a lack of distinction in carer policy between “caring about” someone (the relational aspects of care) and “caring for” someone (the functional aspects of care).

A focus on the separate support needs of family carers over the last two decades is partially a consequence of inadequate and rationed services for people with care needs. Adequate support services for a person who needs support and assistance can create a “respite effect”. It can relieve families from a range of care tasks, help to share the care and support caring families to maintain care at home.

A shift to an entitlement approach to the care of older Australians and their families is an opportunity to:

- Bring the focus back to the interrelated needs of older people and their families
- Reduce competition for resources and support between individuals and families
- Design an aged care system that is both person centred and family focused

Much can be achieved by reviewing the current guidelines for community packaged care such as Community Aged Care Packages and EACH. Currently they are person centred and aim to preserve the autonomy of and provide support to the older person who needs assistance and support. However, they fail to:

- Consider the older person in the context of their relationships with families and friends
- Promote assessing and addressing the needs of caring families
- Support the need for caring families to negotiate and plan together with the older person how the need for care and support and other personal and family needs can best be met
- Encourage family strategies to combine formal and informal care or to share informal care.

2.3 Carers Victoria recommends

That the Productivity Commission promotes the interdependence of caring families and recommends:

- The development of family carer inclusive guidelines for individual support funding entitlements
- That care planning occurs as a partnership between caring families and vulnerable older people on entry to care and at key points of transition.

3 ISSUES IN ACCESS TO THE GATEWAY

The Australian Seniors Gateway Agency (ASGA) is central to the delivery of a single point of entry, nationally consistent information and comprehensive needs assessment services. It will also be essential to determine care entitlements and to organise financial means and assets assessment.

Carers Victoria supports this recommendation. Navigating "the maze" of aged care is currently very problematic for older people and their caring families. However the reality is that entry to aged care services is often crisis driven. Not all aged care consumers have a view that formal services will support them to achieve goals of independence and stay at home. Older people and their families may be fearful that formal services will "take over", leading to a loss of independence and the older person being encouraged into residential care. There are two key assumptions that need to be addressed:

- That prospective consumers will identify that they may have aged care and support needs and initiate contact with the ASGA
- That nationally consistent information will meet the needs of diverse consumers.

3.1 Carers Victoria recommends

That equity of access to the aged care system is addressed. This may include:

- Ensuring the provision of funds for outreach services by specialist provider agencies (e.g. ethno-specific organisations and carer services). These will engage with and ensure that the most isolated and hidden caring families are encouraged to engage with the ASGA
- Supported access to and advocacy with the ASGA via these specialist agencies
- Specialist agency provision of information individualised to the needs of the caring family through access to case management.

4 ASSESSMENT OF FAMILY CARER NEEDS IN THE GATEWAY

The draft report on the care of older Australians proposes a needs assessment framework to establish the needs of older Australians via a nationally consistent aged care needs assessment instrument. It also recommends a separate assessment for carers 'for dedicated services' and their subsequent referral to carer support centres.

Carers Victoria supports the recommendation that carer assessment be a key role of the ASGA. Carers Victoria has made a number of recommendations in the past about improving the focus on carer needs in aged care assessment. Comprehensive needs assessment is essential to the delivery of more person centred, family focused care and to ensuring preventive support and assistance. However the draft report presents a functional view of carer assessment. It proposes that the Gateway assessors will assess the capacity of the carer to provide ongoing support rather than assessing the needs of the care situation.

4.1 Carers Victoria recommends

That assessment should focus on the care relationship:

- The needs of the family carer and older person should be equally considered
- Services should aim to support them both
- The different needs and priorities of the family carer and older person should be acknowledged, negotiated and made explicit.

The diagram below outlines the components of a comprehensive assessment:

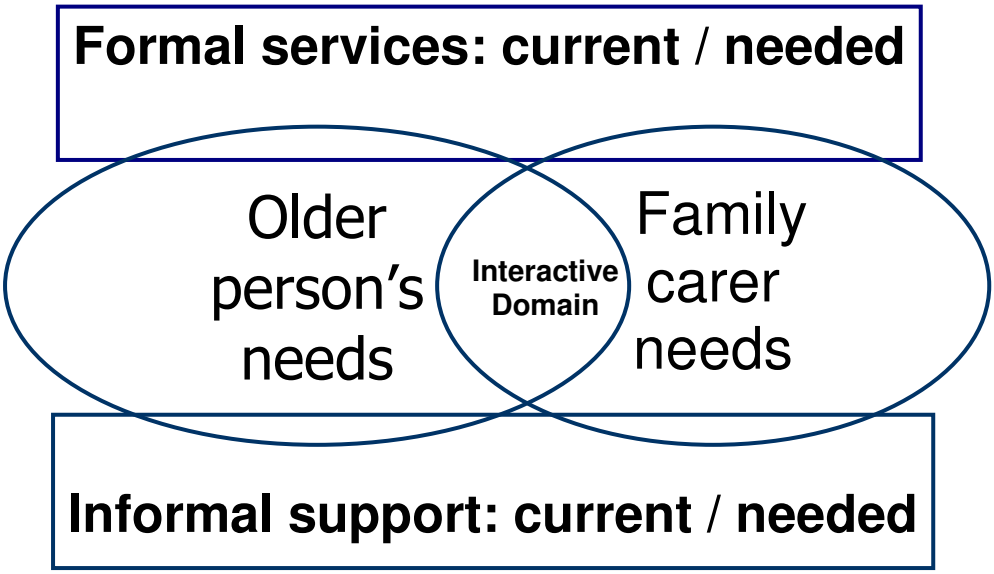


Figure 1: Comprehensive assessment of the care relationship

A focus on needs jointly and separately as well as the capacity of formal and informal supports to the older person, the family carer and the care relationship provides a starting point to address tensions and risks in the care situation that may arise from divergent needs. For example when:

- An older person may be reluctant to engage with formal services from "strangers" preferring family care
- Their family carer may not be in a position to provide all of the support and assistance needed.

It will be important for many caring families to have access to face to face assessment. Telephone or online (self) assessment is only appropriate at the screening level for most older people and their families. Many current clients of aged care services do not have the required level of language, health or computer literacy to be able to engage effectively at this level. Skilled assessors are particularly needed to assist in drawing out circumstances and needs that may require a preventative approach. However future generations may have more knowledgeable and assertive health and aged care consumers.

4.2 Carers Victoria recommends

That older people and their family carers are offered separate needs assessment to enable each the opportunity of an honest appraisal of their own needs and issues. Family carers can feel particularly constrained discussing someone's declining abilities and their own ability and willingness to provide care in the presence of the older person.

4.3 Recommended domains for assessment of family carer needs:

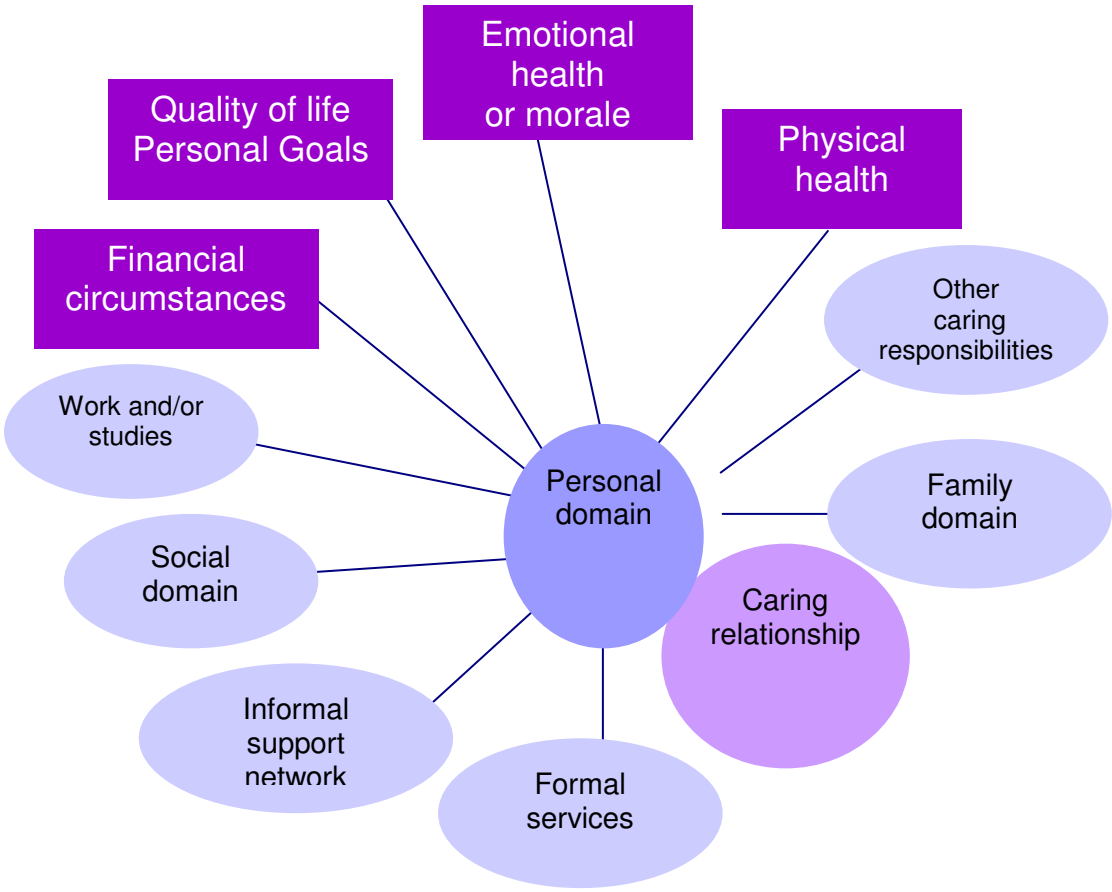


Figure 2: A conceptual model of carer needs assessment

Considerations for each domain:

Oval shapes represent interactions between the family carer's life and caring experiences:

- **Personal domain** includes the family carer's demographic details including cultural background and language(s) spoken
- **Caring relationship domain** includes the history and quality of the personal and care relationship as well as caring tasks and responsibilities
- **Family domain** includes relationships with other family members including family members who provide direct support for both the person with care needs and for the primary carer (if any)
- **Other care responsibilities domain** includes care of other older people, children and adults with a disability, mental or chronic illness as well as regular care of children or grandchildren
- **Work and/or studies domain** includes current employment/study commitments as well as goals to undertake these
- **Social domain** includes friendships, community involvement and recreational/leisure interests

- **Informal support network domain** includes neighbours, colleagues, community and faith based groups
- **Formal services domain** includes the caring family's satisfaction with the support currently used (if any).

Rectangle shapes represent the family carer's personal resources and responses to the caring role:

- **Physical health domain** includes any health condition, disability, chronic illness or injury risk which may affect the capacity of the carer to provide support and assistance
- **Emotional health or morale** domain includes satisfaction, confidence and sense of control in the care situation as well as any feelings of depression, anxiety, grief and guilt
- **Quality of life and personal goals domain** includes the hopes, plans and worries about the future including for life after caring
- **Financial circumstances domain** includes any loss of income, costs of caring, access to concessions and benefits and any legal or financial arrangements.

Gateway assessors will need to establish:

- What are things like now for the family carer in each relevant life domain?
- Have there been major changes since taking on a caring role? What are they? What is their impact?
- How does the family feel about the current situation?
- If there are difficulties, what does the family see are ways of bringing about positive change?

Comprehensive assessment of family carer needs will also highlight any potential risks to the continuation of the care relationship which result from:

- Deterioration in family carer health and wellbeing
- High intensity care (e.g. behaviours of concern/high medical needs)
- Lengthy duration of the caring role (e.g. more than five years)
- Multiple care responsibilities
- Isolated caring with little access to informal or formal support or roles outside caring.
- Conflict within the care relationship.

4.4 Carers Victoria recommends

The following indicators for assessment or re-assessment of the caring family:

- At the point of identification of older person's care needs/diagnosis of condition
- Early signs of stress in the care relationship
- All high intensity care situations
- Any health or behaviour changes in the older person or family carer
- Any major changes in family circumstances
- On transition to residential aged care.

5 CARING FOR OLDER AUSTRALIANS AT HOME

5.1 The need for a preventative approach to addressing the needs of caring families

The Commission has been presented with substantial evidence from many sources concerning:

- Poor family carer health and well being (Cummins 2007; Gill 2007, Grey, Edwards et al 2007)
- Higher rates of disability or chronic illness in family carers (ABS, SDAC 2004, Gill, 2007
- Strained relationships (ABS, SDAC, 2004)
- Reduced opportunity for workforce participation (Taskforce on Care Costs 2007)
- Financial disadvantage and financial stress often compounded by the caring role (over 50% of carers in lowest 2 income quintiles; NATSEM, Access Economics)

The Commission has recognised the substantial contribution of caring families and the estimated replacement cost of their unpaid care. However, the Commission outlines a limited view of family carers as resources who require services that aim to support their capacity to continue to care for older Australians at home. This limits consideration of a broader range of family supports which are needed to prevent family carer stress, family breakdown or premature entry into residential care.

A more preventative focus on family support is needed. It will enable families to undertake the caring journey without compromising their physical and emotional health, wellbeing and participation in life outside of caring.

5.2 A building block approach to the support needs of caring families

Carers Victoria supports a building block approach (Draft Report Fig 3, p.xxix) to assessing and delivering entitlements to aged care and support, with different levels of support available at basic care and complex care levels that can offer preventative support for emerging needs as well as additional entitlements for higher intensity care.

Carers Victoria has analysed the 4 main classification model options contained in Appendix B: New aged care model options. We recommend Model 4: Layered Funding Model as the model with the most preventative approach to the needs of older Australians and the most scope for enhancement to build a more family focused care and support entitlement.

Model 4 includes:

- **Base subsidy** covering IADL and PADL items from low to very high

- Layered **Care Supplements** covering specialist areas (e.g. dementia/behaviour/mental health/health/nursing/continence/palliative care/rehabilitation)

- **Care Supports** which can be provided with all Base and Supplement combinations:
    - Aids and equipment
    - Home modifications
    - Special needs groups
    - Carer supports
    - Respite needs
    - Restorative needs
    - Community transport
    - Social inclusion activities.

5.3 Family focused Care Supplements

Model 4 proposes that layered Care Supplements should apply to care needs that are high incidence and place the older person at risk of residential care.

5.4 Carers Victoria recommends

That access to Care Supplements should also apply in the following situations where the care situation may be at risk:

- Families who have multiple care responsibilities
- Family carers with their own health or disability needs
- Family carers who have little or no extended family or other informal support
- Families who experience conflict.

Family care risk situations can be common (e.g. 25% of family carers have care responsibility for more than one person, (SDAC 2004) and carers are significantly more likely to have chronic conditions when compared to non-carers. (Gill et al 2007). They also place the continuation of care at home at risk.

5.5 Carers Victoria recommends

That risks to family care are identified at assessment and followed by the application of an additional Care Supplement. This will reduce the risks of:

- Further harm to the carer's physical or emotional health
- Breakdown of the care situation
- Premature entry of the older person into residential aged care.

5.6 Family focused Care Supports

Care Supports are identified as areas of need that are not always directly related to functional impairments or conditions of the older person such as home modifications, aids and equipment and carer support. However Carers Victoria acknowledges that both older people and their family carers may have needs related to:

- Information and education about the health condition and it's management
- Peer support – both individually and in groups
- Emotional support and counselling to develop coping skills and deal with change, loss and grief.

These are not just supports for carers.

5.7 Carers Victoria recommends

That the Commission consider an entitlement for both older people and family carers to choose these services.

5.8 Family focused transition Care Supports

The transition support needs of caring families range from those required well before any caring role has commenced and continue after the older person has entered residential aged care and after the older person had died:

- Pre caring, families require support to make plans for future care arrangements
- On transition into caring, families require support to make choices about how the older person can be best supported through both informal and formal support
- Caring families where the older person or carer has increasing needs require regular reassessment of how well formal supports are working for them
- Families caring for an older person where rehabilitation/restoration occurs need to feel confident they can re-engage with support at any time their needs increase

- Families experiencing fluctuating support needs require flexible, responsive services for the higher needs period
- Families experiencing a crisis in care require a rapid response followed by reassessment of needs and services
- Families caring through the transition into residential aged care require support to negotiate how they wish to continue to be involved in care
- Families who are bereaved require support to adjust to the loss of the caring relationship and to re-establish a new life role.

5.9 Carers Victoria recommends

That caring families receive an entitlement to a range of additional time limited practical and emotional Transition Care Supports at times of key transition in their caring journeys. Such a scheme will ensure that resources are available for the provision of early intervention support and assistance at key times of change. Access to short term transition support can ensure older people and their families can regroup and reach a new equilibrium.

Please refer to Appendix 1: Transition support needs for diverse caring journeys, for a more detailed outline of the recommended practical and emotional supports through key transitions.

5.10 Carers Victoria recommends

That the Commission financially model a layered approach to entitlement that is inclusive of:
- Care Supplements for identified risks to family care, identified at assessment and
- Family focused Transition Care Support.

Financial modelling need to be inclusive of both short term care coordination as a proposed function of the Gateway and longer term case management support for caring families delivered by approved service providers.

5.11 Carers Victoria recommends

That the modelling is inclusive of the interface between the Commission's recommendations for disability care and support and recommendations for care of older Australians. As the following case studies illustrate, caring families whose needs can be poorly met by the current system(s) may have an improved experience under an individual funding entitlement system. It is our view that any additional individual support needs that arise as the carer's needs or availability change should be met by the funding system(s) that provide the majority of support for that individual. There may also be the opportunity for caring families with multiple care responsibilities to pool funding from different sources in order to develop individualised supports for their unique family needs.

Case study 1: Multiple caring responsibility

Angela cares for her teenaged son with an intellectual disability (Bruno) and is in the paid workforce. She also commences caring first for one parent (Carlo) and then the other (Daniela).
How family focused support could work:
- Angela would already be identified as a family carer of Bruno through the disability care and support system. Daniela is also recognised as having provided support over many years for both Angela and Bruno
- On commencement of Carlo's care needs, Angela notifies the NDIA of her additional care responsibility and gives permission for her details to be forwarded to the ASGA. This will reduce duplication of assessment
- Bruno's support needs are assessed and Daniela's needs as both an older person and as a carer are also assessed

- The NDIA approves an additional support entitlement for Bruno for the duration of Angela's multiple caring role
- Aged care service providers for Carlo are aware that both Daniela and Angela support Carlo and involve them in all care planning and delivery
- Both also receive support with the transition of Carlo to residential aged care
- On commencement of Daniela's care needs, the ASGA again assesses Angela's needs as a non-co-resident carer who has other care responsibility and workforce participation needs
- Aged care service providers for Daniela involve Angela in all care planning and delivery
- As Angela once again has multiple care responsibility she contacts the NDIA which approves an additional support entitlement for Bruno for the duration of her multiple caring role
- On the deaths of Carlo and Daniela, both Angela and Bruno receive bereavement support.

Case study 2: Ageing parent carer

Zarah is an older parent carer of her middle aged daughter, Yildiz who has psychiatric and sensory disabilities.
How family focused support could work:

- Zarah would already be identified as a family carer of Yildiz through the disability care and support system
- Zarah's emerging aged care and support needs are identified in a periodic review by the NDIA of older parent carers
- Zarah gives permission for her details to be forwarded to the ASGA. This will reduce duplication of assessment
- The ASGA assesses Zarah's aged care and support needs and supports her to engage with formal services. The current provider of disability care and support for Yildiz may provide additional services or act as a lead agency engaging another provider. The ASGA also provides feedback to the NDIA on the outcome of the assessment
- The ASGA also assesses Yildiz's needs as a carer after recognising that she now performs a range of household tasks formerly provided by Zarah and that she is an important source of companionship for her mother.
- When Zarah falls at home and breaks her hip, the NDIA approves an additional support entitlement for Yildiz for the duration of Zarah's hospitalisation, rehabilitation and recovery at home
- When Zarah dies suddenly from complications of her injury, Yildiz receives appropriate crisis and bereavement support and her capacity to remain living alone in the family home with additional support is assessed by the NDIA

Case study 3: Co-caring by partners

Mary is an older woman with severe rheumatoid arthritis. Her partner Morag has been diagnosed with dementia.
How family focused support could work:

- Mary's care and support needs emerged first and Morag has been caring for her. They receive aged care services such as home modification, aids and equipment, transport and house cleaning
- On confirmation of Morag's diagnosis, the ASGA assesses both Mary and Morag's needs as carers for each other
- Both receive information, education and counselling related to loss and grief and living with dementia

- As both have increasing needs they receive case management support and regular re-assessment of needs
- When Mary needs to go to hospital to have surgery, the ASGA approves an additional support entitlement for Morag for the duration of Mary's hospitalisation, rehabilitation and recovery at home
- Mary receives additional education and support with responding to the psychological and behavioural symptoms of dementia
- Mary and Morag are supported to find a residential aged facility that is suitable to both their needs
- Morag receives appropriate palliative care in the residential aged care facility and Mary receives family support through both end of life care and bereavement.

6 THE COMPLEX ISSUE OF RESPITE

The Commission anticipates that the Carer Recognition Act (2010) and National Carer Strategy will address the reforms needed in the provision of respite care and family support. Whether this occurs remains uncertain.

Carers Victoria is aware that there is poor availability of data concerning unmet demand for a variety of aged care supports. However, we are concerned that the calculations of the future costs of aged care by the Commission are based on the current mix of service types. As such they do not address unmet or partially met need for respite and family support services.

Currently aged respite care funds (Commonwealth Department of Health and Ageing) are directed to:

- National Respite for Carers Program (about $200 M nationally) estimated to be only 6.3% of real government expenditure on community aged care and 1.8% of all government aged care expenditure. (Productivity Commission report on Government Services, 2011). This equates to an average annual cost of $1,520 per carer
- Respite care under the HACC program - an average of a little over one hour of care per week for each older HACC client receiving respite care
- Veteran's Home Care – an average of $1,890 per eligible client
- Residential respite care – an average of 30 days per year at an average cost of $3,480 per respite recipient

The current system of respite and family support for older people is highly rationed:

- Only about a quarter (27%) of people approved for residential respite care actually use it within 12 months of their approval (AIHW 2010)
- A developing system of local cottage based facility based respite services is attractive to older people and their families but not widely or universally available
- Planned activity group and social support programs in HACC must tightly ration access. Most programs are not funded to support older people needing high intensity care
- In home respite through the HACC program is tightly rationed with a significant gap between demand and supply. In home overnight care is very difficult to access even in an emergency
- The limited funds available to Commonwealth Respite and Carelink Centres can mean that family support is limited to occasional, episodic and emergency care, rather than ongoing, regular and predictable support.

Traditional models of respite services have been targeted to relieving family carer stress and "burden" This has created significant barriers to usage due to:

- Family carers feelings and past experiences with respite
- Older people's reluctance to use some forms of respite
- Inappropriate, inflexible and poor quality respite services

The combination of these three factors can mean that the respite care experience may be less than satisfactory, and is only used as a last resort (Newman et al (1997) cited in Doyle 2008).

6.1 Respite care as family support

The paradox of respite care is that it is usually a service provided to the older person but is viewed in policy terms as a support for carers. An alternative definition of respite from the Victorian Carer Services Network provides a means of encompassing this dual focus:

> *"Respite is support and assistance to people in a care relationship that enables them both to participate in the community"*

Carers Victoria considers that respite should be seen as an outcome rather than a service type. A wide variety of formal services such as regular personal care, social support, delivered meals, domestic assistance and social participation provide a respite effect for older people and their families. An entitlement approach to the needs of older people which aims to ensure that more of their aged care and support needs can be met by formal service delivery will create a "respite effect" which will benefit many families.

Other family supports such as regular breaks must be delivered flexibly to meet the diverse needs of caring families. At a minimum, respite care must be able to be provided by staff with adequate training to perform the tasks usually performed by family carers including behaviour support, personal care tasks and medication administration.

6.2 Models of respite care and family support

Service delivery models need to include the following range of choices for caring families:

- Regular planned in home individual support for the older person, including outside business hours support
- Occasional extra in home support for attendance by family carers at special events that the older person may be unable to participate in
- Regular planned individual community access support for the older person to participate in social and recreational activities
- Support for the older person to participate in small group outings with other people
- Regular attendance in the home of a support worker by a small group of older people, particularly those with dementia (host home model)
- Regular or occasional attendance at day centres, planned activity groups and "cafés" for older people including those with higher support needs
- Occasional weekends away or other short breaks for the older person and their family carer to attend together with respite staff support provided as required on location
- Regular or occasional overnight care in a familiar environment for the older person (cottage style respite care)
- Regular or occasional respite care in a residential aged care facility, particularly for those caring families contemplating permanent residential care placement
- Emergency care provided when a crisis in a family's situation temporarily overwhelms their capacity to provide care. Care provided to the older person would preferably follow a previously prepared emergency care plan
- Additional amounts or combinations of all of the above supports that are tailored to provide appropriate substitute care of the older person whilst a family carer participates in paid employment

The viability of group activities may require a block funded approach rather than pooling of individual funding entitlements or at least a realistic operational subsidy that is "topped up" with individual entitlement funding and co-payments.

6.3 A respite/family support entitlement

6.4 Carers Victoria recommends

That caring families receive a minimum entitlement to family support (respite) funding to be used flexibly for a range of the above family supports. In today's figures, this would ranges from approximately $4,500 for basic care to high level funding at approximately $11,500 for more intensive care situations.*

It is further recommended that the current entitlement of 63 days of subsidised residential respite based on assessed level of need be retained in a reformed aged care system. Carers Victoria is aware of some submissions recommending the "cashing out" of the Carer Allowance in order to fund additional formal support (respite) services for older Australians. This would release an estimated $480+M based on Commonwealth expenditure in 2008-09.

However, given the low income status of 50% of caring families and their lack of capacity to participate in the paid workforce, the Carer Allowance currently provides a vital income supplement that assists with meeting the higher costs of living with illness/disability and providing care at home. It is unclear that cashing out Carer Allowance would actually enable older people and their families to meet these costs and reduce the need for older Australians to rely on unpaid family care.

6.5 Carers Victoria recommends

That any changes to income support or supplementation for caring families should be part of a broader review of pensions and/or the social security system.

6.6 Addressing workforce participation by family carers

The draft report encourages carer participation in paid employment but does not indicate a commitment to funding and developing appropriate substitute care for older people to enable family carers to participate in study or paid work. Better support to help carers work is a high level goal of the National Carer Strategy, but the Strategy cannot deliver an aged care infrastructure to enable the delivery of services that support both work and care.

The projected increasing gap between the demand for and supply of unpaid family carers indicates the importance of developing services to support and enable family carers who wish to, to participate in the paid workforce whilst also providing care.

6.7 Carers Victoria recommends

That the Commission make specific recommendations to address the need for carers to participate in the paid workforce. This includes:

- A recommendation to the federal Government to amend the Fair Work Act to allow all employees with care responsibilities the right to request flexible working arrangements
- Recommended entitlement to a range of family supports which provide appropriate substitute care of the older person whilst a family carer participates in paid employment

* Figures calculated based on current residential low level respite subsidy of $37.03 + $32.36 respite supplement = $69.39 x 63 days = $4,371.57 and current high level respite subsidy of $103.81 + $77.19 respite supplement = $181 x 63 days = $11,403)

Financial modelling of alternative service types together with combinations of government subsidy and co-payments will be required to ensure substitute care is an affordable and realistic alternative for family carers. It will encourage their ongoing participation in the shrinking paid workforce, and reduce the demand for income support payments. For some caring families it will ensure that poverty is avoided and that resources such as superannuation are available for the future.

6.8 Health outcomes of respite care

It is important that respite care is not considered in isolation from the broader health and aged care system that aims to achieve improved health outcomes for older people and their caring families. In the UK, Arksey (2004) proposed the Effective Respite Pyramid as a way of identifying the key factors that are needed to provide effective respite that supports care relationships and desired outcomes for both older people and family carers. Underpinning factors form the base tier. The second tier shows the key deliverables of effective respite care. Where both tiers of the pyramid exist, people in care relationships are more likely to receive support which maintains or improves their health, well-being or quality of life:

<table>
<tr><td colspan="8">Outcome Sought

Maintenance or improvement of the carer's health, well-being and/or quality of life</td></tr>
<tr><td colspan="8">Effective respite services and short-term breaks are:</td></tr>
<tr><td>Based on assessment and on-going review</td><td>Appropriate to the needs and circumstances of the carer</td><td colspan="2">Appropriate to the age, culture, condition and stage of the illness of the care recipient</td><td>Able to maintain of improve the well being of the care recipient</td><td colspan="2">Delivered by appropriately trained and caring staff</td><td>Affordable to the carer</td></tr>
<tr><td colspan="8">Effective respite services and short-term breaks are underpinned by:</td></tr>
<tr><td>Knowledgeable and supportive doctors</td><td>Appropriate management of the condition (e.g. medication and equipment)</td><td>Responsive social services</td><td>Accessible information</td><td>Fair and understandable benefits system</td><td>Well coordinated services</td><td>Supportive carers' networks</td><td>Helpful family, friends and neighbours</td></tr>
</table>

Figure 3: Effective Respite Pyramid (Arksey 2004)

6.9 Carers Victoria recommends

That the Commission defines respite care as more than a break from caring. Respite care and family support should be seen as a means of promoting the health and wellbeing of both the older person and their family carer.

7 CARING FOR OLDER AUSTRALIANS IN RESIDENTIAL AGED CARE

7.1 The need for protection for family carers residing in the family home after the older person enters residential care

Under current rules set by the Department of Health and Ageing (DoHA) the value of a resident's former home will not be counted as an asset if, at the time of the assets assessment or the date of entry into residential aged care (whichever is earlier):

- the partner or dependent child is living there
- a carer *eligible* for an income support payment has lived there for at least two years
- a close relative who is *eligible* for an income support payment has been living there for at least five years

This provides protection for a co-resident family carer's place of residence at the time of the older person's entry to residential aged care. However, Centrelink re-applies the assets test after two years for the purposes of assessing the resident's eligibility for the aged pension. Even if only assessed on their half share of joint assets, this can have the effect of the resident losing eligibility for a full or part aged pension, therefore increasing the daily care charge. Families may then need to sell the family home in order to afford this. This is even more likely if the family carer remaining in the home is not one of the owners of the family home. Few families appear to be informed about or make use of the hardship provisions through Centrelink.

There are no protections at all for family carers residing in the family home in the draft recommendations. There appears to be an assumption that the "family home" is the asset of one person as opposed to a joint asset. Where a home is a joint asset, it will not be appropriate to sell it for the purposes of purchasing an Australian Pensioners Bond. The proposed Aged Care Equity Release Scheme will only be able to release the aged care resident's half share (or other proportion in the case of tenants in common) of the value. Given their unpaid care contribution, family carers must not be further financially disadvantaged in housing or in access to assets in order to pay for their own aged care services when the time comes.

7.2 Carers Victoria recommends

That the Commission recommend that the current protections of the family home from the assets test remain and that the requirement for Centrelink to re-apply the assets test after 2 years is removed in the case of family carers or adult sons/daughters with a disability who continue to reside in the family home.

7.3 Minimum standard of accommodation in residential care

The older person requires the dignity and privacy of a single room in what for many will be their last home. This should rightly be a different standard than for hospitals where care is more usually provided in a shared ward. The continuation of intimate personal and family relationships requires private space, as does the provision of quality end of life care.

7.4 Carers Victoria recommends

That the minimum standard of accommodation provided in residential aged care should be a single bed room, with either dedicated en-suite or with shared en-suite between a maximum of two rooms. There should not be a different minimum standard for supported residents and residents who have means.

7.5 Lack of family inclusion in residential aged care

Family caring does not stop when an older person enters residential aged care, but it does change. The active and positive involvement of family and friend carers in supporting their relative is a strong guarantee of the resident's wellbeing (Haesler et al 2007). Yet many friends and relatives find the experience of being involved in residential aged care complex, stressful and difficult to negotiate (Carers Victoria 2007). The Commission has made a range of recommendations to reform the funding and delivery of residential aged care. Consideration of the role of family carers is limited to community aged care.

The Commission has an opportunity to make recommendations for an improved framework for partnerships with, and inclusion of, family carers in residential aged care facility standards and practices.

7.6 Carers Victoria recommends

That family carer inclusive policy and program guidelines should be the responsibility of the Department of Health and Ageing with monitoring by the re-governed Aged Care Standards and Accreditation Agency (ACSAA).

At the individual residential facility level these must include:

- A requirement to provide for private space for the continuation of intimate and family relationships
- Appropriate allocation of staff time for responsive communication, information exchange and collaboration with residents and their families
- Required family carer involvement in the development of resident care plans unless they specifically opt out or the resident requests that family is not involved
- Recognition of the advocacy and care provision roles played by family carers
- Professional development training for staff in working in partnership with families
- Comments and complaints that can relate not just to the care of the resident, but to the treatment of family and friends by the aged care facility

At the aged care policy level these must include:

- Modifying the Aged Care Act and Principles to mandate family inclusion
- Establishing a Charter of Rights and Responsibilities for Relatives and Friends to be incorporated with the Charter of Resident Rights and responsibilities.
- Modifying the Aged Care Accreditation Standards and audits
- Developing a funding allocation for psychosocial support for the resident and family in the proposed Aged Care Needs Assessment Instrument

At the family support level these include:

- Funding for a national network of support groups for families and friends of residents
- Funding for delivery of a national family carer education program on:
    - Transition issues including loss and grief
    - The operation of the residential aged care system
    - Resident and family rights
    - Communication and assertiveness
    - Common age-related conditions and disease progression
    - Self care

8 GENERAL ISSUES

8.1 The prospect of market failure

The draft report considers that there are strong rationales for government involvement in aged care, including the pursuit of equity of access to care and correcting market failures (these are defined as information gaps and protection of vulnerable consumers). The Commission is committed to minimizing regulation, reducing rationing and encouraging market competition to enhance service supply, quality and efficiency. Choice and control by older people and their families may drive services improvement, efficiency and innovation.

However there are no recommendations to specifically address market failure in a reformed aged care system. Carers Victoria is concerned that there will still be incentive in a more market based system for service providers to "cherry pick" lower complexity (and cost) clients, especially in the context of a tradable obligation towards supported residents. Carers Victoria remains concerned that high transaction costs imposed by providers in delivering community care will continue to result in aged care consumers getting reduced support from their entitlements.

8.2 Carers Victoria recommends

That the roles of the proposed policy research and evaluation functions of the proposed Australian Aged Cares Regulation Commission, the Department of Health and Ageing and peak advocacy bodies include the following:

- Consultations with individuals and groups to identify consumer need and service gaps
- Personnel and funding to ensure community and service development to meet emerging needs and gaps. The identification of people with similar needs and the initiation of needed innovative small group programs may be difficult in an individualized funding system
- Seed funding of innovative service delivery models to address unmet need

8.3 Carers Victoria recommends

That all aged care providers are set achievable "diversity targets" for a range of "special needs groups" that reflect the population demographics of the catchments and localities they operate within.

8.4 The role of peak bodies in a reformed aged care system

The draft report recommends that carer support centres should be developed from the existing Commonwealth Respite and Carelink Centres. These will provide dedicated carer services such as counselling, capacity building and respite. The role of specialist agencies that provide information, education and training and individual and systemic advocacy such as Alzheimer's Australia, Carer Associations and others are only mentioned briefly in Appendix B. Their specialist expertise should be preserved in a reformed system.

Individualised, consumer directed services will need to be supported by expanded independent consumer and carer advocacy services which can strengthen their individual advocacy role as well as consult with older people and their families and monitor the impacts of system change. A further key issue will be the need of older people and their families for access to a raft of supports such as with employment and bookkeeping to assist them to increasingly direct or self manage their care.

8.5 Carers Victoria recommends

That the Commission identify clear roles for peak bodies in a reformed aged care system including:

- Advocacy – both individual and systemic
- Specialist information and education for caring families
- Accredited and professional development education for the aged care workforce to support cultural and practice change
- Support for caring families to implement consumer directed and consumer managed care
- Conducting and supporting evidence based research on support for caring families
- Dissemination of good practice in family support and inclusion to the aged care workforce

9 CONCLUSION

The Commission has the opportunity to recommend reforms to build a more person centred and family focused aged care system. We can put older Australians first without putting their family carers second.

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http://www.capacitythinking.org.uk/circles.html

Appendix 1: Transition support needs for diverse caring journeys

Pre-caring	Transition into caring	Caring at home
• Individuals and families making financial and lifestyle plans for retirement • Older Australians openly expressed as well as unspoken plans for the future • Families anticipating future care needs and how best to meet these	• May be sudden or gradual • Individuals and families coming to terms with diagnosis of illness or disability • Learning what the condition means and what is involved in caring • Exploring changed roles, responsibilities, expectations (lifecycle cultural, personal) • Loss and grief • Learning about available services, entitlements, supports • Making choices about how caring should occur within the family	• Short, medium and long term conditions • Informal and/or formal support for the older person and their family • Some caring families needing to combine work and care • Some older carers e.g. spouses/partners with needs as a carer as well as needs as an older person
Support	**Support**	**Support**
• Financial and legal information on wills, powers of attorney, guardianship and advance care directives • Information for older individuals and couples on planning for future care needs • Information for adult children about planning for future care needs of parents • Support for families to have meaningful discussions on difficult topics • Support for families to develop legal "family agreements" stating how care and support may be managed within the family e.g. shared care arrangements	• Short term care coordination • Emotional support for the caring family through the period of grieving and adjustment to changed life circumstances • Information about the condition, its management and long-term implications • Information about formal and informal support options, financial entitlements • Family conferences/discussions to encourage shared understanding and action • Raising awareness about need to consider time management/self care • Referral to peer support e.g. condition specific and carer support groups	• Comprehensive assessment of family carer needs and strengths, formal and informal support, care planning • Assessment of degree of respite effect of support services for the older person • Access to regular, planned and flexible respite care if required • Emergency care planning • Monitoring caring family well-being over time via 'Keep in touch' or other monitoring arrangements • Advocacy for family focused aged care services • Ongoing access to information, education and peer support opportunities

Increasing needs	Decreasing needs	Fluctuating needs
• Declining health of family carer or person with care needs • Older person has behaviours of concern • Informal and/or family support is removed or insufficient • Access to formal services changes or reduces e.g. cost of services increases • Family carer needs are not shared or accepted by older person e.g. refusal of formal care services, respite, social support	• Rehabilitation or restored health reduces family care tasks • Caring family is 'settled' with an appropriate level of support • Individual and family are satisfied with the balance of formal and informal support • Caring family is confident about access to re-assessment and review, complaints and advocacy • Family involvement or other informal support increases – e.g. shared care • Move to a location with more support e.g. retirement village	• Episodic changes in health status of family carer or person with care needs e.g. mental health needs, dementia with Lewy bodies • Short term changes in role demands, circumstances or needs of caring family, which require support or respite • Existing support and respite arrangements are temporarily insufficient for caring families needs
Support	**Support**	**Support**
• Review formal support arrangements • Case management support • Reassessment of needs and discussion of options • Reviewing family willingness and capacity to continue with the role • Emphasis on quality of life for all parties • Open exploration of conflicting needs with access to conflict resolution if required • Advocacy for long-term increases in individual service access • Introduction of new support and respite services • Referral for counselling, specialist behaviour support, palliative care services etc	• ' Keep in touch' arrangements to monitor the continued well-being of the care situation • Clear pathway for caring families to request re-assessment, review or to re-engage with formal services	• Comprehensive reassessment of care situation • Short term care coordination • Increased support services for the period of increased need • Access to funding for short term episodic respite and other support arrangements

Crisis situations	Transition to residential care	Post caring
• Changes in the family's situation which overwhelm their capacity to provide care e.g. hospitalisation, health crisis, exhaustion, death in family, major family crisis and a need for immediate respite • Crises may occur in conjunction with continuing, increasing or decreasing needs	• Major change in life circumstance • Familiar formal services and supports need to be reorganised and replanned • Loss and grief • Change in caring role to that of "care guardian" • Loss of former support from and relationships with community care service providers	• Bereavement following death of the older person • Loss and grief • Loss of former support from and relationships with service providers
Support	**Support**	**Support**
• Implementation of emergency care plan (if one exists) • Assessment of crisis situation/presenting problem(s) and assistance to family to develop/organise appropriate response • Practical and emotional support • Assessment of degree and severity of stress in crisis situation and family's capacity to manage • Short term care coordination • Comprehensive reassessment to address any longer term issues reflected in the crisis and referral for case management if required	• Emotional support through the period of grieving and re-adjustment to changed roles and responsibilities • Exploration of potential new life challenges for family carers • Negotiation of transition from community care services • Case management support or advocacy with the residential aged care facility concerning family involvement in ongoing care • Information and education regarding what to expect in residential aged care • Involving families and residents in care planning • Provision of family support in end of life care	• Emotional support through the period of grieving and re-adjustment to loss of caring role and responsibilities e.g. counselling, grief education • Exploration of potential new life challenges for the family carer • Negotiation of transition from aged care support services to mainstream bereavement counselling and other long term community support as available • Support to access aged care and support in their own right as appropriate