



**Carers WA**



**Carers WA Policy Submission**  
**WA Eating Disorder Framework**  
**September 2024**

## About Carers WA

---

Carers WA is the peak body representing the needs and interests of carers in Western Australia and is part of a national network of Carers Associations. Carers provide unpaid care and support to family members and friends with disability, mental health challenges, long term health conditions (including a chronic condition or terminal illness), have an alcohol or drug dependency, or who are frail aged. The person they care for may be a parent, partner, sibling, child, relative, friend or neighbour.

Caring is a significant form of unpaid work in the community and is integral to the maintenance of our aged, disability, health, mental health, and palliative care systems.

Some important facts about carers include:

- There are currently 3.04 million unpaid carers in Australia.
- There are more than 320,000 families and friends in a caring role in Western Australia.
- The replacement value of unpaid care, according to a report undertaken by Deloitte, Access Economics, "The economic value of unpaid care in Australia in 2020" is estimated at \$77.9 billion per annum.

### Acknowledgement of Country

Carers WA acknowledges the Wadjuk Noongar Nation's lands, water, customs, and culture of which the Carers WA Head Office is located. Carers WA recognises our services reach beyond the Perth (Boorlo) region, and so we also acknowledge the cultural diversity of First Nation Peoples across our state and throughout Australia.



### Enquiries

**Carissa Gautam**  
Systemic Policy and Strategy Officer  
Email: [policy@carerswa.asn.au](mailto:policy@carerswa.asn.au)

**Stuart Jenkinson**  
Systemic Policy and Strategy Officer  
Email: [policy@carerswa.asn.au](mailto:policy@carerswa.asn.au)

# Contents

---

Acknowledgement of Country .....	1
Enquiries .....	1
1.0 Recommendations .....	3
2.0 Introduction .....	5
3.0 General Feedback .....	6
3.1 Context.....	6
3.2 Carers WA Survey of Carers of People with Eating Disorders .....	8
3.3 Feedback on the Draft WA Eating Disorder Framework .....	15
4.0 Conclusion.....	22
References .....	23
APPENDIX 1: Detailed Feedback .....	24
WA Eating Disorder Framework .....	24

# 1.0 Recommendations

---

1. Terminology be adopted within the draft Framework to consistently refer to ‘families and carers’, with a supporting definition within the ‘key terms’ section of the paper as per the definition under the *Carer Recognition Act 2004* (WA):
  - ‘A carer is an individual who provides care and assistance to another person/s who has disability, chronic illness, mental illness, or who because of frailty requires assistance with carrying out everyday tasks<sup>1</sup>. A carer does not include someone who provides care or assistance as part of a contract for services or community work. A carer may include a friend, family member, significant other, neighbour or other contact<sup>2</sup>. Carers can be aged under 25 (young carers) or be older carers.
2. The proposed changes be made to the Guiding Principles, as outlined in section 3.3.1 of this submission.
3. Further clarity be provided in the final Framework on actions to be achieved, and the inclusion of an implementation plan and deliverables to track progress of the actions, strategic priorities and key focus areas.
4. For Focus Area 1, Carers WA recommends:
  - Rephrase focus area 1 to be: ‘Develop and establish prevention and early intervention programs and services in the community for all ages, particularly in regional areas’.
  - Inclusion of a strategic priority in focus area 1 to include education and specialization on eating disorders in key Vocational Education and Training courses for community early intervention professions.
  - Amend strategic priority 1.5 to- Ensure access to person-centred, trauma-informed and timely treatment in the community, at the level of intensity people require, as close to home as possible (including digital options and virtual care pathways).
  - Amend strategic priority 1.3 to - Strengthen awareness in the Western Australian community and amongst health professionals of eating disorders, including common signs and symptoms and the importance of early intervention.
5. Online programs be established to support carers to provide care for people at home while waiting for appointments, treatment and/or diagnosis.

---

<sup>1</sup> (Government of Western Australia, 2004)

<sup>2</sup> (Government of Western Australia, 2004)

6. Engagement with the Department of Education on eating disorders, including:
  - Targeted training for school psychologists.
  - Training for teachers.
  - Inclusion in health and nutrition classes in schools.
  - Strengthening referral pathways to supports for families and carers of people with an eating disorder.
  - Early intervention initiatives in schools.
  - Review of healthy eating programs in schools, including the traffic light system and use of BMIs.
7. Broadening of focus area 3 to 'Increase education, training and system navigation support to education, health and mental health professionals, and Lived Experience (Peer) workers (carer and consumer) in community, health and education services'.
8. Inclusion of a strategic priority in focus area 3 which provides incentives and/or scholarships for staff and students to undertake extra education and training on eating disorders.
9. Inclusion of strategic priorities and actions in focus area 3 which address the need for increased engagement with the Department of Education and education professionals.
10. Establishment of local community-based residential rehabilitation programs, which also offer services for respite (focus area 4).
11. Amendment to strategic priority 4.1 in focus area 4 to 'Establish options for the provision of community-based, in-home, respite and residential rehabilitation care within the system of care that supports individuals and their carers and families.'
12. The establishment of a centre of excellence to be responsible for eating disorder research for WA and building an evidence base.
13. The inclusion of a specific focus area for carers and families of people with an eating disorder. This focus area is recommended to be 'Focus Area 6: Provide evidence-based support and tangible recognition for carers and families of people with an eating disorder'.

## 2.0 Introduction

---

Carers WA (CAWA) appreciates the opportunity to provide feedback to the WA Mental Health Commission, in response to its *Western Australian Eating Disorders Framework 2025-2030: Consultation Draft Priorities Paper* (the draft Framework).

CAWA is pleased to see the strong focus within the draft Framework on lived experience, training and involvement of families in treatment plans. We are also pleased to see a person-centred approach to the Framework, and the clear adoption of the tiered step-up-step-down system embraced within the National Eating Disorder Strategy.

However, CAWA is concerned that the draft Framework does not include or define the role of carers, recognition of carers, or support for carers. Feedback from carers indicates that, while the draft Framework is seen as a significant improvement for people with eating disorders, targeted recognition and support for carers remain inadequate in what is a very challenging space for carers and families.

For the purposes of this submission, the term ‘carer’ is defined as per the meaning under the *Carer Recognition Act 2004* (WA), this being an individual who provides care and assistance to another person/s who has disability, chronic illness, mental illness, or who because of frailty requires assistance with carrying out everyday tasks<sup>3</sup>. A carer does not include someone who provides care or assistance as part of a contract for services or community work. A carer may include a friend, family member, neighbour or other contact<sup>4</sup>. Carers can be aged under 25 (young carers) or be older carers.

This submission has been informed by ongoing feedback from carers, ongoing consultation with WA metropolitan and regional communities, feedback from an online survey for carers of people with eating disorders, and a targeted consultation session with carers of people with eating disorders.

---

<sup>3</sup> (Government of Western Australia, 2004)

<sup>4</sup> (Government of Western Australia, 2004)

## 3.0 General Feedback

---

### 3.1 Context

In Australia, 1.1 million Australians or 1 in 23 people live with an eating disorder (4.45% of Australians)<sup>5</sup>. The financial impact of eating disorders, including on individuals, their families and carers, governments and society is estimated to exceed \$66.9 billion per annum (\$60,654 per person with an eating disorder)<sup>6</sup>. Carers WA considers this estimate and the number of people with an eating disorder to be conservative due to the stigmatisation and lack of understanding around these health conditions. For every person with an eating disorder, there are multiple carers, family members and friends helping to support them in their journey. These carers may be parents, significant others, siblings, young carers aged under 25 years, children – the list goes on. Recognition of these important support people is substantially important.

Having carers and families of people with eating disorders involved in their treatment is invaluable, offering benefits such as prioritisation of the person receiving care, assisting in decision making, and offering support<sup>7</sup>. However, this also has adverse impacts on carers and families, on their relationships, identity, physical, emotional and mental health. Carers and families also often bear other costs such as treatment costs for their loved one, costs to support the carer's own physical and mental wellbeing from the stress of their caring role, and financial costs from reduced ability to work, superannuation, private health insurance, and life savings<sup>8</sup>. Indeed, carers have significantly higher rates of psychological distress than the average Australian. Over half of carers have poor wellbeing, compared to 25.4% of adult Australians. Only 17.1% of carers reported having good health, compared to 47.9% for the average Australian<sup>9</sup>.

Further, by age 67 primary carers will lose \$175,000 in superannuation and \$392,500 in lifetime earnings. For every year someone is a primary carer they will lose on average \$17,700 in superannuation and \$39,600 in lifetime earnings<sup>10</sup>. The most impacted 10% of primary carers lose an average of \$444,500 in superannuation and \$940,000 in lifetime earnings by age 67<sup>11</sup>.

---

<sup>5</sup> (Deloitte Access Economics, 2024)

<sup>6</sup> (Deloitte Access Economics, 2024)

<sup>7</sup> (Deloitte Access Economics, 2024)

<sup>8</sup> (Deloitte Access Economics, 2024)

<sup>9</sup> (Schirmer, Mylek, & Miranti, 2022)

<sup>10</sup> (Furnival & Cullen, 2022)

<sup>11</sup> (Furnival & Cullen, 2022)

While the draft Framework and supporting research<sup>12</sup> report that on average, carers for someone within an eating disorder will provide 12.4 hours of care per week, this is also a conservative figure based on other research. The 2022 National Carer Survey found that carers provided an average of 103.8 hours per week of care, with half of respondents providing 24/7 care<sup>13</sup>. Given the type of support provided by respondents to Carers WA's survey of carers of people with an eating disorder (see section 3.2.2 for a summary), 12.4 hours per week does not even begin to cover the time spent by carers and families in supporting their loved ones.

Practical and tangible targeted support for carers and families of people with eating disorders is not an option, it is a necessity. This was strongly demonstrated in consultations conducted by Carers WA with carers, families and people with lived experience of eating disorders.

#### **Carers WA recommends:**

- 1. Terminology be adopted within the draft Framework to consistently refer to 'families and carers', with a supporting definition within the 'key terms' section of the paper as per the definition under the Carer Recognition Act 2004 (WA):**
  - **'A carer is an individual who provides care and assistance to another person/s who has disability, chronic illness, mental illness, or who because of frailty requires assistance with carrying out everyday tasks<sup>14</sup>. A carer does not include someone who provides care or assistance as part of a contract for services or community work. A carer may include a friend, family member, significant other, neighbour or other contact<sup>15</sup>. Carers can be aged under 25 (young carers) or be older carers.**

---

<sup>12</sup> (Deloitte Access Economics, 2024)

<sup>13</sup> (Carers NSW, 2023)

<sup>14</sup> (Government of Western Australia, 2004)

<sup>15</sup> (Government of Western Australia, 2004)



## 3.2 Carers WA Survey of Carers of People with Eating Disorders

### 3.2.1 Demographics

Carers WA conducted a broad survey of carers of people with an eating disorder, which attracted 52 responses.

Of the survey respondents, 94.23% were from current carers, 3.85% of responses were from former carers, and 1.92% identified as not being in either of these groups. 78.85% of respondents were female, and 21.15% were male. 1.92% of respondents were from an Aboriginal or Torres Strait Islander background, and other respondents identified that they were born in Australia, the United Kingdom, England, New Zealand, South Africa, India, Rhodesia, and Ireland. 96.15% of respondents identified as only speaking English at home, and 3.85% advised they spoke additional languages such as Italian and French.

Carers identified that they provided care for their husband (1.92%), wife (9.62%), daughter (51.92%), son (23.08%), or grandchild (3.85%). In addition, 9.62% of survey respondents identified that they provided care for their mother, carer, foster child and friend.

The care that was provided was specified to be for health conditions including Anorexia Nervosa (34.62%), Bulimia Nervosa (5.77%), Binge Eating Disorder (13.46%), Avoidant/Restrictive Food Intake Disorder (ARFID) (25.00%), or Other Specified Feeding & Eating Disorder (OSFED) (3.85%). Further, 17.31% of respondents identified other or alternate health conditions, including: multiple age-related comorbidities, Dementia, anxiety, depression, anaemia, coeliac, endometriosis, mental health conditions, comfort eating, autism, ADHD, adult-onset anorexia, both ARFID and emerging anorexia, or which were in the process of being diagnosed.

### 3.2.2 Type of care provided

Carers of people with an eating disorder reported that they provided a wide variety of support to their loved ones. This support included:

- Practical support: transport, shopping, domestic, cleaning, cooking, home maintenance, 24-hour supervision and support.
- Mental health support: emotional support, support socially and relationships, encouragement, peer and counselling support, provide distraction and safety in times of distress.
- Personal care: showering, dressing, day to day care, sleep support, ensuring does not exercise excessively.
- Meal preparation, eating and monitoring: prompting, weight records, support, liaising to ensure eating, nutrition, monitoring bathroom visits to ensure no purging.
- Financial support.
- Advocacy: at appointments, with specialists, in the community.

- Organisation/administration: for medical appointments, with accommodation and therapy team, case management, education and homeschooling support, managing family-based treatment, appointment management, researching.
- Supporting recovery from self-harm episodes.
- Liaising with specialists, doctors, schools, etc.
- Medication and supplement management
- Support for related health issues.
- Everything.

### 3.2.3 Things that are working well

*'There is no support for carers and it takes a horrific toll on the family and children in it.' – response from a carer*

Many (36.5%) of the carers who responded to the survey were either not aware of any supports for carers of people with an eating disorder, or responded that there was nothing available. A large portion of the remainder of the survey respondents were either focused on supports for the person they cared for, or had heard of some supports but were not able to access them. Particular things identified as working well (when carers and consumers were able to access them) included:

- The person being cared for having access to NDIS capacity building funding.
- When specialists are trauma informed.
- When there are specialists that understand co-occurring health conditions and their impact on each other. i.e. ASD, ADHD and Anorexia.
- Online support groups
- Peer support
- Facebook groups for carers
- More recognition for eating disorders as legitimate mental health disorders by government, medical, psychiatrists and more specialists being available.
- Family based treatment – with increased support for the family.
- When treatments for people with eating disorders are customized/individualized.
- Greater recognition and understanding for carers and families, and that they are part of the recovery solution.

Particular support options which carers said were helpful were: the EDFA Facebook group for carers; the Feed the Gap program; school support for when person being cared for is in hospital; Perth Children's Hospital eating disorders clinic; the SWAN Clinic; the ESUS Centre; FEAST online forum; and the DOR program by Ellyn Satter in the USA.

### 3.2.4 Things that are not working well

#### Mental health services and supports

*‘Certainly not the mental health system that hospitalised her and saw her deterioration to the point she needed resuscitation.’ – response from a carer*

Carers reported that mental health services and supports were not adequate to support people with eating disorders, their carers and families. This was especially in regard to the number of subsidised appointments available through the GP Mental Health Plan, with only ten appointments considered to be nowhere near enough.

In addition, carers raised concerns regarding:

- The lack of training in mental health teams and
- The limited amount of psychiatric and psychological help available.
- Waiting lists in the mental health system
- Suitably qualified mental health supports for older adults
- Limited access to urgent or acute care outside of traditional mental health units.
- Mental health support to treat eating disorders.
- Lack of understanding of eating disorders as a mental health condition.

#### Stigma and lack of understanding

*‘There is not enough support for carers at all. I am reliant on information sharing through Facebook groups, and most of that information comes from an international group. I have to advocate so hard all the time. There is a major lack of knowledge and information in our community and with providers.’ – response from a carer*

Carers reported that many things were not working well for not only carers and families, but also for the person with an eating disorder. Carers raised that they were not aware of any supports, and felt like they were doing it all on their own. This was especially prevalent concerning conditions which were considered to be not as well known such as AFRID.

Survey respondents raised that there was prevailing stigma towards people with eating disorders, even amongst medical professionals and specialists. There was also a lack of understanding and knowledge amongst GPs and other medical professionals. Carers experienced advice from their GP for their loved one to ‘eat a burger’, with no follow-up appointments, blood tests or investigation given. Carers raised that these comments impacted families and carers, as it made them feel as if there is a lack of understanding of their loved one’s needs and therefore a lack of legitimate support for carers.

Carers reported that, in general, there was a significant lack of current skills and knowledge on eating disorders by GPs, clinical psychologists, dieticians, psychiatrists and all levels of hospital staff.

## Service access

Carers described waiting months for an appointment and for appropriate treatment, and raised there were an inadequate number of services in Perth for eating disorders. Many services interstate were very eastern-states focussed, including those with supports for carers. Carers reported issues with accessing appointments and supports due to availability of appointments and online supports at times which were not suitable for the Perth timezone. Further, carers also raised there being limited access to meaningful help for families in regional areas.

Where specialists and services were able to be accessed for eating disorders, carers reported a lack of holistic treatments. The specialists were reported to each work on their own area, but nothing was tied together. Particular gaps were identified in services for eating disorders in young children, 16-18 year olds, and people aged over 65.

## Treatment cost and financial impact on the carer

*'There are not enough services, wait times are long and the financial cost is high. I have spent thousands of dollars on treatment for him since February. I have also had to take heaps of leave from work, averaging about 2 days per week since February to take him to appointments, sometimes across three days per week. This makes it hard to maintain my job. My boss has asked me to go part time to accommodate this, but I need the income to pay for the appointments.'* – response from a carer

Cost was raised as being a barrier to accessing supports, with thousands of dollars being spent per year on treatments for loved ones. In addition, carers reported taking significant amounts of leave from work while incurring these costs, resulting in difficulties in maintaining paid work and increased financial stress.

This was particularly pronounced for carers in regional areas. Carers reported needing to take time off work and quickly running out of leave, especially when needing to attend appointments that took four or more hours to drive to. Regional carers also reported a lack of training in hospitals about eating disorders, unless they were at a major hospital. If living regionally, the nearest hospital that was equipped to handle caring for someone with an eating disorder was often four or more hours away.

## Reluctance to include carers and families

*‘There is still a lot of reluctance by clinicians and others to include carers/families in all aspects of therapy/treatment. There are still a number of health professionals who blame families/parents. There are still clinicians who use coercive control tactics in the child and adolescent cohorts threatening to report parents to child protection services. Particularly when the carer/parent is challenging the treatments/therapies that are excluding them.’ – response from a carer*

Many carers were supportive of the use of family based therapy in treatment plans, as well as the inclusion of carers and families in treatment. Carers raised that alongside this needed to be support for the family and carers as well as the person with an eating disorder, as well as options for when the family and carer are not able to partake in this method of treatment.

Survey respondents raised that often resources were limited and client-focused with little to help the families and carers. Carers raised this made them feel like the value and impact of family contributions in caring and provision of assistance were being ignored.

### 3.2.5 Areas of unmet need and gaps in services

The biggest areas of unmet need and gaps in services which carers identified included:

- Services for men.
- Psychological support.
- Education:
  - In schools to review healthy eating programs and rewards, etc.
  - For medical professionals and specialists on eating disorders.
  - For the community to spread awareness and reduce stigma.
- Mental health support to treat eating disorders.
- Recognition of ARFID as an eating disorder under the Eating Disorder Plan.
- Availability of quality therapy and medical care that is timely, local and affordable.
- In-home intensive support.
- Step-up Step-down services.
- Cost of services and wait-times for services.
- Lack of services for early intervention and awareness.
- Individualised support that is ongoing.
- A dedicated remote and regional eating disorder team.
- Under resourcing of WAEDOCS (WA Eating Disorder Outreach Consulting Service).
- Exclusion of carers from the clinical processes and subsequent damaging outcomes of clinical sessions with patients.
- Lack of screening for neurodivergent conditions and associated adaption of treatment methods in response to the results of that screening.

### 3.2.6 Biggest areas of need for carers

Carers raised that the biggest areas of need for carers of people with an eating disorder included:

- Respite.
- Practical support for carers, which is responsive to the needs of the carer and family.
- In-home meal support.
- Local support for carers of people with eating disorders.
- Support for young carers (aged under 25) and siblings of people with an eating disorder.
- Financial support and affordable care.
- Mental health support.
- Education on how to manage eating disorders.
- Family therapy.
- Increase in community understanding of eating disorders.
- Education for parents and carers, especially at the start of the caring role.
- Lack of current psycho-education for carers and how to be a carer for different types of eating disorders.

### 3.2.7 Solutions

Survey respondents were asked their thoughts on any immediate or 'quick win' actions that could be taken to address the identified unmet needs and gaps in services.

Options which were identified included:

- More financial support for therapy and treatment costs;
- Information and education resources which included autism and older adults;
- More freely available education and counsellors;
- Introduction of Temperaments Based Therapy with Supports (TBT-S) in line with actions being taken in Victoria to do so;
- Increased GP and other health professional information and knowledge on eating disorders;
- Putting in more carer supports;
- Carers leave;
- Step up-step down programs;
- Better training for staff looking after patients;
- Increased public awareness and visibility of eating disorders; and
- A consolidated directory for eating disorder services.

However, many carers also raised that there are no quick wins with eating disorders, and that they require long term funding, support and understanding.

Additional longer-term actions which were identified as being needed included:

- The development of holistic, comprehensive services that specialize in eating disorders and also support carers and families.
- One stop shop clinics for people with eating disorders.
- Review of NDIS access for psychosocial conditions to include eating disorders.
- Support programs to help carers learn how to care.
- Ensure the WA Department of Education and the private school systems have eating disorders on their list and follow the most up to date prevention and early identification strategies.
- A dedicated facility for eating disorder in children and young adults which is a caring and supportive, compassionate environment away from the children's hospital.
- Bring services to regional Australia, better training and awareness.
- Enhance the resourcing of WAEDOCS, so it emulates the Centre for Excellence in Eating Disorders (CEED) in Victoria.

## 3.3 Feedback on the Draft WA Eating Disorder Framework

### 3.3.1 Draft Vision and Guiding Principles

Carers felt that the draft Vision *'All Western Australians experience optimal mental health and wellbeing to reduce the impact of eating disorders in our community'* was one which was too big and unachievable for the draft Framework. It was recommended that the vision be revised to focus on a more measurable outcome such as increasing awareness of eating disorders, developing primary prevention measures and addressing the underlying influences which contribute to the development of eating disorders.

Carers also raised the need to include in the draft purpose, that the framework, eating disorders and treatment needs to be for all ages, due to identified gaps in services for children, 16–18-year-olds and people aged over 65. Carers WA recommends the draft purpose be amended to *'To provide a framework to guide a coordinated approach to address and prevent eating disorders in Western Australia from 2025-2030, that supports a person-centred, comprehensive, equitable and culturally responsive system of care for all ages.'*

#### **2. In the Guiding Principles of the draft Framework, Carers WA recommends the following amendments be made:**

- **Person and family-centred care, which recognises the unique and differing needs of individuals, their families and carers**
- **Recovery-oriented care, recognising that there is no single or consensus definition of recovery**
- **Lived experience guidance and leadership**
  - **Carers WA recommends more clarity and guidance be provided regarding this principle, and in what context leadership is referred to. i.e. Leadership from the family, more broadly in the community, or the importance of the system to listen to those with lived experience, etc.**
- **Lived experience workforce, including young people and carers**
- **Innovative, evidence-based and evidence-generating approaches**
- **Timely and flexible treatment and support pathways**
- **Equity of access including for priority groups and within regional and remote areas**
- **Trauma-informed care that acknowledges co-occurring conditions**
- **Culturally safe, sensitive, and competent practice.**

Carers also queried whether the 'What this may look like' sections within the draft Framework were ones which would definitely be carried over into the final document, with supporting action plans and deliverables to track achievement of the actions, strategic priorities and key focus areas.



**Carers WA recommends:**

- 3. Further clarity be provided in the final Framework on actions to be achieved, and the inclusion of an implementation plan and deliverables to track progress of the actions, strategic priorities and key focus areas.**

### **3.3.2 Focus Area 1: Strengthen prevention and early intervention programs and services in the community, particularly in regional areas**

Carers were generally supportive of this focus area and its inclusions, but recommended the following changes be made to clarify and broaden the focus area.

**4. Carers WA recommends:**

- **Rephrase the focus area to be: ‘Develop and establish prevention and early intervention programs and services in the community for all ages, particularly in regional areas’.**
- **Inclusion of a strategic priority to include education and specialization on eating disorders in key Vocational Education and Training courses for community early intervention professions such as the:**
  - **Certificate IV in Mental Health Peer Work**
  - **Certificate IV in Mental Health**
  - **Diploma of Counselling**
  - **Diploma of Mental Health**
  - **Advanced Diploma of Nursing**
  - **Allied Health Assistance – Nutrition and Dietetics Skill Set.**
- **1.5- Ensure access to person-centred, trauma-informed and timely treatment in the community, at the level of intensity people require, as close to home as possible (including digital options and virtual care pathways).**
- **1.3 - Strengthen awareness in the Western Australian community and amongst health professionals of eating disorders, including common signs and symptoms and the importance of early intervention.**

### **3.3.3 Focus Area 2: Improve access to system navigation and transition support between programs and services, as well as psychosocial support across the care continuum**

Carers were supportive of this focus area, describing it as critical, not just for carers and consumers but also for all the other services that are in the system.

Carers raised the need for an independently funded advocacy and system navigator services, stating that generally when a family and consumer needs advocacy, things are not going very well. It was raised that due to the complexity of eating disorders, there was a real need for something to help carers and consumers that are going through it, which would in turn take the pressure off some of the services.

Carers also spoke on the need for programs to support carers while consumers were on waitlists to receive treatment, or going through diagnosis.

#### **Carers WA recommends:**

- 5. Online programs be established to support carers to provide care for people at home while waiting for appointments, treatment and/or diagnosis.**

### **3.3.4 Focus Area 3: Increase education, training and system navigation support to health and mental health professionals and Lived Experience (Peer) workers in community and health services**

Carers raised concerns about not being taken seriously by health professionals, being perceived as being over the top or that they were the problem. It was raised that sometimes in these cases, child protection action could be taken. Carers recommended the need for health professionals who are more informed and understanding of the situation that carers and families are going through when they are caring for someone with an eating disorder, as well as the emotions which the family is going through (stress, anxiety, frustration, anger, guilt, etc). Carers WA recommends that increased education and staff training around eating disorders in health, community and related sectors be established; coupled with increased employment of carer and consumer peer workers.

Carers also raised that one big area which was missing from the draft Framework, was engagement with the Department of Education on eating disorders, as well as inclusion of eating disorders in training and education for community professionals.

#### **Carers WA recommends:**

- 6. Engagement with the Department of Education on eating disorders, including:**
  - Targeted training for school psychologists.
  - Training for teachers.
  - Inclusion in health and nutrition classes in schools.
  - Strengthening referral pathways to supports for families and carers of people with an eating disorder.
  - Early intervention initiatives in schools.
  - Review of healthy eating programs in schools, including the traffic light system and use of BMIs.
- 7. Broadening of focus area 3 to 'Increase education, training and system navigation support to education, health and mental health professionals, and Lived Experience (Peer) workers (carer and consumer) in community, health and education services'.**
- 8. Inclusion of a strategic priority which provides incentives and/or scholarships for staff and students to undertake extra education and training on eating disorders.**
- 9. Inclusion of strategic priorities and actions which address the need for increased engagement with the Department of Education and education professionals.**

### 3.3.5 Focus Area 4: Improve equitable access to trauma-informed, specialised bed-based care within hospitals and the community that addresses the complexities of co-occurring conditions

Carers were supportive of actions for multidisciplinary teams, but raised concerns over the practical application of multidisciplinary teams, stating that in their experience when in hospital, the person with an eating disorder often moved between many different teams. Throughout this process, coordination of care often did not happen in practice, although it was something that should be happening. One carer described how an eating disorder diagnosis did not happen until they demanded a multidisciplinary meeting with everyone caring for their loved one, and all the specialists were able to compare notes. Other carers described how on medical wards even multidisciplinary teams were just not talking to each other when a person was transferred from one specialist to another.

Carers were also in support of the Focus Area 4 action for ‘undertaking needs assessments to determine the need and scope of a community based residential rehabilitation program’. It was raised that some Western Australians with eating disorders were using interstate or international residential services, with nothing available locally while waiting for services. Carers spoke of the need for local residential facilities which offered treatment away from a hospital bed, with the opportunity to be in the sunshine and make some connections. This type of facility was especially noted as being needed for carers to have respite, particularly for carers of children, to have a place they trusted to care properly for their loved ones.

#### Carers WA recommends:

- 10. Establishment of local community-based residential rehabilitation programs, which also offer services for respite.**
- 11. Amendment to strategic priority 4.1 to ‘Establish options for the provision of community-based, in-home, respite and residential rehabilitation care within the system of care that supports individuals and their carers and families.’**

### **3.3.6 Focus Area 5: Build an evidence-base for eating disorders programs and services, with a focus on research, data and evidence generation across the care continuum, particularly for priority populations**

Carers were supportive of this focus area, including the focus on priority populations, but raised that there also needed to be a focus in general on eating disorders. Carers raised experiences in which treatment options which were working for their loved ones were discarded

#### **Carers WA recommends:**

#### **12. The establishment of a centre of excellence to be responsible for eating disorder research for WA and building an evidence base. This should include:**

- **Co-design, co-produced research in collaboration between researchers, people with lived experience of an eating disorder, carers, families and service providers.**
- **Identification of and action on research gaps.**
- **Early identification and prevention.**
- **Development of a directory of treatment approaches, as well as the evidence available for each approach.**
- **Actively monitor eating disorder activity.**
- **Ensuring input from a diverse range of people, especially from priority groups.**

### 3.3.7 Focus Area 6: Provide evidence-based support and tangible recognition for carers and families of people with an eating disorder

Within the *Carers Recognition Act 2004* (Cth), the Western Australian Carers Charter states specifically that:

1. 'Carers must be treated with respect and dignity.
2. The role of carers must be recognized by including carers in the assessment, planning, delivery and review of services that impact on them and the role of carers.
3. The views and needs of carers must be taken into account along with the views, needs and best interests of people receiving care when decisions are made that impact on carers and the role of carers.
4. Complaints made by carers in relation to services that impact on them and the role of carers must be given due attention and consideration.'

In its current form, the draft Framework does not adequately recognise the role of carers, the views of carers or the needs of carers. In fact, the term 'carer' is barely included or defined at all within the draft framework. This was noted by carers during consultations, and if the draft framework is finalised in its current form, will continue the current substantial lack of recognition, inclusion and support of carers in the eating disorder sector.

**For this reason, Carers WA recommends:**

- 13. The inclusion of a specific focus area for carers and families of people with an eating disorder. This focus area is recommended to be 'Focus Area 6: Provide evidence-based support and tangible recognition for carers and families of people with an eating disorder'. Strategic priorities for this focus area are recommended to include:**
  - Provide education, training and support to carers and families from the beginning of their caring journey.
  - Ensure carers are able to access local, affordable and suitable respite for the person they care for.
  - Carers and families are recognized and included in line with the WA Carers Charter and the Carer Recognition Act 2004 (WA).
  - Carers are able to access services to support themselves in their caring role.
  - Health, Education and Community sector employees are aware of carers and know how to refer them to appropriate services for themselves.

## 4.0 Conclusion

---

Should the Mental Health Commission require any further information regarding the comments included within this submission, or assistance from the perspective of WA carers, Carers WA would be delighted to assist. Please contact the Carers WA Policy Team at [policy@carerswa.asn.au](mailto:policy@carerswa.asn.au).

## References

---

- Carers NSW. (2023). *2022 National Carer Survey: Full Report*. Sydney: Carers NSW. Retrieved from <https://www.carersnsw.org.au/about-us/our-research/carer-survey>
- Deloitte Access Economics. (2024). *Paying the Price, Second Edition: The economic and social impact of eating disorders in Australia*. Retrieved from [chrome-extension://efaidnbnmnnibpcajpcglclefindmkaj/https://butterfly.org.au/wp-content/uploads/2024/03/Paying-the-Price\\_Second-Edition\\_2024\\_FINAL\\_0724.pdf](chrome-extension://efaidnbnmnnibpcajpcglclefindmkaj/https://butterfly.org.au/wp-content/uploads/2024/03/Paying-the-Price_Second-Edition_2024_FINAL_0724.pdf)
- Furnival, A., & Cullen, D. (2022). *Caring Costs Us: The economic impact on lifetime income and retirement savings of informal carers*. Canberra: Evaluate and Carers Australia. Retrieved from <https://www.carersaustralia.com.au/wp-content/uploads/2022/04/Final-Economic-impact-income-and-retirement-Evaluate-Report-March-2022.pdf>
- Government of Western Australia. (2004). *Carers Recognition Act 2004*. Perth, WA, Australia. Retrieved from [https://www.legislation.wa.gov.au/legislation/prod/filestore.nsf/FileURL/mrdoc\\_28814.pdf/\\$FILE/Carers%20Recognition%20Act%202004%20-%20%5B01-e0-01%5D.pdf?OpenElement](https://www.legislation.wa.gov.au/legislation/prod/filestore.nsf/FileURL/mrdoc_28814.pdf/$FILE/Carers%20Recognition%20Act%202004%20-%20%5B01-e0-01%5D.pdf?OpenElement)
- Schirmer, J., Mylek, M., & Miranti, R. (2022). *Caring for others and yourself: 2022 Carer Wellbeing Survey*. Canberra: Carers Australia & University of Canberra. Retrieved from [https://www.carersaustralia.com.au/wp-content/uploads/2022/10/2022-CWS-Full-Report\\_221010\\_FINAL.pdf](https://www.carersaustralia.com.au/wp-content/uploads/2022/10/2022-CWS-Full-Report_221010_FINAL.pdf)



## APPENDIX 1: Detailed Feedback

WA Eating Disorder Framework		
Section and Page	Quote	Carers WA Feedback
Key Terms (pg 3)	-	<p>Inclusion of a definition of 'carer' as defined by the <i>Carer Recognition Act 2004 (WA)</i>:</p> <p>A carer is an individual who provides care and assistance to another person/s who has disability, chronic illness, mental illness, or who because of frailty requires assistance with carrying out everyday tasks<sup>16</sup>. A carer does not include someone who provides care or assistance as part of a contract for services or community work. A carer may include a friend, family member, significant other, neighbour or other contact<sup>17</sup>. Carers can be aged under 25 (young carers) or be older carers.</p>
Eating Disorder Facts	-	<p>Carers and families are not recognised adequately in these dot points. Include in dot points:</p> <ul style="list-style-type: none"> <li>• Having carers and families of people with eating disorders involved in their treatment is</li> </ul>

<sup>16</sup> (Government of Western Australia, 2004)

<sup>17</sup> (Government of Western Australia, 2004)

		<p>substantially valuable, offering benefits such as prioritisation of the person receiving care, assisting in decision making, and offering support<sup>18</sup>.</p> <ul style="list-style-type: none"> <li>• Caring responsibilities have adverse impacts on carers and families, on their relationships, identity, physical, emotional and mental health<sup>19</sup>.</li> <li>• Carers have significantly higher rates of psychological distress than the average Australian. Over half of carers have poor wellbeing, compared to 25.4% of adult Australians. Only 17.1% of carers reported having good health, compared to 47.9% for the average Australian<sup>20</sup>.</li> <li>• By age 67 primary carers will lose \$175,000 in superannuation and \$392,500 in lifetime earnings. For every year someone is a primary carer they will lose on average \$17,700 in superannuation and \$39,600 in lifetime</li> </ul>
--	--	--

---

<sup>18</sup> (Deloitte Access Economics, 2024)

<sup>19</sup> (Deloitte Access Economics, 2024)

<sup>20</sup> (Schirmer, Mylek, & Miranti, 2022)

		earnings <sup>21</sup> . The most impacted 10% of primary carers lose an average of \$444,500 in superannuation and \$940,000 in lifetime earnings by age 67 <sup>22</sup> .
Stepped System of Care for Eating Disorders (pg 10)	‘with stakeholders to build and embed a system of care that meets the needs of people experiencing or at risk of eating disorders, and their families and communities.’	‘with stakeholders to build and embed a system of care that meets the needs of people experiencing or at risk of eating disorders, <del>and</del> their families, <u>carers</u> , and communities.’
Stepped System of Care for Eating Disorders (pg 11)	‘involvement of person, family/supports and community’	‘involvement of person, family, <u>carers</u> and community’
Stepped System of Care for Eating Disorders (pg 11) - Prevention.	‘; lived experience organisations; media and social media; individuals, families, and communities.’	‘; lived experience organisations; media and social media; individuals, families, <u>carers</u> , and communities.’
Stepped System of Care for Eating Disorders (pg 11) - Identification.	‘Contexts: individuals and families;’	‘Contexts: individuals, families <u>and carers;</u> And <u>Inclusion of identification of carers and families and referral or provision of information on support services for the carers, families and support persons.</u>
Stepped System of Care for Eating Disorders (pg 11) – Initial response.	‘encourage the involvement of the person’s family/supports and community’	‘encourage the involvement of the person’s family, <u>carers</u> and community. <u>This should include education for the person’s family and carers on how to support the person and themselves during this journey. Ensure that the person’s family/carer/supports are referred to supports for</u>

<sup>21</sup> (Furnival & Cullen, 2022)

<sup>22</sup> (Furnival & Cullen, 2022)

		<u>themselves as well</u>
Stepped System of Care for Eating Disorders (pg 11) – Psychosocial and Recovery Support	‘support the broader psychological and social needs of the person experiencing or at risk of an eating disorder and their family/supports and community’	‘support the broader psychological and social needs of the person experiencing or at risk of an eating disorder and their family, <u>carers</u> and community’
Stepped System of Care for Eating Disorders (pg 11) – Psychosocial and Recovery Support	‘improved quality of life and assist family/supports and community in their caring role’	‘improved quality of life and assist family, <u>carers</u> and community in their caring role’
Stepped System of Care for Eating Disorders (pg 11) – Psychosocial and Recovery Support	‘People experiencing eating disorders and their families/supports may engage in a range of psychosocial and recovery support services and programs’	‘People experiencing eating disorders and their families <u>and carers</u> may engage in a range of psychosocial and recovery support services and programs’
Eating Disorder Programs and Services in Western Australia (pg 12)	‘However, program and service gaps remain across the stepped system of care, particularly for priority populations including children and young people, LGBTQIA+ people, neurodiverse people, Aboriginal and culturally and linguistically diverse people, and people living in regional areas.’	‘However, program and service gaps remain across the stepped system of care, <u>for families and carers</u> , and particularly for priority populations including children and young people, LGBTQIA+ people, neurodiverse people, Aboriginal and culturally and linguistically diverse people, and people living in regional areas.’
Eating Disorder Programs and Services in Western Australia (pg 12)	-	<p>Recommended inclusion of programs and services for families and carers of people with an eating disorder, including:</p> <p>Non-specific programs and services for families/carers/supports of people with an eating disorder in WA include:</p> <ul style="list-style-type: none"> <li>• Carer Gateway</li> </ul>

		<ul style="list-style-type: none"> <li>• Carers WA services</li> </ul>
Section 2: Draft Vision, Principles and Focus Areas (pg 13)	<p>Vision: ‘All Western Australians experience optimal mental health and wellbeing to reduce the impact of eating disorders in our community.’</p>	<p>The vision be revised to focus on a more measurable outcome such as increasing awareness of eating disorders, developing primary prevention measures and addressing the underlying influences which contribute to the development of eating disorders.</p>
Section 2: Draft Vision, Principles and Focus Areas (pg 13)	<p>Goal: ‘To prevent and reduce the prevalence and impact of eating disorders for individuals, families and communities in Western Australia.’</p>	<p>Goal: ‘To prevent and reduce the prevalence and impact of eating disorders for individuals, families, <u>carers</u> and communities in Western Australia.’</p>
Section 2: Draft Vision, Principles and Focus Areas (pg 13)	<p>Purpose: ‘To provide a framework to guide a coordinated approach to address eating disorders in Western Australia from 2025 to 2030, that supports a comprehensive, equitable, and culturally responsive system of care.’</p>	<p>Purpose: ‘To provide a framework to guide a coordinated approach to address <u>and prevent</u> eating disorders in Western Australia from 2025 to 2030, that supports a comprehensive, equitable, and culturally responsive system of care.’</p>
Guiding Principles (pg 14)	<ul style="list-style-type: none"> <li>• Person and family-centred care, which recognises the unique and differing needs of individuals</li> <li>• Recovery-oriented care, recognising that there is no single or consensus definition of recovery</li> <li>• Lived experience guidance and leadership</li> <li>• Evidence-based and evidence-generating approaches</li> </ul>	<ul style="list-style-type: none"> <li>• Person and family-centred care, which recognises the unique and differing needs of individuals, <u>their families and carers</u></li> <li>• Recovery-oriented care, recognising that there is no single or consensus definition of recovery</li> <li>• Lived experience guidance and leadership</li> <li>• <u>Lived experience workforce, including young people and carers</u></li> <li>• <u>Innovative</u>, evidence-based and evidence-generating approaches</li> </ul>

	<ul style="list-style-type: none"> <li>• Timely and flexible treatment and support pathways</li> <li>• Equity of access including for priority groups and within regional and remote areas</li> <li>• Trauma-informed care that acknowledges co-occurring conditions</li> <li>• Culturally safe, sensitive, and competent practice.</li> </ul>	<ul style="list-style-type: none"> <li>• Timely and flexible treatment and support pathways</li> <li>• Equity of access including for priority groups and within regional and remote areas</li> <li>• Trauma-informed care that acknowledges co-occurring conditions</li> <li>• Culturally safe, sensitive, and competent practice.</li> </ul>
Focus Area 1 (pg 16) – key issues	‘Providing people including individuals, families and communities with easy-to-access information and location-based navigation support, will mean that people receive the care and support they require, at an earlier stage of their condition.’	‘Providing people including individuals, families, <u>carers</u> , and communities with easy-to-access information and location-based navigation support, will mean that people receive the care and support they require, at an earlier stage of their condition.’
Focus Area 1 (pg 16) – draft strategic priorities	‘1.4 Facilitate access to innovative, evidence-based programs to support individuals prior to receiving treatment.’	‘1.4 Facilitate access to innovative, evidence-based programs to support individuals prior to receiving treatment, <u>as well as their carers and families</u> ’
Focus Area 1 (pg 16) – what this might look like	‘Developing and implementing innovative digital programs to support people in the interim prior to receiving treatment.’	‘Developing and implementing innovative digital programs to support people in the interim prior to receiving treatment, <u>as well as their carers and families.</u> ’
Focus Area 1 (pg 16) – what this might look like	‘Strengthening Lived Experience (Peer) and psychosocial support programs for people, their families and/or significant others in community mental health services.’	‘Strengthening Lived Experience (Peer) and psychosocial support programs for people, their families and <u>carers</u> in community mental health services.’
Focus Area 2 (pg 19)	‘The provision of coordinated, accessible and tailored information, guidance, and navigation support to individuals, their families and/or	‘The provision of coordinated, accessible and tailored information, guidance, and navigation support to individuals, their families <u>and carers</u> can

	significant others can assist them...'	assist them...'
Focus Area 2 (pg 19) – key issues	'People experiencing eating disorders, their families and/or significant others may also seek to engage in a range of psychosocial and recovery support services and programs across the system of care, at different stages of their journey.'	'People experiencing eating disorders, their families <u>and carers</u> may also seek to engage in a range of psychosocial and recovery support services and programs across the system of care, at different stages of their journey.'
Focus Area 2 (pg 19) – draft strategic priorities	<p>13.1 Promote person-centred care that is inclusive of families/significant others.</p> <p>13.2 Support people experiencing or at risk of eating disorders and their families/significant others to easily locate and navigate services in a timely manner.</p> <p>13.3 Support continuity of care for people experiencing or at risk of eating disorders and their families/significant others to transition between services and levels of treatment, through clear communication and tailored care navigation.</p> <p>2.5 Facilitate opportunities for people and their families/significant others to access timely and responsive individual advocacy, to provide a voice to those impacted by eating disorders.</p> <p>2.7 Strengthen and facilitate access to psychosocial, Lived Experience (Peer) support groups, recovery support services and</p>	<p>2.1 Promote person-centred care that is inclusive of families <u>and carers</u>.</p> <p>2.2 Support people experiencing or at risk of eating disorders and their families <u>and carers</u> to easily locate and navigate services in a timely manner.</p> <p>2.3 Support continuity of care for people experiencing or at risk of eating disorders and their families <u>and carers</u> to transition between services and levels of treatment, through clear communication and tailored care navigation.</p> <p>2.5 Facilitate opportunities for people and their families <u>and carers</u> to access timely and responsive individual advocacy, to provide a voice to those impacted by eating disorders.</p> <p>2.7 Strengthen and facilitate access to psychosocial, Lived Experience (Peer) support groups, recovery support services and programs and the NDIS for people experiencing eating disorders and their families <u>and carers</u>.</p>

	programs and the NDIS for people experiencing eating disorders and their families/significant others.	
Focus Area 2 (pg 19) – what this might look like	‘Developing a system navigation resource for GPs and other health professionals to support people, their families and/or significant others find the help they need.’	‘Developing a system navigation resource for GPs and other health professionals to support people, their families <u>and carers</u> find the help they need.’
Focus Area 3 (pg 22)	‘Increase education, training and system navigation support to health and mental health professionals and Lived Experience (Peer) workers in community and health services’	‘Increase education, training and system navigation support to education, health and mental health professionals, and Lived Experience (Peer) workers ( <u>carer and consumer</u> ) in community, health and <u>education services</u> ’
Focus Area 3 (pg 22) – key issues	‘Educating, upskilling, and providing opportunities for supervision will empower the broader health and mental health workforce to better support people with eating disorders.’	‘Educating, upskilling, and providing opportunities for supervision will empower the broader health and mental health workforce to better support people with eating disorders, <u>their families and carers.</u> ’
Focus Area 3 (pg 22) – key issues	‘...sector. However, for some health and mental health professionals who do not specialise in eating disorders, the system can appear fragmented and challenging to navigate. Integrating services...’	‘...sector. <del>However, for some health and mental health professionals who do not specialise in eating disorders, the system can appear fragmented and challenging to navigate.</del> Integrating services...’
Focus Area 4 (pg 25) – draft strategic priorities	‘4.1 Explore options for the provision of community-based residential rehabilitation care within the system of care that support individuals and their families/significant others.’	‘4.1 Explore options for the provision of community-based residential rehabilitation care within the system of care that support individuals and their families <u>and carers.</u> ’