The Royal Australian & New Zealand College of Psychiatrists
Tu Te Akaaka Roa
New Zealand National Office

Your Health in Mind
Hauora hinengaro Manatuhia

Carers’ Strategy Action Plan

Ministry of Social Development

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Excellence and equity in the provision of mental healthcare

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Royal Australian and New Zealand College of Psychiatrists submission

Carers’ Strategy Action Plan Consultation 2026

The Royal Australian and New Zealand College of Psychiatrists (RANZCP) is the peak body representing psychiatrists in Australia and New Zealand. We are a binational college that trains doctors to become medical specialists in psychiatry. We support and enhance clinical practice, advocate for people affected by mental illness and addiction, and advise governments on matters related to mental health and addiction care.

We represent over 8,730 members, including more than 6,000 qualified psychiatrists and 2,500 trainees. Our training, policy, and advocacy work is led by expert committees of psychiatrists and subject-matter experts with academic, clinical, and service-delivery experience in mental health and addiction.

RANZCP has a longstanding commitment to improving outcomes for people living with mental illness and for the families, whānau, aiga and communities who love and support them. This submission is offered in that spirit — drawing on the clinical expertise of our members and the lived realities of those who come to us for care.

Executive Summary

The RANZCP welcomes the development of a new Carers’ Strategy Action Plan and commends the Ministry of Social Development for its commitment to supporting, valuing and recognising carers across Aotearoa New Zealand.

However, we submit that the draft Action Plan, as currently framed, does not adequately address the distinct and complex realities facing carers of people with mental illness, addiction, suicidality, eating disorders, psychogeriatric conditions, intellectual disability, and autism spectrum disorder. Carers — who are often family members, partners, and children — carry an enormous and largely invisible burden. They are among the least likely to identify as carers, least likely to seek financial support, and most likely to fall through the gaps of a system designed around more visible and stable caring relationships.

This submission identifies the following critical gaps and calls for the Action Plan to explicitly recognise and respond to them:

- Mental health carers are not specifically recognised within the strategy
- The strategy does not account for fluctuating nature of mental illness
- Inadequate financial support is driving unnecessary institutional care
- Financial support remains inaccessible for those who need it most
- Child carers in mental health households are invisible to the strategy
- Bereavement after caring is entirely absent from the strategy
- Cultural dimensions of care require structural, not only service-level, responses
- Carers of people with intellectual disability and autism face lifelong burnout with serious downstream consequences — and young people with ASD but without ID are currently ineligible for respite care, a critical inequity
- Respite is inadequately addressed for all carer groups, with serious clinical consequences
- Child-to-parent violence and abuse (CPVA) is unrecognised and unsupported
- The safety of carers is at risk when trusted, quality respite is unavailable
- The evidence base for mental health carers is insufficient to drive future action
- Carers of older people with dementia — including older spousal carers, sandwich-generation adult children, and carers managing BPSD — are not specifically recognised or supported

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Introduction: The Mental Health Caring Relationship

1. The Recognition Gap: Carers in Mental Health Contexts

Carers of people with mental illness, addiction, suicidality, eating disorders, and psychogeriatric conditions are among the least visible and least supported carer populations in Aotearoa New Zealand. A number of intersecting factors contribute to this, which must be specifically addressed within the Action Plan.

Barriers to disclosure and self-identification

Families supporting a loved one through mental illness, addiction, or suicidality frequently face significant social and structural barriers to seeking help. Concerns about how they or their loved one might be perceived — and about the potential consequences of disclosure — stop many from coming forward to services or identifying themselves as carers. This is not a failure on the part of families. It is an understandable response to an environment that has not yet made it consistently safe or straightforward to ask for help. Policy must respond to this reality, rather than assume that support will be sought when it is needed.

Absence of formal carer recognition pathways

In many physical health and disability contexts, a caring role is recognised through formal assessment, diagnosis, or enrolment in a service. Unfortunately, this formalisation is rarely available or accessible in mental health contexts. A family member providing intensive emotional support, crisis management, safety monitoring, and practical care for a loved one with serious mental illness may never be identified as a carer — unless they actively seek that recognition, which most do not due to the barriers described above. The result is a population carrying substantial responsibility, often over many years, with little or no formal acknowledgement or support.

The unseen work of mental health care

The work that mental health carers do — the sustained vigilance, the emotional attunement, the navigation of complex systems at moments of acute distress, the absorbing of another person’s distress while managing their own — is not well captured by the framework of ‘daily living assistance’ that underpins much of the Carers’ Strategy. It is rea and demanding work that can carry profound consequences for the health and well-being of those who do it. For the Action Plan to reach carers and be effective, it must first develop language and frameworks that make their contribution visible and valued.

2. The Non-Linear, Fluctuating Nature of Mental Illness

One of the most significant gaps in the current draft is its implicit assumption of a stable caring relationship. The strategy is built around the idea that someone is unwell, and someone else provides care. This model does not fit the lived reality of mental illness, addiction, or psychogeriatric conditions, where the person being cared for may be well for extended periods and then not.

A person with bipolar disorder, severe depression, or an addiction may cycle through periods of stability and periods of acute crisis. During stable periods, the family member may not identify as a carer and may not be enrolled in a service or access supports. When crisis hits unexpectedly, they face the system for the first time — at the moment they are least equipped to navigate it. This cycle repeats, and with each repetition, the accumulated toll on the carer grows.

There is also the burden of anticipatory vigilance and constant background monitoring that carers of people with mental illness carry even during periods of wellness. A parent whose adult child has experienced a mental health crisis does not stop watching, even when their child is well. This chronic, unrelenting vigilance is entirely invisible to current policy.

3. The Financial Trap: When Inadequate Support Drives Institutional Care

The draft Action Plan’s Financial Security priority area focuses on understanding carers’ financial needs and mapping available supports. The RANZCP welcomes this intent but submits that it does not go far enough in naming a systemic failure with significant human and economic consequences.

Many families want to care for their loved one at home or within their community. This is not only their preference, but also often clinically preferable, culturally appropriate, and more cost-effective for the system. However, carers face a fundamental financial contradiction: to care for a loved one with serious mental illness, they may need to leave paid work or reduce their hours. But without income, they cannot survive. The result is that people who are loved, who could be cared for at home, end up in residential care or hospital not because that is best for them, but because the people who love them cannot afford to care for them.

This is a systemic failure with direct financial consequences for the health and social services system. Hospital admissions and residential care placements are significantly more costly than supported community care. The investment in carers is not only a matter of equity — it is an economic argument.

4. Trust-Based, Flexible Financial Support

For carers of people with mental illness, addiction, or suicidality, the experience of approaching the Ministry of Social Development for financial assistance is a barrier. Many carers have watched their loved ones struggle with bureaucratic systems that are difficult to navigate. Approaching MSD as a carer means re-entering a system that may have already failed the person they love.

The timeliness of financial support is also critical. Carers tend to reach out for financial support at points of acute crisis — precisely when they are least equipped to complete forms, make phone calls, gather evidence, or advocate for themselves. A system that requires sustained administrative effort from people at their lowest point will consistently fail to reach those who need it most.

Some carers are in poverty. Some face geographic barriers that make caring for a loved one financially impossible — the cost of travel, accommodation, and time away from paid work placing the caring role entirely out of reach. For Māori and Pacific whānau in particular, the desire to manaaki and provide tautoko is not a preference but a deep cultural obligation. When financial barriers prevent this, the harm is cultural and spiritual as well as practical. The Action Plan must respond to these realities directly.

The RANZCP submits that trust-based, flexible financial support — rather than compliance-based gatekeeping — is essential. This means:

- Support flowing through existing trusted relationships: mental health teams, GPs, community workers, and peer support services who already know the family
- Flexible eligibility that adjusts to the episodic nature of caring without requiring reapplication each time circumstances change
- Recognition of the cumulative, hidden financial costs of mental health caring — including lost career progression and out-of-pocket costs when public services are inadequate
- Travel and accommodation support for carers in poverty who face geographic barriers
- Non-stigmatising, compassionate, and trauma-informed engagement at every point of contact

5. Child Carers: A Critical and Overlooked Population

The draft Action Plan acknowledges that young people can be carers. However, it does not specifically address one of the most vulnerable carer populations in Aotearoa New Zealand: children who care for a parent with serious mental illness, addiction, suicidality, or psychogeriatric conditions.

Children in these households are not simply doing extra household tasks, they may be managing a parent's crisis episodes, monitoring a parent's safety, providing emotional regulation for a parent in acute distress, protecting younger siblings, and navigating their own development without the parental support they need — all while concealing what is happening at home.

The ACEs evidence base

The Adverse Childhood Experiences (ACEs) research — one of the most robust bodies of evidence in public health — clearly establishes that parental mental illness, addiction, and related family adversity are recognised as adverse childhood experiences with significant and well-documented consequences for long-term health, educational, social, and economic outcomes. The original ACE Study (Felitti et al., 1998) and subsequent research demonstrate a dose-response relationship: children exposed to multiple ACEs face substantially elevated risks of mental illness, addiction, chronic physical health conditions, educational underachievement, and involvement in the justice system in adulthood. These are not inevitable outcomes — they are preventable. But prevention requires that the system sees these children early, responds with appropriate support, and does not leave families to carry these burdens alone.

The Supporting Parents Healthy Children (SPHC) model

The Supporting Parents Healthy Children (SPHC) programme represents an important and evidence-based model for responding to the needs of families where a parent has a mental illness. SPHC takes a whole-family approach, recognising that supporting the parent and supporting the child are not separate tasks. Research on SPHC and equivalent programmes internationally (including COPMI — Children of Parents with Mental Illness frameworks) consistently demonstrates improved outcomes for both parents and children when support is delivered in this integrated way. However, in Aotearoa New Zealand, SPHC remains insufficiently resourced and inconsistently available. Its existence demonstrates that the system knows what good practice looks like. The Carers' Strategy Action Plan presents an opportunity to embed and expand this approach at scale.

Educational and developmental impact

The impact on children's education is cumulative and often invisible to schools. A child who is chronically exhausted, anxious, or absent because of what is happening at home is frequently labelled as disengaged or underperforming. Māori and Pacific young people are disproportionately represented in this population and are more likely to provide high-intensity care in contexts of social deprivation. The long-term consequences such as reduced educational attainment, attachment difficulties, elevated rates of mental illness are well-documented and largely preventable with timely, appropriate support.

6. Bereavement After Caring: A Missing Dimension

Neither document addresses what happens when a caring role ends through the death of the person being cared for. For carers of people with mental illness, addiction, or suicidality, this gap is particularly significant.

When death is by suicide, carers face a form of grief that is among the most difficult and isolating, compounded by guilt, unanswered questions, and a social environment that often does not know how to respond. Even where death is not by suicide, carers may carry complex grief with relief alongside loss, and guilt alongside exhaustion; this is rarely acknowledged and poorly supported.

The transition out of a caring role is also a profound identity disruption. A person who has structured their life around caring for someone with serious mental illness faces, at the point of bereavement, not only grief but the collapse of their role, their routine, and in many cases their financial stability. Financial supports cease. Services may disengage. They are alone with their grief in a system that has stopped looking.

7. Cultural Dimensions of Caring: Manaakitanga, Tautoko, Aroha

The draft Action Plan acknowledges cultural diversity and the importance of cultural safety in service delivery. The RANZCP welcomes this intent. However, we submit that the cultural dimensions of caring for someone with mental illness go deeper than service delivery and navigation.

For Māori, concepts of manaakitanga, tautoko, and aroha are not supplementary to caring — they are the foundation of it. Caring for whānau is an expression of identity, relationship, and communal responsibility. When the system fails to support whānau to enact these values — through financial barriers, geographic separation, or institutional responses that displace family care — the harm is cultural and spiritual as well as practical.

For Pacific communities, intergenerational and communal care is similarly foundational. The inability to fulfil caring obligations because of poverty, work obligations, or a system that does not support them carries profound consequences for wellbeing and identity.

The Action Plan’s commitment to cultural safety must translate into structural changes that enable whānau and aiga to fulfil their caring roles, instead of culturally sensitive communication about services they still cannot access.

8. Carers of People with Intellectual Disability and Autism: Lifelong Burnout and Downstream Consequences

Carers of people with intellectual disability (ID) or autism spectrum disorder (ASD), who are often parents and whānau, occupy a distinct and frequently overlooked position within the carer population. Their caring role is not episodic or time-limited: it is lifelong, often highly intensive, and may intensify rather than ease over time. Many have been providing full-time care for decades. Burnout in this group is significant, cumulative, and well-documented in research literature (Griffith & Hastings, 2014; Emerson & Giallo, 2014). As carers age, profound anxiety about future care arrangements compounds the daily weight they already carry.

A critical eligibility gap: young people with ASD but not ID

One of the most significant and inequitable structural gaps in the current system is the lack of respite care for young people under 18 who have ASD but do not have a co-occurring intellectual disability. This means that some of the most challenging and demanding caring situations: families supporting a young person with autism and significant behavioural needs, but no cognitive impairment receive no access to the very resource that might prevent family breakdown and hospitalisation. This gap must be closed.

A postcode lottery of provision

Access to support for carers of people with ID and ASD is heavily dependent on geography. In areas where well-resourced NGOs operate, families may access good community support. In areas where they do not, families receive nothing. This creates a postcode lottery that is fundamentally unjust and clinically indefensible. If Community Child and Adolescent Mental Health Services (CAMHS) were better funded and resourced to serve neurodiverse young people, the pressure on families would be significantly reduced and consequently reduce inpatient admissions. Currently, CAMHS capacity constraints mean that families with neurodiverse young people often cannot access timely community support, forcing escalation to crisis and inpatient pathways.

Geographic displacement in inpatient care

When inpatient admission does occur, the consequences for whānau can be devastating. Currently, some young people with ASD who require inpatient psychiatric care are being placed significant distances from their homes, sometimes even on a different island. This separation from whānau, from familiar environments, and from the very relationships that support their wellbeing is clinically contraindicated and causes profound distress to both the young person and their family. It is also expensive and unsustainable. It reflects not clinical need but the absence of adequately resourced local alternatives.

Housing, trained staff, and the limits of NGO reliance

Housing is a critical barrier to discharge for many young people with ID and ASD from inpatient settings. But having a house is not sufficient without the adequately trained and supported staff to make it a safe and therapeutic environment. Each region has attempted to address this, but resources, training, and systemic support are scarce and becoming scarcer. The RANZCP submits that the system must move away from its current over-reliance on NGOs for this function. While some NGOs provide exceptional services, they are rarely nationally joined-up, and even the best face sustainability challenges. The Carers' Strategy should advocate for more formally and structurally supported provision through Te Whatu Ora, rather than depending on the variable capacity of the community and NGO sector.

The false economy of under-investment

The financial case for adequate carer support in this population is compelling. When whānau carers do not receive adequate respite, support, and community-based alternatives, the costs fall elsewhere — on inpatient wards, emergency departments, youth justice, and child protection. These downstream costs are substantially higher than the upstream investment that could have prevented them. This is not only a fiscal argument: the individual, their whānau, and the system all pay more — financially and emotionally — when early support is withheld. Aotearoa New Zealand can learn from Australia, where the Roadmap for Improving the Health of People with Intellectual Disability and the National Autism Strategy provide models for targeted, nationally consistent action on these gaps.

Youth justice overrepresentation and the OPCAT evidence

OPCAT reports on New Zealand's youth justice estate have consistently documented the high prevalence of ID and neurodevelopmental conditions among young people in detention. The Section of Child and Adolescent Forensic Psychiatry has highlighted this in previous submissions. These young people are not in youth justice because of their conditions: they are there because the system failed to support them and their carers. Investment in carers of people with ID and ASD is therefore not only a matter of carer wellbeing, but it is also a primary prevention strategy with direct implications for youth justice, child protection, and long-term social outcomes. The Action Plan must recognise this explicitly and in the strongest possible terms.

9. Respite for All Carers: A Clinical and System Priority

The draft Action Plan commits to mapping and promoting respite options as an immediate deliverable under the Health and Wellbeing priority. The RANZCP welcomes this but submits that mapping what exists is not sufficient. The evidence is clear that respite is inadequate in availability, accessibility, flexibility, and cultural responsiveness across all carer groups. For carers of people with mental illness, respite looks different from traditional models and is rarely recognised as such. For carers of people with ID or ASD, respite must be provided by people known and trusted by the person receiving care, not a generic service. For Māori and Pacific carers, respite must be culturally grounded.

The clinical consequences of inadequate respite

The clinical consequences of inadequate respite are concrete and well-known to practitioners yet rarely named in policy. When carers of young people with ID or ASD reach breaking point through exhaustion, the young person is frequently admitted to an inpatient psychiatric ward or presents to an emergency department; not because their clinical needs have changed, but because their carer can no longer cope. In these settings, antipsychotic medications are too often prescribed or increased not to treat an underlying condition, but to manage behaviour and to maintain safety in an environment that is itself not well-suited to the young person's needs. This represents a failure of care that is costly, potentially harmful, and in many cases entirely preventable. The medication is in effect managing the consequences of a system that did not provide adequate respite. The RANZCP submits that this pattern is a direct and measurable consequence of under-investment in carer respite, and that it must be named and addressed as such.

Step-down beds and residential support: an urgent gap

Beyond day and overnight respite, there is a significant and largely unaddressed need for step-down beds and targeted residential support services for tāngata whaikaha living with intellectual, neurodevelopmental, and psychosocial disabilities. These placements would prevent unnecessary hospital admissions, support timely discharge, and reduce the burden on whānau carers at critical pressure points. Currently, the absence of such provision creates a system in which inpatient beds are occupied not because inpatient care is clinically required but because there is no appropriate alternative for the person to go to. This is a waste of clinical resource, a denial of the person's right to community living, and a source of significant and sustained distress for their carers.

The quality of respite matters as much as its availability

Access to respite alone is not sufficient if carers cannot trust that their loved one will be safe, well cared for, and treated with dignity in their absence. For many carers, this trust has been hard-won or has been broken by previous experiences with services that did not meet their loved one's needs. When carers cannot trust alternative care providers, they cannot genuinely rest even when respite is technically available. The system must invest in the quality and consistency of respite provision alongside its availability. Staff providing respite, particularly for people with complex neurodevelopmental needs, must be adequately trained and properly supported. The current workforce shortage in this area is a significant constraint on quality.

10. Child-to-Parent Violence and Abuse (CPVA): An Unrecognised Caring Crisis

A significant and growing body of evidence documents the experience of child-to-parent violence and abuse (CPVA): violence directed by a child or young person toward a parent or caregiver. CPVA is as real and as damaging as other forms of family violence, yet it remains largely unrecognised by the agencies that families turn to for help (Holt, 2016; Wilcox, 2012).

New Zealand research by VisAble, a disabled person-led organisation, found that 92% of 91 caregivers surveyed had experienced physical abuse from their disabled child.

The majority of children involved had at least one disability or mental health diagnosis, including autism spectrum disorder, fetal alcohol spectrum disorder (FASD), and ADHD. This means that parents and whānau caring for children with these conditions are disproportionately affected.

Because CPVA is not formally recognised as a form of family violence in New Zealand, affected families cannot access family violence support services. Police responses are inconsistent. Mental health services may decline to engage. Families are passed from agency to agency with no one equipped or willing to help. Some parents have been arrested when reporting violence from their child. Others have had children removed into state care — an outcome that, as the evidence shows, frequently makes things worse. When no appropriate support is provided, the youth justice pathway becomes, by default, the only intervention available: a punitive response to what is fundamentally an unmet support need.

Supporting a family experiencing CPVA is expensive, but far less costly than placing a young person into state care or the justice system (Tempest, VisAble, 2025). The Carers' Strategy has both an opportunity and an obligation to name and address this gap.

11. The Evidence Base: What Is Needed to Drive Future Action

Aotearoa New Zealand has very limited data on the outcomes of mental health carers, and almost none on child carers in mental health households. Without this foundation, future actions cannot be well-targeted. The intersecting factors that shape mental health caring — poverty, ethnicity, geography, gender, age — compound each other in ways that existing datasets do not capture.

Fragmented data on disabled people and their carers

Current reporting processes are fragmented and provide insufficient data to allow effective monitoring of the experiences of tāngata whaikaha and their whānau. Disabled people — including those with intellectual, neurodevelopmental, and psychosocial disabilities — cannot be consistently identified across existing data systems, dashboards, and reports. This invisibility in data perpetuates invisibility in policy. The RANZCP endorses recommendations from the disability sector for working with relevant agencies, tāngata whaikaha, whānau, and tāngata whenua to develop options for identifying disabled people across the spectrum on existing data systems — including data on seclusion and forensic mental health services — to allow meaningful monitoring and accountability.

OPCAT reports and the youth forensic evidence base

New Zealand's OPCAT (Optional Protocol to the Convention Against Torture) inspection reports on youth justice facilities have repeatedly documented the high prevalence of intellectual disability and neurodevelopmental conditions — including ASD, FASD, and ADHD — among young people in detention. This evidence base, developed and cited in previous submissions by the Section of Child and Adolescent Forensic Psychiatry, provides a compelling and specific case for early intervention with carers and families. It is available to inform the Action Plan and should be used to do so. The current absence of any connection between this evidence and carer support policy is a significant gap.

Targeted action plans and international models

The Carers' Strategy Action Plan, given its broad scope, cannot address the needs of all carer groups in equal depth. However, RANZCP recommends that the strategy explicitly commit to the development of targeted action plans for groups whose needs are persistent, complex, and poorly served by generic provision — in particular, carers of tāngata whaikaha living with intellectual and neurodevelopmental disabilities. New Zealand should draw on recent work completed in Australia, including the Roadmap for Improving the Health of People with Intellectual Disability and the National Autism Strategy, as useful resources for this mahi.

Future actions also risk being driven by political priorities rather than carer need, without independent accountability mechanisms in place.

The rolling Action Plan format, while welcome in principle, must be accompanied by governance structures that ensure it remains responsive to those it is designed to serve.

12. Old Age Psychiatry and Dementia Carers: A Distinct and Overlooked Population

The draft Action Plan makes no specific reference to carers of older people with mental illness, and in particular to carers of people with dementia. This is a critical omission. Dementia is now the leading cause of death for New Zealand women and among the most common causes overall. Carers of people with dementia represent one of the largest, most burdened, and most isolated carer populations in the country. Their experiences are clinically and experientially distinct from other caring roles in ways that require specific recognition within the strategy.

Ambiguous loss and anticipatory grief

Unlike most other caring contexts, dementia carers grieve their loved one while they are still alive. The person they know — their personality, their memory, their capacity for relationship — is progressively lost, often over many years. This experience, described in the literature as 'ambiguous loss' (Boss, 1999), is a form of grief that is disenfranchised and largely unrecognised by support systems. It does not meet the threshold for bereavement services, yet it is a profound and sustained psychological injury. Carers describe mourning someone who has not yet died, and living in an extended liminal space between loss and presence. This experience is compounded by social isolation, as the person with dementia may be unable to participate in shared social life, and the carer withdraws with them.

The older spousal carer

A significant proportion of dementia carers are themselves elderly. A person in their late seventies or eighties, managing their own chronic health conditions, possible mild cognitive impairment, reduced mobility, and limited social network, may be providing round-the-clock care for a spouse. These carers are among the most invisible in the system: they do not identify as carers, they do not present to services, and they are often managing on the basis of love and duty long past the point of safety for either themselves or the person they are caring for. When this carer reaches crisis — through their own health deterioration, a fall, or complete exhaustion — the consequences are immediate and severe for both. The strategy must develop specific proactive outreach to this population rather than relying on self-identification.

The sandwich generation

Adult children — predominantly women in their fifties and sixties — who are caring for a parent with dementia while simultaneously managing their own children, grandchildren, and employment carry a compounded caring burden that is rarely named. These carers face income loss, career disruption, and relationship strain while navigating a health and support system that often does not adequately involve them in care planning for their parent.

Behavioural and Psychological Symptoms of Dementia (BPSD) and carer safety

The submission addresses child-to-parent violence and abuse (CPVA) in the context of disability and ASD. There is an equally serious and under recognised risk of carer harm arising from Behavioural and Psychological Symptoms of Dementia (BPSD). People with dementia may experience paranoia, psychosis, agitation, and disinhibition that can result in physical violence toward their carer. Unlike CPVA, the person has no insight, no intent, and no capacity to modify their behaviour. Carers of people with BPSD are frequently injured, frightened, and ashamed — and rarely disclose what is happening. The health system must create safe, non-stigmatising pathways for these carers to access support and safety planning without fear that disclosure will result in forced placement or loss of the caring relationship.

Transition to residential care: when caring continues beyond home

The draft Action Plan implicitly frames caring as occurring in the home. But for many dementia carers, the point of residential care placement is not the end of caring — it is a transition to a different, often more complicated, form of it. Carers visiting rest homes and memory care units continue to provide emotional, practical, and advocacy support. Many experience profound guilt, grief, and disorientation following placement. They monitor the quality of their loved one's care, advocate for person-centred approaches, and remain the primary holders of that person's history and preferences. The strategy must recognise and support the ongoing caring role that continues after residential placement, including specific support for the transition itself.

Capacity, legal, and end-of-life decision-making

Carers of people with dementia are often required to navigate complex legal and ethical terrain with little guidance or support: Enduring Powers of Attorney, welfare guardianship applications, advanced care directive decisions, and ultimately decisions about withholding or withdrawing treatment. These decisions carry profound ethical weight and long-term psychological consequences for carers. Many make them alone, without access to legal advice, ethical support, or adequate information. The strategy should ensure that carers have access to appropriate support when navigating these processes.

Post-bereavement in dementia: a distinct clinical picture

Research consistently demonstrates that bereavement following dementia death is clinically distinct from other forms of grief. Carers have typically been grieving for years before their loved one dies, and the death itself can trigger a complex and contradictory emotional response — including relief, which then generates guilt, shame, and social silence. The risk of complicated grief disorder is elevated in this population, particularly for spousal carers who lose not only the person but their entire daily identity, structure, and social context. The submission’s existing recommendation on bereavement must be extended to specifically address dementia bereavement, including the post-placement grief that precedes death.

Responses to Consultation Questions

Q1: The ‘Rolling’ Action Plan

RANZCP supports the concept of a rolling Action Plan in principle. The fluid and evolving nature of caring relationships — particularly in mental health contexts — means that fixed, time-limited plans frequently become outdated before their goals are achieved. However, we note that a rolling plan without adequate accountability structures and regular public reporting risks becoming a mechanism for deferring action rather than enabling it. We recommend that the governance framework include independent oversight, mandatory reporting cycles, and meaningful involvement of carer communities in monitoring progress.

Q2: Immediate Deliverables

The immediate deliverables as proposed are reasonable starting points but do not go far enough for carers in mental health contexts. The commitment to map respite services and financial supports is welcome. However, for these actions to be meaningful, they must be accompanied by honest acknowledgement of the significant gaps that exist for mental health carers specifically — including the absence of flexible, trust-based financial support, the lack of bereavement services, and the complete absence of any response to CPVA.

Q3: Government and Community Partnership

RANZCP recommends that government work with the mental health sector — including NGOs, peer support organisations, and mental health services — as the primary pathway for reaching carers in mental health contexts. These organisations already hold trusted relationships with families. Financial support should be able to flow through these relationships, reducing the administrative burden on carers and increasing the likelihood that support reaches those who need it.

Q4: Additional Considerations for Implementation

Agencies should ensure that implementation:

- Involves genuine co-design with people who have lived experience of mental health caring, including former young carers — not consultation after decisions are made
- Establishes cross-agency coordination mechanisms so that carers do not have to tell their story repeatedly to systems that do not communicate with each other
- Is trauma-informed at every touchpoint, requiring sustained investment in training and organisational culture — not one-off workshops
- Shifts from passive availability to proactive identification, particularly for child carers and carers of people with mental illness, ID, and ASD who are unlikely to self-present
- Accommodates the episodic nature of mental illness, allowing carers to re-engage with support quickly after periods of stability without bureaucratic re-qualification
- Treats suicide bereavement as a distinct implementation priority with specialist provision
- Establishes a national coordinated response to CPVA in partnership with relevant agencies
- Develops specific, proactive outreach to older spousal carers and carers managing BPSD who are unlikely to self-identify or seek support

Q5: What Should Inform Future Actions

Future actions should be informed by:

- A dedicated longitudinal evidence base on mental health carers, carers of people with ID and ASD, and child carers in mental health households
- Cost modelling of the relationship between carer financial support and rates of hospitalisation, residential care placement, and youth justice involvement
- A standalone suicide bereavement action area with dedicated funding
- Long-term tracking of children who were carers, drawing on existing datasets such as Growing Up in New Zealand
- The ACEs evidence base and SPHC/COPMI frameworks as foundations for whole-family approaches
- International models of CPVA response, particularly those developed in the UK and Australia
- OPCAT inspection reports on youth justice facilities as a key evidence source for the prevalence of ID and neurodevelopmental conditions and the downstream consequences of inadequate carer support
- Australian models including the Roadmap for Improving the Health of People with Intellectual Disability and the National Autism Strategy as templates for targeted sub-action planning
- Improved cross-agency data systems that can identify tāngata whaikaha — including those with intellectual, neurodevelopmental, and psychosocial disabilities — across health, justice, and social service datasets
- Independent accountability mechanisms that ensure the rolling Action Plan responds to carer need rather than shifting political priorities
- Genuine attention to intersectionality — recognising that poverty, ethnicity, geography, gender, and age compound each other in ways that require specific rather than generic responses

Summary of Recommendations

Recommendation 1

Explicitly name carers of people with mental illness, addiction, suicidality, eating disorders, and psychogeriatric conditions as a distinct and priority carer group. Develop targeted outreach and identification strategies that do not rely on self-identification.

Recommendation 2
Recognise the episodic and fluctuating nature of mental illness and design supports accessible at any point in the caring journey. Eligibility criteria should not require ongoing, full-time caring to be demonstrated.

Recommendation 3
Address the relationship between inadequate carer financial support and unnecessary hospitalisation and residential care through cost modelling and targeted investment.

Recommendation 4
Commit to trust-based, flexible, and trauma-informed financial assistance — including geographic support — accessible at any point of crisis without requiring sustained administrative effort.

Recommendation 5
Develop a dedicated whole-family focus on children in households where a parent has a mental illness, drawing on the ACEs evidence base and SPHC/COPMI models, with adequate resourcing and national consistency.

Recommendation 6
Provide explicit support for carers at the point of bereavement, with specialist pathways for those bereaved through suicide, and continuity of financial support through a transition period.

Recommendation 7
Develop culturally grounded approaches in genuine partnership with Māori and Pacific communities, enabling whānau and aiga to fulfil their caring roles on their own terms.

Recommendation 8
Develop nationally consistent, structurally supported provisions for carers of people with ID and autism: close the ASD-without-ID respite eligibility gap; resource community CAMHS for neurodiverse young people; address geographic inequity including distant inpatient placements; move beyond NGO reliance toward Te Whatu Ora–supported provision; and draw on Australian models (Roadmap for Improving the Health of People with Intellectual Disability; National Autism Strategy).

Recommendation 9
Expand high-quality, trusted, and culturally responsive respite for all carer groups, including a review and expansion of step-down beds and residential support services for tāngata whaikaha with intellectual, neurodevelopmental, and psychosocial disabilities. Treat the avoidance of unnecessary inpatient admission and reduction of inappropriate antipsychotic prescribing in young people as explicit outcome measures.

Recommendation 10
Formally recognise CPVA as a form of family violence and develop a national coordinated therapeutic response in partnership with disability, mental health, justice, and family violence agencies.

Recommendation 11
Establish a dedicated longitudinal evidence programme for mental health carers, commission cost modelling of the institutional care dynamic, and establish independent oversight of the rolling Action Plan with mandatory public reporting.

Recommendation 12
Explicitly recognise dementia and old age psychiatry carers as a distinct priority group. Implement proactive outreach to older spousal carers, support for anticipatory grief and ambiguous loss, safe reporting pathways for carers experiencing BPSD, transition support at residential care placement, legal and ethical guidance for capacity decisions, and specialist bereavement support recognising the complex grief profile of dementia carers.

Conclusion

RANZCP commends the Ministry of Social Development for renewing the Carers’ Strategy and welcomes the opportunity to contribute to this consultation. The families, whānau, aiga, and individuals who love and care for people with mental illness, addiction, suicidality, eating disorders, intellectual disability, and autism deserve to be seen — fully and specifically — in a strategy that purports to represent them.

They are carrying something profound, often in silence, often in poverty, often across distance, often from childhood. They are doing it out of love. The system’s obligation is to meet them where they are — with flexibility, with trust, and with genuine recognition of what they give.

RANZCP is committed to working with the Ministry, the Carers Alliance, and the wider sector to ensure this Action Plan delivers for those who need it most.

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