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THE NATIONAL AGENDA FOR EATING DISORDERS 2017 TO 2022



Butterfly
Foundation for Eating Disorders

**Establishing a Baseline of Evidence-based Care for any
Australian with or at risk of an Eating Disorder**

Foreword

Eating disorders are complex neuropsychiatric disorders. They will affect up to 9% of the Australian population in their lifetime, with an increase to 15% for females. They have amongst the highest fatality rates of any psychological disorder, and only 25% of Australians with an eating disorder are known to the health system.

The stated aim of this, the First National Agenda for Eating Disorders, is to establish a baseline of evidence-based care. How can it be that this is the situation for such a serious disorder in 2017? Surely the aim should be to accelerate the finding of a cure, the implementation of widespread prevention practices and supporting sustained recovery?

Australia has barely even commenced to address proper treatment for eating disorders. Accordingly it is critically urgent that a minimum standard of evidence-based care is established across the health system, as has been done historically for critical conditions such as heart disease, diabetes and cancer. This would commence the process of participation in current and future health improvements and address the current significant underinvestment.

Eating disorders affect all ages and genders of people, irrespective of socio-economic factors. However, they are also most prevalent in our young Australians – increasingly young. Establishing a baseline of evidence-based care is an investment not only in current terms but most importantly in the future for so many of our Australian youth. There is a demonstrable benefit-to-cost of effective early intervention with these illnesses – reducing duration and impact of illness, and enhancing return to a fully productive life. That benefit-to-cost

has been quantified as over \$5 for every \$1 investment.

Please join with me in supporting and implementing this crucial First National Agenda for Eating Disorders. The Agenda is a national policy document that can and should be embraced and implemented in practice by every level of government and health service in Australia.

On behalf of Butterfly, we thank every person who has contributed to this Agenda – those on the Expert Advisory Group for their leadership and commitment to this project, those who provided submissions for our consultation process, and most importantly, those with a lived experience. Your knowledge and experience has helped shape this seminal document.

Thank you.

David Murray AO
Chair, Butterfly Foundation

Professor Susan Paxton
Chair, Expert Advisory Group
Director, Butterfly Foundation

Developing a National Agenda for Eating Disorders

Over the past ten years, national and state-based eating disorder organisations have developed a substantial suite of documents on the evidence-based standards and practices of delivering effective treatment to people with eating disorders. The National Agenda for Eating Disorders brings together the evidence and consensus-based expert opinion behind these documents into a summary of the priorities for mental health system reform to address the needs of people with eating disorders and their families.

Development of the National Agenda has involved broad consultation with individuals and organisations in every state and territory. Over 700 individuals with lived experience of eating disorders and their family members contributed to the development of the agenda. All state-based eating disorder organisations contributed as did key national stakeholders, including the Australia and New Zealand Academy of Eating Disorders (ANZAED), the National Eating Disorders Collaboration (NEDC) and the Royal Australia and New Zealand College of Psychiatrists (RANZCP).

An Expert Advisory Group was appointed to review the existing evidence and new submissions, and guide the development of a consensus-based agenda. This Group was selected to represent the different sources of knowledge and experience which are vital to the development of effective treatment services: the lived experience knowledge of people who have had eating disorders and their families; the knowledge of health professionals and the knowledge of researchers.

The National Agenda for Eating Disorders is a coproduced document developed by representatives of all key stakeholders working together in equal partnership. The approach adopted is consistent with the New Economics Foundation (NEF) definition of co-production:

“Designing and delivering services and systems in an equal and reciprocal relationship between professionals, people using services, their families and their community.”

(Adapted from NEF, 2011)

Integration of the experience-based knowledge of people with personal experience of eating disorders and their families and other carers with other sources of knowledge is the foundation for implementation of all aspects of the National Agenda. Equal partnerships that integrate experience-based knowledge are essential for the development of a mental health system that is able to meet the needs of people with eating disorders and their families.

Expert Advisory Group

Professor Susan Paxton (Chair)	Professor, School of Psychology & Public Health, La Trobe University; Director Butterfly Foundation
A/Professor Susan Byrne	School of Psychological Science University of Western Australia, Director Eating Disorders Service
Ms Belinda Caldwell	Executive Director, F.E.A.S.T.(Families Empowered and Supporting Treatment of Eating Disorders); Carer Consultant & Project Manager Victorian Centre of Excellence in Eating Disorders
Ms Joanne Cook	Founder & Director, TRED (Tasmania Recovery from Eating Disorders)
Ms Lesley Cook	Director, Partners in Practice
Ms Claire Diffey	Consultation & Education Service, Victorian Centre of Excellence in Eating Disorders
Ms Anne Doherty	Director, Butterfly Foundation
Dr Anthea Fursland	A/Director, Consultant Clinical Psychologist Centre for Clinical Interventions (CCI); WA Eating Disorders Outreach & Consultation Service (WAEDOCS)
Professor Phillipa Hay	Foundation Chair of Mental Health, School of Medicine and Centre for Health Research, Western Sydney University
Ms Kathy Logie	Project Officer, Princess Margaret Hospital Eating Disorders Program (WA); Project Officer Peer Support WA Eating Disorders Outreach & Consultation Service (WAEDOCS)
Dr Sloane Madden	Sydney Children's Hospital Network Eating Disorders Coordinator, Department of Psychological Medicine
Dr Sarah Maguire	Director Centre for Eating & Dieting Disorders
Ms Danielle Maloney	A/Statewide Eating Disorder Coordinator NSW
A/Professor Richard Newton	Medical Director, Mental Health Austin Health; Director Butterfly Foundation
Professor Tracey Wade	School of Psychology, Flinders University
Dr Warren Ward	Director of the Eating Disorder Service, Royal Brisbane & Women's Hospital
Ms Christine Morgan	CEO & Director Butterfly Foundation
Ms Frances Cook	National Manager, Knowledge, Research and Policy, Butterfly Foundation
Dr Michelle Blanchard	Butterfly Foundation
Ms Helen Searle	Project Manager, Consumer & Carer Engagement, Butterfly Foundation

Purpose of the First National Agenda for Eating Disorders

The First National Agenda for Eating Disorders sets out a national approach for collaborative effort to develop nationally consistent responses to people with eating disorders and their families and carers.

An agenda is an outline of what needs to be considered or done to achieve a stated purpose. The National Agenda for Eating Disorders sets out a shared direction for change to assist in prioritization of action by all stakeholders in mental health. An agenda is not a detailed plan of action or detailed practice standards; these documents sit behind the Agenda to enable the Agenda to be implemented.

The purpose of the first National Agenda for Eating disorders is to provide guidance for the development of a minimum effective level of evidence-based care that is accessible for all Australians who are affected by eating disorders. Our vision is that every Australian affected by eating disorders, and their families and carers has access to a range of safe, evidence-based treatment and support delivered by skilled health professionals when it is needed, early in the development of symptoms and early in subsequent episodes of illness.

Establishing a baseline of evidence-based care may not seem ambitious but is essential for people with eating disorders in Australia where gaining access to effective evidence-based treatment that is delivered in sufficient dosage and for sufficient duration to reduce the impact of illness and support sustained recovery continues to be a struggle.

Consultation with people with lived experience and their families during the development of this Agenda identified their three most important areas for action as:

1. Affordable treatment
2. Early diagnosis and access to treatment
3. Access to a full stepped continuum of care

The overwhelming priority for people with eating disorders and their families is early, affordable access to a range of safe, evidence-based treatments and recovery support that is specific to their illness and inclusive of support for the critical role of families and carers.

Establishing a baseline of accessible evidence-based treatment is the core focus of the National Eating Disorders Agenda. Establishing the basics will not meet the needs of everyone affected by eating disorders. It will, however, create a strong foundation on which to build future improvements.

The Context of the National Agenda for Eating Disorders

The National Agenda for Eating Disorders has been developed in parallel with the Fifth National Mental Health Plan (Fifth Plan). Like the Fifth Plan, it is inspired by a vision of more people with eating disorders recovering and living a life that contributes to the wider community, with good mental and physical health. People with eating disorders and their families should expect to have positive experiences of care and support from a service system which is responsive to individual and family needs, and to be safe from avoidable harm, including hospitalisation and suicide.

The stated intention of the Fifth Plan is to focus on the most significant issues that need to be addressed as part of a

"It all needs doing"

"Finding a service was a huge struggle. We bounced around psychologists with minimal training in managing eating disorders, then struggled to access a more intense therapeutic service when things became worse. There was a real lack of knowledge as to the services available and how best to access them, especially as quickly as we needed to find help."

"The lack of affordable and accessible public services, lack of awareness, lack of integrated treatment approach, and lack of trained specialised hospital staff is appalling. The wait list for the public outpatient services is at least 6 months. [People] are discharged from hospital and have no access at all to ANY services and are struggling immensely because of the long wait lists or because they do not meet the criteria for admission."

national approach. This is also the focus for the National Eating Disorders Agenda. The aims of the Fifth Plan, include integration, safe care, suicide prevention and coordinated care for people with severe illness, which are important for people with eating disorders. However, these aims can only be of relevance in the context of consistent access to eating disorder-specific treatment and support. The National Eating Disorders Agenda (the Agenda) aims to contextualise the National Fifth Mental Health Plan (the Fifth Plan) to the specific challenges facing people with eating disorders, their families and the health professionals who work with them. As far as possible and appropriate, the priorities and terminology of the Fifth Plan has been used in the Agenda.

Working together to achieve change

Development of safe, effective responses to eating disorders will require collaborative effort between states and territories, between public and private health, between medical and mental health services and between diverse professional groups.

The National Eating Disorders Agenda is relevant to all stakeholders in mental health and everyone involved with people with eating disorders. The plan is of immediate relevance to the Commonwealth, State and Territory Governments, and through these governments, to Primary Health Networks and Local Hospital Districts.

The Case for Change

Eating disorders are serious and complex mental illnesses associated with high levels of psychological distress and significant physical health complications. Eating disorders have a high prevalence, with approximately 1 in 20 Australians currently having an eating disorder (Hay et al., 2008).

These disorders have been shown to have one of the highest impacts on health-related quality of life of all psychiatric disorders (AIHW, 2008). They carry the highest mortality rate of all psychiatric illnesses, including a high risk of suicide (Arcelus, Mitchel, Wales & Nelson, 2011).

Eating disorders most frequently start in childhood and youth, consequently impacting on education, identity formation and physical growth. With a high risk of recurrence and chronicity, eating disorders can impact on health and quality of life for the whole life span. Recovery from an eating disorder is a long-term process, lasting on average for seven years but affecting up to 25% of people as a severe and enduring illness.

Eating disorders are not self-limiting illnesses and early intervention is required to reduce the severity, duration and impact of illness (AED, 2011). When people are unable to access the right treatment when it is needed, early in illness, they are put at risk of a longer duration and greater severity of illness, with potential chronicity and a high suicide risk. Eating disorders represent the 12th leading cause of mental health hospitalisation costs within Australia (Mathers, Vos & Stevenson, 1999).

The economic cost in Australia is conservatively estimated at \$69.7 billion per year, of which \$19.9 billion is the cost of health services. The burden of disease costs for eating disorders, estimated to be \$52.6 billion in 2012, are comparable to the estimates for anxiety and depression (\$41.2 billion), and for obesity (\$52.9 billion) (Deloitte Economics, 2012)

A number of evidence-based treatment approaches are available and full recovery from an eating disorder is achievable. The positive side to the story of eating disorders is often lost in the complexity of these illnesses. Person-centred care, tailored to suit the person's illness, situation and needs, is the most effective way to treat someone with an eating disorder (Hay et al., 2014). Good outcomes are achieved by people who receive this type of treatment early in illness and early in subsequent episodes of illness (NICE Clinical Guidelines 9, 2004).

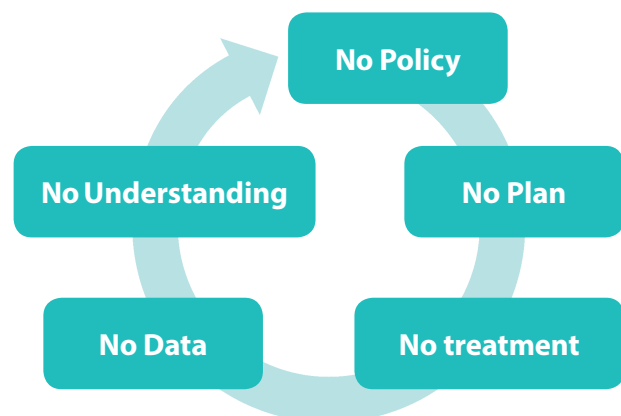
Evidence-based treatment approaches are available and full, sustainable recovery from an eating disorder is achievable.

Early detection and intervention is critical to successful outcomes. People who have had an eating disorder for less than 2 years are likely to respond more quickly to treatment and experience a shorter duration of illness with fewer physical health consequences. When delivered early in illness by health professionals with appropriate knowledge and skill in eating disorders, this treatment can lead to full clinical recovery and improved quality of life for about 75% of people with eating disorders. Despite this it is estimated that only one in ten people with eating disorders receive appropriate treatment (Noordenbos, 2002) and even fewer receive early intervention.

Since 2009 when the Commonwealth Government first engaged the National Eating Disorders Collaboration (NEDC) to map the eating disorders services and resources available in Australia, there have been a number of initiatives in various States that have started to prioritize the development of health system responses for people with eating disorders and their families. In particular, New South Wales, Queensland and South Australia have joined Victoria in implementing eating disorder service plans. There has also been development of professional training resources, delivered by state-based eating disorder organisations. However, there continue to be significant gaps in the continuum of care for people with eating disorders, and variability in the quality and accessibility of services for people living in different areas of Australia. There continue to be areas where eating disorders are not yet on the agenda for health service planning, and mental health services which exclude eating disorders from their service provision.

Without access to the right type of service, people experience a longer and more severe course of illness. Without services, diagnoses are not made, people are not referred and data is not collected. The absence of eating disorders from many health policies, plans and protocols reflects a history of failure to treat eating disorders as serious and complex illnesses. A cycle has developed in which the needs of people with eating disorders are not prioritised and therefore people continue to experience avoidable harm.

Investment in the development of appropriate mental health system responses to eating disorders to date has been insufficient to make a discernible impact on the lives of people affected by eating disorders and their families. To improve the outcomes of people with eating disorders, their families and their communities, the cycle of neglect needs to be broken. There are opportunities for national leadership in areas of policy, adoption of evidence-based standards, workforce development and targeted investment in innovative approaches to service delivery.



An Agenda for Change

The purpose of the Agenda is to provide guidance for the establishment of a baseline of accessible evidence-based treatment for people with eating disorders and their families defined as: early, affordable access to a variety of safe, evidence-based treatment and recovery support that is specific to eating disorders and inclusive of support for the critical role of families and carers.

To achieve this purpose, health service providers will need to be enabled to provide:

1. The right type of treatment
2. Earlier access to treatment
3. Enabling sustainable recovery

The concept of 'right' type of treatment aligns to the concepts and language of the Fifth Plan.

These are the changes that will be discernible to people with eating disorders and their families, and that will have an impact on their wellbeing. Behind these changes, there is a need for a number of systemic changes at national, state and regional levels in service policy and planning. Without systemic change it will not be possible to make progress towards delivery of early access to the right treatment and sustainable support for recovery.

Systemic changes identified in this agenda include:

- Inclusion of people with lived experience of eating disorders and their families in all areas of service planning, design, development, delivery and evaluation
- Identification of eating disorders as core business for all mental health services and in all related policy and initiatives
- Implementation of national standards for eating disorders
- Workforce development to ensure a workforce that is knowledgeable and skilled to identify eating disorders and deliver treatment for eating disorders
- Targeted service development to address gaps in the continuum of care
- Accountability measures to ensure that service planning and development at all levels continues to prioritize the development of a variety of evidence-based responses to eating disorders

National Eating Disorders Agenda - 2017 to 2022

Purpose: Establishing a baseline of accessible evidence-based treatments

Everyone affected by eating disorders in Australia has early, affordable access to a variety of safe, evidence-based treatment and recovery services that are specific to eating disorders and inclusive of the critical role of families and carers.

Aim	Health Service Response	Foundations for Change
<p>1. The right type of treatment</p> <p>Access to safe treatment that addresses all aspects of illness through integrated, deliver treatment for eating disorders.</p>	<ul style="list-style-type: none"> → Therapies delivered in an evidence-based dosage → Safe treatment complies with national standards and clinical guidelines → Integrated multi-disciplinary care across physical and mental health → Delivered by professionals who are educated and supervised to provide eating disorder treatment → Trained and supervised peer support is integrated into treatment 	<p>National leadership of systemic change to provide a foundation for developing the right type of early treatment and recovery services for people with eating disorders:</p> <p>Standards</p> <ul style="list-style-type: none"> → Implement existing national standards and workforce competencies → Develop national guidelines on coordinated stepped care for people with eating disorders <p>Systems</p> <ul style="list-style-type: none"> → Identify eating disorders as core business for mental health → Establish the enablers for integrated medical and mental health care → Align medical benefits and health initiatives with the evidence base for eating disorders treatment
<p>2. Earlier access to treatment</p> <p>Early access to safe treatment, early in subclinical presentation, early in illness and early in subsequent episodes of illness, is the best-known approach to reduce the impact of illness and the risk of suicide and support sustainable recovery.</p>	<ul style="list-style-type: none"> → High-risk populations are screened and accurately diagnosed → Referral pathways are clearly documented → Targeted prevention programs meet the needs of children and adolescents with early sub-clinical symptoms → Community-based intermediate levels of care → Delivered by professionals who are educated and supervised to diagnose eating disorders and work as part of an eating disorder treatment team 	<p>Workforce</p> <ul style="list-style-type: none"> → Coordinate collaborative dissemination of existing education in eating disorders → Support development of tertiary outreach capabilities to enable consultation and supervision → Service Development → Develop existing eating disorder digital services to include prevention, self-help and recovery assistance → Develop models for community-based intermediate levels of care
<p>3. Enabling sustainable recovery</p> <p>The work of recovery takes time and occurs in the context of everyday life. Families play a vital role in helping people to identify risks, seek help, engage with treatment and sustain recovery.</p>	<ul style="list-style-type: none"> → Person-centred and recovery-oriented practice → Services are redesigned to facilitate integration of families in treatment teams → Community-based and online recovery and education services are accessible throughout recovery → Practical in-home support services are accessible to avoid unnecessary hospitalisation → Peer support workers are provided with education and professional supervision to enable them to provide safe effective recovery support 	<ul style="list-style-type: none"> → Support development of tertiary outreach capabilities → Models of family-inclusive practice are described and promoted <p>Accountability</p> <ul style="list-style-type: none"> → Monitor and report on progress against the National Agenda → Ensure that collection of data on eating disorders → Include people with lived experience and their families and carers in all aspects of service planning, development, delivery and evaluation

National Eating Disorder Agenda



People with eating disorders and their families do not have reliable access to safe evidence-based treatment and support when they need it, early in illness and early in subsequent episodes of illness.

Experiences include:

- Missed opportunities to diagnose and misdiagnosis
- Lack of treatment options
- Entry criteria exclude early help seekers and severely unwell
- High costs of treatment and lack of public health services
- Lack of health professionals knowledgeable and skilled in eating disorders
- Lack of collaboration between medical and mental health
- Lack of rural services. Evidence supports early intervention with safe, evidence-based treatment as the most effective response for all eating disorders. Without this there are high risks of:
- Long duration of illness
- Development of chronic physical and mental illness
- Hospitalisation
- Suicide
- Premature mortality

1. The Right Treatment

- Evidence-based treatment specific to illness
- Integrated medical, psychological, nutritional and functional treatment
- Evidence-based dosage and duration of treatment

2. Earlier Access

- Screening and assessment of people at high risk
- Targeted prevention programs including online self-help
- Referral pathways
- Evidence-based entry criteria for early treatment at appropriate level of intensity
- Community-based intermediate levels of care
- Tertiary outreach to support local service provision

3. Enabling Sustainable Recovery

- Person-centred support for recovery
- Online and telephone support specific to illness
- Peer support
- Education and support for families and carers
- In home and respite care where required
- Inclusion of families and carers in treatment team

Standards

- Existing national standards (e.g. NEDC Standards Schema and RANZCP Guidelines) adopted as national performance standards
- Adoption of existing eating disorder workforce competencies
- Develop eating disorder guidelines for coordinated stepped care

Systems

- Eating disorders identified as core business
- Eating disorders within scope for complex care pathways
- Medical benefits based on evidence-based treatment standards

Workforce Development

- Nationally coordinated dissemination of existing professional education resources
- Tertiary outreach: Replicate existing successful tertiary outreach approaches

Service Development

- Digital access: Enhance existing National Eating Disorders Helpline to include online prevention and early access pathways
- Intermediate levels: Support development of community based approaches

Accountability

- Eating disorders data collected
- People with lived experience influence all aspects of service development and delivery

Performance Measures

- ✓ Increase in early help seeking
- ✓ Reduced severity and duration of illness
- ✓ Reduced hospitalisation
- ✓ Reduced suicide risk
- ✓ Reduced medical complications
- ✓ Reduced impact on families
- ✓ Increased rates of sustained recovery
- ✓ Increased rates of participation in employment and education

Supporting Documents

This Agenda is designed to be read in conjunction with the following documents:

- **National Eating Disorders Framework (refer to Appendix 1 for the National Standards Schema)**
National Eating Disorders Collaboration (NEDC) (2012). An Integrated Response to Complexity: National Eating Disorders Framework. Report to the Australian Government Department of Health and Ageing, March 2012. NEDC: New South Wales, Australia.
- **Clinical Practice Guidelines**
Hay, P., Chinn, D., Forbes, D., Madden, S., Newton, R., Sugenor, L., Touyz, S. & Ward, W. (2014). Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the treatment of eating disorders. Australian & New Zealand Journal of Psychiatry, 48(11): 1–62. Available from: <https://www.ranzcp.org/Files/Resources/Publications/CPG/Clinician/Eating-Disorders-CPG.aspx>
- **Workforce Competencies**
National Eating Disorders Collaboration (NEDC) (2015). Competence to Prevent and Treat Eating Disorders: Establishing a Foundation for Safe Effective Responses to People with Eating Disorders. Workforce Development Blueprint to the Australian Government Department of Health, May 2015.
- **Stepped Care Approaches for Eating Disorders - Service Implementation Guide**
The Stepped Care Approaches for Eating Disorders Guide (NEDC, 2017) is part of the NEDC resource 'Practical Responses to Eating Disorders: A Guide to Implementing Responses to Eating Disorders in General Health Services' (2014). Information resource available from www.nedc.com.au
- **Insights in Recovery Guide**
Butterfly Foundation (2016). Insights into Recovery from Eating Disorders: A consumer-informed guide for health practitioners working with people with eating disorders. Sydney, Mental Health Commission of NSW.
- **National Framework for Recovery-oriented Mental Health Services**
The Department of Health (2013). National framework for recovery-oriented mental health services: Policy and theory. Canberra: Commonwealth of Australia. Available from: [http://www.health.gov.au/internet/main/publishing.nsf/Content/B2CA4C28D59C74EBCA257C1D0004A79D/\\$File/recovpol.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/B2CA4C28D59C74EBCA257C1D0004A79D/$File/recovpol.pdf)

This Agenda is designed to be implemented in the context of the Fifth National Mental Health Plan and the Mental Health Plans and Eating Disorder Service Plans for each state and territory.

Priority 1: The right type of treatment

The right type of treatment for people with eating disorders is specific to illness, safe, integrated, and delivered in an evidence-based dosage and duration sufficient to support sustainable recovery.

Safe Integrated Care

The national standard for safe treatment indicates that:

“Safe treatment for eating disorders addresses all of the aspects of illness assisting people to meet their physical, psychological, behavioural, nutritional, occupational and social needs. Treatment is provided by a multi-disciplinary team who work in partnership with the person, their family and other health and support providers, including treatment of co-morbid issues” (National Standards Schema, NEDC, 2012).

In general, brief clinical services are not suitable for people with eating disorders except as a preventive measure.

Current best available evidence supports the delivery of the following psychological therapies for people with eating disorders:

Anorexia Nervosa

- Maudsley Family Based Therapy (FBT) for adolescents – between 20 and 30 sessions
- Cognitive Behavioural Therapy (CBT) for adults – a minimum of 20 sessions with extension to 50 sessions as required
- Specialist Supportive Clinical Management (SSCM) for adults – delivered by health professionals with experience in eating disorders with the same number of sessions as CBT
- Nutritional Interventions as an adjunct to therapy

Bulimia Nervosa and Binge Eating Disorder

- Cognitive Behavioural Therapy – 20 sessions delivered over a minimum 5 months period
- Interpersonal Psychotherapy – delivered over an 8 to 12 months period
- Nutritional Interventions as an adjunct to therapy

To comply with the standard for safe treatment, psychological therapies should be delivered as part of a multidisciplinary team approach, including primary and allied health care professionals such as General Practitioners and Dietitians.

Safe treatment responds rapidly to the changing physical and nutritional status of the person. Where rapid weight loss has been experienced and the person is in a state of starvation, irrespective of whether the person is at a low BMI, it may be necessary to provide acute inpatient renourishment. The need for such treatment can be urgent and critical, and must be evidence-based and compassionate.

Current challenges to accessing the right type of treatment

The delivery of safe treatment is reliant on the availability of a skilled health professional workforce delivering treatment collaboratively within an integrated health care system.

A Skilled Workforce

The delivery of safe, quality treatment at any level in the service continuum is dependent on the availability of a workforce

that is knowledgeable and skilled in eating disorders. 97% of the health workforce has not received sufficient training in eating disorders to feel confident to provide treatment (NEDC, 2012).

All health professionals working with high-risk populations, and all professionals required to work in the multi-disciplinary team require training in eating disorders to raise their awareness of the serious nature of eating disorders and to enable them to identify, assess and contribute to the treatment of eating disorders. National coordination is required to reduce the current level of duplication of effort and inequity in access to treatment and support for people in different regions. Without a national response to embed adequate eating disorder training in health qualifications and professional development, other priorities in the Eating Disorder Agenda will not be achievable.

Workforce development requires the implementation of existing national workforce competencies for eating disorders (NEDC, 2015); coordinated dissemination of existing education; and support for outreach by existing tertiary centres, to enable supervision and consultation support for newly trained health professionals.

"As someone who has lived with a severe eating disorder for 4 years, one of the biggest obstacles I've found is finding health professionals who all understand what I'm going through. I'm forced to see a GP who thinks that because I'm eating 'something' 3x a day that I'm recovered and well. It's so hard for people suffering from an eating disorder to have health professionals of all sorts invalidating their mental struggle because of their weight or food intake."

"I think a huge barrier is the lack of training that medical staff gets, they don't have a good understanding as to how an eating disorder works, they make us eating disorder patients feel like we are wasting their time."

Integrated physical and mental health care

Eating disorders are associated with significant physical complications. Eating disorder symptoms can escalate rapidly with serious consequences for physical health and risk of mortality. People with any eating disorder may require rapid access to integrated medical and psychiatric inpatient treatment. Integration is required in order to safely address all aspects of illness. This involves establishing mechanisms to enable professionals from different disciplines, often working for different health service providers, to work together in a coherent and coordinated way as a team.

At present the separation of physical and mental health service systems does not readily support the delivery of integrated medical and mental health treatment.

"Being hospitalised on a medical ward on several occasions was traumatic. Every staff member demanded something different of me, doctors fought with my psychologists, nursing staff all allowed different things to happen and no one was ever on the same page."

Affordable treatment

To achieve the goal of safe treatment, that treatment also has to be affordable. For people with moderate to severe presentations of eating disorders a relatively long course of intervention is required to address all aspects of the illness and reduce the risk of relapse and chronicity. People may require recurrent episodes of treatment, at different levels in the continuum of care and from different service providers. The impact of an extended period of illness on people and their families often reduces their ability to pay for treatment from the private health sector.

There is a need to align medical benefits with the evidence for safe treatment. Medicare and private health insurance benefits should support an evidence-based dosage of treatment for each eating disorder diagnosis including access to multi-disciplinary services. Without affordable community-based care, people with eating disorders will continue to present for the first time to Emergency Departments with all the attendant consequences for their own health and safety as well as costs to the health system.

Specific areas where changes to the scope of benefits for people with eating disorders could increase access to safe treatment and reduce the impact of severe illness include:

- Inclusion of eating disorders in scope of Chronic Care Management Plans and Integrated Care Plans
- Medical benefits based on standards for safe evidence-based treatment
- Medical benefits support services delivered through Skype, telephone and online
- Enhanced working partnerships between public and private health to improve access to appropriate care

Establishing National Foundations

National leadership is required to support development of the right type of treatment:

Systems

- Include eating disorders as severe mental illnesses within scope for all mental health plans, policies and initiatives including coordinated treatment and support
- Eating disorders to be core business for all mental health services (inpatient, outpatient and community-based)
- Establish the enablers to support integrated planning and service delivery between physical and mental health at all service levels
- Include evidence-based treatments for people with eating disorders, including evidence-based dosage and duration of treatment, in medical benefits

Standards

Support implementation of existing national standards (e.g. NEDC National Eating Disorders Framework; RANZCP Clinical Practice Guidelines)

- Support implementation of existing national workforce competencies (NEDC, 2015)
- Develop national guidelines on coordinated stepped care for people with eating disorders

Workforce

- Work with State Governments, Primary Health Networks and Secondary Care providers to support national dissemination of existing education resources
- All mental health clinicians be trained to identify, assess and refer for eating disorders, as appropriate within their scope of practice
- Support implementation of tertiary outreach models replicating existing successful tertiary outreach approaches

Priority 2: Earlier access to treatment

Early identification and prompt intervention are necessary to reduce the severity, duration and impact of eating disorders. The evidence indicates that people who have had an eating disorder for less than 2 years are likely to respond more quickly to treatment and experience fewer physical health consequences. Earlier access must be early in presentation of

sub-clinical signs, early in episodes of illness, early in help seeking and early in subsequent episodes of illness. Early access is dependent on a skilled workforce, particularly those who are the first point of contact, including GP's, paediatricians and those working in youth services.

Intervening early in illness and early in help seeking

The national standard for early identification and intervention indicates that:

"People have access to services as soon as they are needed: early in the development of the illness, early in help seeking and early in recurrent episodes of illness, with immediate access to treatment and support" (National Standards Schema, NEDC, 2012).

Recovery is possible at any age or stage of illness with prompt access to treatment and support when the person seeks help. Failure to provide care when it is needed, early in illness and early in subsequent episodes of illness is associated with a longer duration of illness, severity of illness, serious physical health consequences and a higher risk of mortality including risk of suicide.

"Treatment for EDs needs immediate action and in some cases drastic action. 'Watchful waiting' is not an option, particularly as suicide risk is high in people with ED."

Early access to safe treatment is the best-known approach to prevent suicide for people with eating disorders. People with eating disorders represent a population group with a consistently higher rate of suicide attempts than the general population.

People with eating disorders need to be able to access a continuum of services at different levels to meet their changing needs, experiencing their care as connected and coherent. Episodes of treatment need to work together to support incremental change towards recovery. The National Standards Schema for Eating Disorders identifies a continuum of care that includes targeted prevention, primary, intermediate, secondary and tertiary treatment, and community-based recovery support. Wherever treatment occurs in the continuum of care from early intervention to recovery support, there must be access to tertiary-level expertise for consultation, supervision, guidance and referral if required (National Standards Schema, NEDC, 2012).

Most people with eating disorders may be treated successfully by appropriately trained health professionals in outpatient and community settings. Management of eating disorders on an outpatient basis in a community location enables the patient to remain close to family and social relationships, continue engagement in work or education where possible, and generalise new behaviours into everyday situations. Intermediate levels of treatment between primary and secondary care are essential to ensure the continuum supports sustainable recovery. Without these intermediary levels of treatment, more people require hospitalisation.

Current challenges to earlier access

Early access requires a knowledgeable primary care workforce able to identify eating disorders and an integrated continuum of care with clear referral pathways.

Early Identification

Early identification and appropriate referral are dependent on the knowledge of the health professionals most likely to be the first point of contact. This group includes General Practitioners, Nurse Practitioners, Dentists, Dietitians, Psychologists and Emergency Department personnel. The current lack of knowledge surrounding eating disorders and their associated stigma play a role in reducing the early identification of eating disorders.

For children and younger adolescents, diagnostic criteria may not be sufficient to identify those at high risk early in the development of illness. Food avoidance and/or determined weight loss provide good indicators of risk (Khan and Chowdhury, 2011) and need to be embedded in primary health care assessment and referral processes. Targeted prevention programs are required to address sub-clinical presentations of eating disorders in children and adolescents before illness significantly impacts on their physical, cognitive and social development.

Gaps in the Continuum of Care

The location and method of delivery of care and the cost of care strongly influence a person's ability to access care. Responses to eating disorders vary considerably between health regions with people in rural areas being most disadvantaged in terms of access to treatment. At present no health region in Australia has a full eating disorders continuum of care. For many people with eating disorders, finding any form of care between their General Practitioner and the Emergency Department can be impossible.

The separation of primary care and care originating from hospital leaves the intermediate levels of care to be delivered by private health providers. This is not an effective approach to meeting the needs of people with eating disorders who require longer term, multi-disciplinary and relatively intensive treatment and recovery support which cannot be readily provided in primary health. This gap in community-based care directly contributes to the escalation of both physical and psychological health problems and the risk of suicide. The solution to the significant gap in the mental health system lies between primary and secondary care, in genuine community-based care of intermediate intensity.

The development of a secondary community-based model of mental health care that is able to provide both clinical treatment and non-clinical recovery support for people with serious and complex mental illnesses is the approach most likely to contribute to reducing unnecessary hospitalisation. In turn, this reduces the risk of suicide and reduces the strain on the families of people living with eating disorders. In this context, community-based models are understood to be eating disorder-specific programs that provide an intermediate level of care and support between primary health and hospital interventions.

Meeting the Needs of Young Adults

While eating disorders can occur in people of all ages, they most commonly begin in adolescence or early adulthood. For those who do not receive effective early intervention treatment, the long course of illness will involve the young person transitioning between children's services and adult services. Again, early intervention depends upon the skill of the health professional who is the first point of contact being trained to identify, diagnose and refer for eating disorders. Provision of mental health services for young people between the ages of 16 and 25 varies between states and territories.

Young people and their families need to receive the same level of safe coordinated treatment regardless of their chronological age. Without effective models of youth mental health systems for people with eating disorders, young adults can find themselves without access to treatment; families find themselves excluded from treatment although they continue to be the primary support network for their child.

"All illnesses are better caught young, but there will always be people like myself who slip through the fingers...become severe when an adult (19 for me)...and there was no help. Help for all ages is appropriate."

Establishing National Foundations

National leadership is required to support earlier access to treatment:

Systems

- Establishing the enablers for the provision of the right type of treatment for young adults and their families
- Develop national criteria for entry to eating disorders treatment and local and national referral pathways

Workforce

- Work with State Governments, Primary Health Networks and Secondary Care providers to support national dissemination of existing education resources

Service Innovation

- Develop innovative models of community-based intermediate levels of care
- Extend existing eating disorder national helpline services to include:
 - Targeted development of online access to self-screening and self-help for people at risk of or with mild presentations of bulimia nervosa and binge eating disorder
 - Telephone and online access to professionals skilled in eating disorder treatment for immediate support, initial intervention, referral and follow-up

Priority 3: Enabling sustainable recovery

Eating disorders occur in the context of a person's life and the life of their family. An eating disorder will have an impact on every aspect of life. People need to receive treatment and support that is based on an integrated understanding of their lives (Stewart, 2001) that can equip them for the long journey of recovery.

Person-centred care, tailored to suit not just the person's illness but their life situation and needs, is the most effective way to treat someone with an eating disorder (Hay *et al.*, 2014). The perspective of the individual provides a vital framework for recovery as it is the individual who decides how to engage in treatment and recovery (Butterfly Foundation, 2016). To move towards recovery, it is critical that people with eating disorders feel consulted and engaged in their treatment. The loss of identity and self-worth, lack of control and sense of connectedness experienced during an eating disorder are exacerbated by treatment that is not person-centred and recovery-oriented.

Recovery is a process that may take an extended period of time, both during and after participation in treatment (NEDC, 2012). Relapse and recurrence are significant issues, with rates of relapse ranging from 22% to 51% across studies of people with anorexia nervosa and bulimia nervosa (Keel *et al.*, 2005). These setbacks are a common part of the process of recovery. With access to treatment and support setbacks do not have to be major obstacles to recovery. People with eating disorders need access to recovery support services and re-admission treatment plans to support sustainable recovery.

Families and carers play a vital role supporting treatment and recovery. Without family support, there is likely to be a need for higher levels of intensity in treatment and more frequent episodes of illness.

The National standards for person and family-centred care indicate that:

“Treatment and support is delivered within a person-centred, family and culture-sensitive and recovery-oriented framework. Services are delivered with a strengths-focussed approach, supporting long-term recovery, tailored to meet individual decision-making capacity and needs as they develop over the course of the illness. Individual treatment plans are developed within a person-centred, family and culture sensitive and recovery oriented framework. Services are delivered with a strengths-focussed approach, supporting long-term recovery, tailored to meet individual decision-making capacity and needs as they develop over the course of the illness.”

“Families and carers are recognised as integral members of the treatment and support team. They receive support, skills and strategies, education and information to enable them to support the person with an eating disorder and to maintain personal good health” (National Standards Schema, NEDC, 2012).

Current challenges to enable sustainable recovery

Sustainable recovery requires access to eating disorder specific assistance within the person’s home community, when it is needed, throughout treatment and personal recovery.

Assisting the Process of Personal Recovery

People with eating disorders experience the move between treatment and self management as extremely challenging and this contributes to the high rate of setbacks and recurrence of symptoms. Part of the solution may be found in establishing the intermediate levels of community-based care discussed under Priority 2: Earlier access to treatment. However, there is also a need for specific recovery services delivered post-intensive treatment or in parallel with intensive treatment. To ensure that this is accessible in all communities, digital as well as face to face recovery support services are required.

“My experience was that once I left inpatient treatment there was not adequate community support to help me to stay well.”
“There needs to be a smoother transition between inpatient admissions and going back to living an everyday life. The big change is usually inadequately supported, making relapse rates very high and likely.”

Provision of recovery services for people with eating disorders currently varies considerably between states and territories and between individual communities. Non-government organisations play a critical role in the provision of these services within their limited resources.

Meeting Needs for Self-Directed Recovery

At a minimum people who have an eating disorder need to know where they can go for assistance during the often long process of self-directed recovery. The assistance required may include:

- **Recovery planning** – ensuring that people leaving treatment have clear plans and support strategies to assist them to transition to self-directed recovery
- **Counselling** and brief clinical interventions to sustain the outcomes of treatment during periods of difficulty
- **Peer support** and peer mentoring – access to communities of recovery to sustain the outcomes of treatment
- **Life skills education** – group-based and self-directed learning opportunities to develop capabilities related to sustaining a healthy relationship with food and exercise, and coping strategies
- **Re-entry to treatment pathways** for earlier intervention during setbacks to recovery
- **Case coordination** for people who require ongoing access to multiple services

Families and Carers

People with moderate to severe eating disorders require the assistance of family or other carers to support them to contain eating disorder behaviours and implement treatment in the practice of daily living. Family or other carer assistance plays an important role in reducing the level of intensity and the duration of treatment required. It is therefore important that family or other carers be actively engaged and supported in the treatment process. The role of family or carers is so important to the success of treatment that they cannot be excluded from the treatment team without consequences for the effectiveness of that treatment.

Caring for a person with an eating disorder is a highly stressful and time-consuming process with implications for the wellbeing of the family. At present the health system relies on the work of families to implement treatment at home and support recovery but does not consistently support those families to carry out this vital work.

Like recovery support, the current provision of family support services varies considerably between states and territories and between individual communities, with non-government organisations taking on the significant role of supporting families. A strong argument is made by people with lived experience and by their families and carers for better support for families to be integrated into eating disorders care. Improved coordination is also required between family support services and eating disorder treatment services.

"The time commitment and impact on the family as a whole and as individuals is enormous and often not mentioned or valued and yet the family is the support mechanism the person needs to support their recovery."

"This is an extremely expensive experience for our family both emotionally and financially. Support for families who care for people with eating disorders should be part of the treatment."

"Families supporting patients also need support, it is a full-time job supporting someone through recovery often having to break from work, focus has to be on patient but so hard if no support."

"Carers/parents can be so exhausted, dejected, feel overwhelmed, depressed, even suicidal themselves. If we don't look after the carers who will look after the sick children? This is an important area to be addressed."

"There needs to be more support available for carers, for example carer consultants who work closely with the families of sufferers to give on-going advice and support through each stage of treatment."

Meeting Family Needs

At a minimum, families and carers need to be:

- Identified as the key people providing assistance to the person with an eating disorder
 - Informed about eating disorders and specific treatment options and provided with opportunities to share information with the treatment team
 - Referred to health, education and support services to meet their own needs
- Families and carers who play an active role in the provision of care need to be:
- Included in team decision-making about treatment plans
 - Educated to ensure that they have the skills required to carry out their role
 - Relieved – access to respite services such as in-home meal support
 - Mentored - supervision and personal support to enable debriefing
 - Peer support – opportunities to learn from other families and carers who have experienced the role of carer for someone with an eating disorder and provide mutual support
 - Sibling support – formal and informal support for siblings who may experience disruption in their daily lives, and distress.

Establishing National Foundations

National leadership is required to ensure that recovery support and support for families is an integral part of treatment for eating disorders:

Systems

- Establish the enablers for the provision of the right type of treatment for young adults and their families
- Include recovery support for individuals and support for families as integral parts of treatment within policy, funding, protocols and medical benefits.
- Ensure that people with severe eating disorders have access to a care coordinator throughout treatment and recovery

Workforce

- Develop mechanisms to support a trained and supervised peer workforce
- Disseminate training in recovery-oriented practice, informed by the evidence for eating disorders

Service Innovation

- Develop innovative models of community-based intermediate levels of care
- Develop models of recovery support to ensure that families, including siblings, have access to education, and health services to meet their own needs
- Develop models of practical in-home support to reduce the need for hospitalization
- Extend existing eating disorder national helpline services to include targeted development of recovery support and family education and support.

Improving Effectiveness

Accountability is essential to ensure that the actions outlined in the National Eating Disorders Agenda make a genuine difference for people affected by eating disorders. Key performance indicators should be able to demonstrate the impact of actions on people's wellbeing and not simply the outputs of those actions.

The eating disorder sector acknowledges that there are gaps in the current knowledge of eating disorders which may limit the effectiveness of the base line treatments outlined in this Agenda. Approximately one quarter of people who develop eating disorders will experience an enduring illness and evidence on more effective approaches for these people is still emerging. There has been no national investment to date on areas of key importance within the Fifth Mental Health Plan. These include developing knowledge about the experience of Aboriginal and Torres Strait Islander communities, where eating disorders are as prevalent as they are in the general population. No investment has been made in exploration of alternative approaches to preventing the high risk of suicide amongst people with eating disorders.

The National Eating Disorder Agenda prioritizes evaluation, research and data collection as essential foundations for improved effectiveness in the prevention and treatment of eating disorders.

Generating new evidence is a principle of the National Standards Schema for Eating Disorders:

“Research and evaluation are integral to the design and delivery of health promotion, prevention, early intervention, and treatment approaches for eating disorders. People with personal experience of eating disorders are involved at all levels of research, service development and evaluation” (NEDC, 2012).

Establishing National Foundations

National leadership is required to ensure that the National Eating Disorder is implemented to achieve real outcomes for people with eating disorders and their families:

Systems

- Include people with lived experience of eating disorders, and their families and carers in service and system evaluation and development
- Ensure that collection of mental health data includes collection of data on eating disorders as both primary and secondary diagnosis
- Include eating disorders within scope of integrated planning and service development for Aboriginal and Torres Strait Islander mental health and suicide prevention

Accountability

- Implement monitoring and accountability measures to ensure that Primary Health Networks and all health service providers take relevant action to implement the National Eating Disorders Agenda

Foundations for Change – Required National Action

The National Eating Disorders Agenda focuses on establishing a basic level of evidence-based service for people affected by all eating disorders at all stages of illness. To achieve this, actions are required at national, state and regional levels in order to ensure that mental health systems and the mental health workforce provide a supportive context for change.

1. Systems and Standards Informed by Evidence

A number of adjustments are required at a systems level to make it possible for people with eating disorders and their families to have earlier access to the right treatment and recovery support. The specific adjustments identified in this Agenda may be summarized as:

- **Core business:** Eating disorders are named as ‘within scope’ in all mental health policy, initiatives and service provision
- **National standards:** Guidelines and standards reflect the evidence for eating disorders treatment and recovery

- **Evidence-based:** Policy, initiatives, service provision and medical benefits are based on evidence-based treatment for eating disorders
- **Accountability:** Monitoring and reporting of mental health reform includes accountability for implementation of the National Eating Disorders Agenda and related national standards
- **Lived Experience:** All mental health reform initiatives involve people with lived experience of eating disorders and their families and carers

2. Targeted National Service Development

To address gaps in the continuum of care, two areas of development are identified in the Agenda which will most appropriately be implemented at a national level to support the implementation of state eating disorder service plans:

- Workforce development: Coordinating the dissemination of professional education to avoid duplication of effort and ensure consistent national standards of professional care
- Digital services: Extending existing eating disorder-specific online and telephone services to include:
 - Self-help programmes for people with mild or subclinical bulimia nervosa and binge eating disorder
 - Recovery services for individuals, families and carers

3. Modelling the Way Forward

Documented exemplar models are required, based on current best practice services in Australia, to facilitate the development of a continuum of community-based care:

- Flexible community-based eating disorder programs at an intermediate level between primary and secondary care
- Community-based recovery and family support
- Tertiary outreach to support the development of community services
- Youth-specific service streams to support young adults and their families

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Appendix 1:

National Standards Schema from the National Framework for Eating Disorders

The following practice principles are described in the National Eating Disorders Framework (NEDC, 2012). When implemented together, these principles provide the foundation for an effective and nationally consistent approach to eating disorders.

Practice Principles

Recovery-oriented person and family-centred care

Individual treatment plans are developed within a person-centred, family and culture-sensitive and recovery-oriented framework. Services are delivered with a strengths-focussed approach, supporting long-term recovery, tailored to meet individual decision-making capacity and needs as they develop over the course of the illness; and

Prioritization of early identification and early intervention

Early identification and prompt intervention are necessary to reduce the severity, duration and impact of the illness. People have access to services as soon as they are needed: early in the development of the illness, early in help-seeking and early in recurrent episodes of illness, with immediate access to treatment and support; and

Safe treatment options

Safe treatment for eating disorders addresses all of the aspects of illness assisting people to meet their physical, psychological, behavioural, nutritional, occupational and social needs. Treatment is provided by a multi-disciplinary team who work in partnership with the person, their family, and other health and support providers, including treatment of co-morbid issues; and

Flexible treatment and recovery pathways

People have access to a range of safe treatment options which meet different needs at each stage of risk, illness and recovery. Clearly identified entry points, ideally located in the community, assist people to make informed decisions about treatment options and engage with accessible services. Community-based recovery support is integrated into treatment pathways; and

Equity of access and entry

People have access to treatment and support services when and where they are needed, early in the illness and early in each episode of illness. The requirements of regional and rural areas are recognised and technological solutions to providing accessibility are provided. The entry requirements and the costs, subsidies or fee rebates for treatment take into consideration the long-term and complex nature of eating disorders and the need to ensure they are accessible and affordable to all; and

Support for families and carers as integral members of the team

Families and carers are recognised as integral members of the treatment and support team. They receive support, skills and strategies, education and information to enable them to support the person with an eating disorder and to maintain personal good health.

Implementation Principles

To implement each of the practice principles, action will be required in five domains:

Evidence-informed and evidence-generating approaches

Research and evaluation are integral to the design and delivery of health promotion, prevention, early intervention, and treatment approaches for eating disorders. People with personal experience of eating disorders are involved at all levels of research, service development and evaluation; and

A skilled workforce

All health professionals working with high-risk populations and all professionals required to work in the multi-disciplinary team receive training in eating disorders to raise their awareness of the serious nature of eating disorders and to enable them to identify, assess and contribute to the treatment of eating disorders; and

Accessible tertiary consultation

Wherever treatment occurs in the continuum of care from early intervention to recovery support there must be access to tertiary-level expertise for consultation, supervision, guidance and referral if required; and

Evidence-based community communication

Consistent and appropriate messages are provided to make sure that the community is aware of eating disorders as serious mental and physical illnesses. Eating disorder prevention integrates with wider physical and mental health promotion strategies to provide consistent health information that promotes wellbeing; and

Systems support integration and collaboration

Policy and systems support collaboration between physical and mental health services, private and public health services, health promotion, prevention and treatment, health and community services and between professional disciplines. People with personal experience of eating disorders are involved at all levels of policy development, planning and systems development.



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