

NSW Service Plan for
**People with
Eating Disorders**

2013–2018



Health

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Foreword

The tragic impact an eating disorder has on those who suffer from it and their loved ones cannot be understated. There are few conditions that are more cruel and more debilitating - and that will inflict more torment and suffering on those it impacts – than eating disorders.

For too long in NSW there has not been enough focus on prevention and early intervention to help support people before eating disorders become long-term problems. In addition, local clinicians have often lacked the confidence to treat people with an eating disorder, creating additional pressures on specialist services.

The NSW Government recognises the serious nature of eating disorders, the burden placed on sufferers and their families as a result, and the complex mental and physical health components of this disorder. We also understand just how cruel and distressing eating disorders can be and the impact living with an eating disorder can have on a person's life. This is why we are committed to ensuring that people suffering with eating disorders have access to the most appropriate support and treatment, with local treatment options wherever possible.

Through the *NSW Service Plan for Eating Disorders*, the NSW Government is committed to a comprehensive response that:

- ▶ Supports early and effective interventions to minimise distress to people with an emerging disorder, their families and carers;
- ▶ Prevents the escalation of symptoms;
- ▶ Promotes early recovery; and
- ▶ Ensures access to specialist care.

This Service Plan outlines the role for Local Health Districts in ensuring local eating disorder care across the state. Over the life of the Service Plan the NSW Government will provide funding and overhaul service delivery to support better access, innovation and improvement in care for people with eating disorders, no matter where they live in the state.

The implementation of the Service Plan will place NSW at the forefront of eating disorders care both nationally and internationally and provide a strong platform for improvement in care into the future. Most importantly, it will provide some of the most vulnerable people in our communities with the help they need, when and where they need it.



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Executive Summary

Eating disorders are a group of illnesses which have an adverse impact on physical and mental health and development. Without effective treatment they can cause serious and permanent harm or even death.

NSW has been at the forefront of service and workforce development in eating disorders. For instance, the *Eating Disorders Online Training Program* (www.cedd.org.au) builds workforce skill in the diagnosis, assessment and management of eating disorders and is the first of its kind internationally. However, there are recognised gaps in service availability and the interventions available, with regional differences in access to services and service options. The *NSW Service Plan for People with Eating Disorders* (the Service Plan) supports better access, good governance, innovation and improvement in quality care as key drivers of service development in NSW.

Historically, there has been a lack of clarity about which clinical system holds primary responsibility for care of people with eating disorders. In some cases this has resulted in a lack of clinical leadership, poorly developed pathways to care and inadequate coordination of care.

Over the past ten years, several treatment models delivered in various settings have been demonstrated to deliver significant rates of full remission from eating disorders. Other models have proven effective in supporting improvement or stabilisation of symptoms and bringing about improvements in quality of life even where recovery is significantly delayed.

While NSW Local Health Districts (LHDs) and Networks have responsibility for assessing and delivering treatment to people with eating disorders, they are at different stages of readiness to provide more than short-term non-specialist responses, delivered through general services (see Appendix B for current status of services).

The Service Plan establishes a clear service goal for LHD Mental Health Services, to establish models of care that support a significant degree of clinical expertise and self-sufficiency. The aim is to ensure timely access to

developmentally appropriate services that respond to all levels of clinical need. To support our clinicians, The Service Plan includes a focus on strong governance, linkages and structures to support clinicians and service access across the state. In delivering the Service Plan, NSW Health recognises the significant contribution that primary and private health providers can make to the comprehensive management of these disorders.

Services should be developmentally appropriate, flexible and reflect the difficulties associated with early engagement, ongoing treatment and fluctuations in risk. The range of eating disorder service options that are therefore needed across the health system can be conceptualised in four main delivery areas: community-based interventions, specialist outpatient treatment, hospital-based interventions and tertiary specialist inpatient treatment.

Key principles for services are early identification; flexible entry and care delivery options; targeted services; family and carer engagement and collaboration; local capacity and access to specialist treatment; comprehensive and integrated care; continuity across setting and over time; partnerships for recovery; and consultation with consumers.

The Service Plan and the *Guidelines for the Inpatient Management of Adult Eating Disorders in General Medical and Psychiatric Settings in NSW*, which sit within the Plan, provide direction and support enhanced and expanded service delivery in NSW.

To deliver on the directions set within this Service Plan, the NSW Government will:

► **Release the NSW Eating Disorders Service Plan and Adult Inpatient Management Guidelines**

The Service Plan requires and supports LHDs to build capacity to provide assessment and treatment for eating disorders, with pathways to options for more intense and specialist treatment to be established. Strong governance, linkages and structures to support clinicians and service access across the state are key features within the Service

Plan. Fundamentally, statewide access to treatment and support will be supported by the Statewide Eating Disorder Service Coordinator who will operate within a Centre of Excellence, working with four Eating Disorder Service Coordinators and a network of identified LHD clinicians. These positions will operate as the specialist front line, supporting all LHDs to develop local capacity, to treat more people where they live and to get access to more intensive specialist treatment for those who need it.

These structures will be supported by data collection, service access monitoring and an annual service development forum to assist the implementation of the Service Plan. System monitoring and feedback is an element of the Service Plan which will guide implementation and improvement. Data will be collected by the Ministry of Health with six-monthly data reports indicating service utilisation for eating disorders. The NSW Chief Psychiatrist will be engaged in an oversight role, assisting to resolve clinical placement or other issues where necessary. The Agency for Clinical Innovation (ACI) will ensure that clinicians from relevant ACI Clinical Networks provide input and support for the development of the processes by the Ministry of Health. This will enhance access to inpatient and community-based treatment services, build clinical capacity and support regional capability, to better respond, early and effectively, to people with eating disorders.

An annual budget will be set aside to support broad engagement and additional training of clinicians and service providers.

► **Establish a Child & Adolescent Day Program**

In the NSW public health system there are more than twenty (20) specialist eating disorder beds for children and young people up to 18 years of age. However, Sydney Children's Hospital Network advise that since 2000 there has been a fourfold increase in admissions to the Children's Hospital at Westmead and a tenfold increase in outpatient care. To address the need for care, a community-based Pilot Child and Adolescent Day Program model has been developed by Sydney Children's Hospital Network in partnership with the Butterfly Foundation (an eating disorder advocacy NGO). This program will be trialled over the life of the Service Plan. The day program will provide options that reflect levels of need including greater intensive early intervention as well as building further capacity to support child and adolescent eating disorders care through LHDs.

The new service will operate five days a week as a statewide tertiary eating disorders day program for people aged 10-18 and their families. The model includes family, individual and group work clinical interventions, meal support, maintenance of developmentally appropriate education and psychosocial wrap around support.

To provide greater clinical support and care integration to families from across the state, the model includes additional staffing to provide consultation and education through telehealth and abridged residential treatment programs that will reduce the duration young people and their families need to be away from home.

► **Expand Adult Tertiary Eating Disorder Services**

In 2013, the NSW public health system has five (5) adult specialist eating disorders beds. Over the life of the Service Plan the NSW Government will expand the tertiary adult eating disorders bed base to nine (9) beds.

Royal Prince Alfred Hospital located within Sydney LHD will increase to a six (6) bed statewide adult eating disorders unit linked to a day Clinic and Day Program with a statewide catchment. This expanded tertiary model will support the development of a team with high-level skills to deliver best practice care to approximately 48 of the most complex cases (severely medically compromised patients and those with high risk behaviours associated with the illness and treatment failure) referred from across the state annually. The unit will have appropriate staff levels, health discipline mix and skill level required to manage the most complex cases. It will also provide support to LHDs for ongoing care when people return to their local services.

To support better care in regional areas, the service will provide statewide training and supervision to support LHDs' capacity to provide levels of care, to minimise demand on the limited tertiary beds and improve outcomes through ongoing local care delivery.

The NSW Government will also provide funds to allow some additional access to private eating disorders beds, to allow maximum access to tertiary beds and flexible care options for those with extended inpatient care needs.

► Enhance Adult Eating Disorder Day Programs

Two current Day Programs are offering statewide intensive community treatment services. These are a stand-alone community early intervention service located within Central Coast LHD and a step up, step down service linked to the eating disorders services provided at Royal Prince Alfred Hospital in Sydney LHD. Under the Service Plan, additional funding will be provided to each service to enhance these programs' ability to access medical and psychiatric support, to strengthen the provision of care in the community.

► Establish a New Adult Eating Disorder Day Program

Building on local capacity and networks, additional funds will be allocated to establish a new adult Day Program in the Hunter Region, to commence full operation from 2014/15. This funding will allow eight (8) adult specialist eating disorder clinical places. This specific investment is in addition to the regional and local supports imbedded in some of the other initiatives under this Service Plan.

In summary, in releasing the Service Plan, NSW Health aims to support LHDs to build capacity, to provide assessment and treatment for eating disorders and with pathways to care by:

- Ensuring every health service which may be a point of entry to eating disorder care has the capacity (e.g. policy, protocols, access, referral pathways and information resources) and capability (e.g. staff knowledge and skill) to provide all necessary services for people who have, or are at risk of developing, an eating disorder;
- Ensuring every health service has the capability to link with and be supported by specialist eating disorders expertise;
- Ensuring eating disorder outpatient programs are accessible within the patient's LHD on a flexible basis to allow patients to transition between general and intensive outpatient treatment;
- Increasing access by expanding services (adult; and child and adolescent); and
- Funding the development and expansion of tertiary eating disorder services and support across the system; the dissemination of high level clinical skills; support best practice for eating disorders; and maximise the use of limited tertiary beds.

Introduction

This NSW Service Plan for People with Eating Disorders (the Service Plan) supports timely access to a range of developmentally appropriate services for people with eating disorders. It reflects a population health perspective, where support and treatment is delivered in response to level of need and capacity for engagement. Services reflect varying degrees of specialisation and access occurs from community-based primary care through to specialist service models. Appropriate support and treatment reduces suffering, illness duration and burden on families and carers, as well as morbidity and mortality.

The Service Plan includes:

1. Prevention through the promotion of positive self-image and healthy behaviours;
2. Early recognition of risk behaviours and early signs of physical and psychological distress related to eating and body image and access to appropriate interventions;
3. Responsiveness to levels of need with evidenced-based interventions to promote recovery; and
4. Early access to acute intensive and integrated care to minimise harm, including medical, psychological and psychiatric treatments.

Responsibility for service development is shared by the Commonwealth and State governments, as well as public, private and non-governmental organisation (NGO) providers. This Service Plan is a guide for service development across providers in NSW and forms part of the NSW Government's response to delivering on its priority goals as expressed in NSW 2021:

- Goal 11: Keep people healthy and out of hospital
- Goal 12: Provide world class clinical services with timely access and effective infrastructure.

Section One outlines the case for an increased focus on eating disorders from health services in terms of demand, complexity and emerging evidence for recovery. It describes current treatment, service delivery models and contemporary research informing how sectors of the health system relate to strategic directions contained in the Service Plan.

Section Two outlines the Service Delivery Framework for Eating Disorders across NSW including standards, setting-specific models and strategic priorities.

Scope of the Plan

While all eating disorders are relevant to this plan, service development priorities are the four most common eating disorders: anorexia nervosa (AN), bulimia nervosa (BN), eating disorders not otherwise specified (EDNOS) and binge eating disorder (BED).

Disordered eating is a broader public health issue not directly addressed in this Service Plan. However, health promotion, early intervention and prevention strategies will address the risk associated with disordered eating which progresses to an eating disorder.

Obesity, while an important public health issue, is not directly addressed in this Plan. However, prevention and health promotion targeted towards those who engage in disordered eating is relevant. In the context of BED, overweight and obesity can form part of the clinical presentation and services need to be equipped to deal with this aspect of treatment.

While Feeding Disorders of infancy and early childhood such as rumination, picky and fussy eating, phobias associated with severely restricted eating and pervasive refusal syndrome are of significant concern, they are outside the scope of this Plan, except as they relate to prevention, health promotion and treatment of comorbidities.

Issues for an Eating Disorders Service Plan

1.1 Reasons for an Eating Disorders Service Plan

Eating disorders cause significant morbidity and mortality

Eating disorders are a group of mental illnesses which can adversely impact or permanently impair physical and mental health, growth and development. Eating disorders have very high rates of comorbidity and can be fatal. They cause distress, anxiety and burden to sufferers, their family, carers, partners and friends.

Service gaps exist

In Australia and overseas there are gaps in the range of services for people with eating disorders and regional differences in access to and delivery of services, particularly between urban and rural areas and between patients accessing private versus public services.

The needs of children and adolescents differ from those of adults and transition of care between age sectors is a period of high risk. The integration of medical, mental health and allied health interventions also remains underdeveloped.

People with eating disorders usually require the input of health practitioners from various clinical backgrounds, with particular knowledge and skills. This has resulted in treatment services being isolated in a highly specialist area of psychiatry, paediatric or adolescent medicine, rather than with clinicians in mainstream services who may nevertheless encounter people with eating disorders as part of routine service delivery. This lack of clarity about which clinical system should be primarily responsible has in some cases led to a lack of clinical leadership, poorly developed pathways to care and inadequate coordination of care.

While there have been improvements over time, some health practitioners who are in the position to support patient engagement within the health system lack the knowledge to identify those at risk or presenting with illness, or to link people to appropriate care.

Burden of illness is significant

Eating disorders comprise a group of illnesses that encompass both moderately serious illness with a high prevalence (such as BN and BED) and very serious illness of relatively low prevalence (AN). Incidence of these disorders often begins in childhood and peaks in the adolescent years but can be present at any stage of life. While the literature on the prevalence of eating disorders varies depending on data sources, diagnostic thresholds and the availability of reliable service use data from across public and private sectors, the 2012 Report commissioned by the Butterfly Foundation (*Paying the Price: the economic and social impact of eating disorders in Australia*, Deloitte Access Economics, 2012) suggests around 4% of the population is affected to clinically significant levels, 64% of which are female. International epidemiological studies reflect similar prevalence rates around 4%. Based on this estimate, in NSW at any one time there are 289,560 people with a clinically significant eating disorder. Lifetime prevalence of a diagnosable eating disorder requiring clinical intervention in Australia may be approximately 8% and up to 15.4% in females (Wade et al., 2006) with some evidence that the overall prevalence of eating disorders may be increasing (Hay et al, 2008). Eating disorders occur across the whole lifespan, with AN and BN most common from 15 to 30 years of age while BED and EDNOS occur in significant numbers from 15 to 65 years of age.

The 2012 *Paying the Price* report calculated that the per person hospital inpatient cost for eating disorders overall is \$13,123. The average patient stayed in hospital for 19.5 days, more than 6.5 times longer than the average patient stay (2.9 days) – longer for example than the average coronary bypass. The Australian Institute of Health and Welfare reports health system expenditure for eating disorders of \$80.4 million in 2008-2009 (\$99.9 million in 2012 dollars). The report highlighted the need for greater focus on people with eating disorders across the whole of the health system (including Commonwealth funded health services) and greater financial support through increased private health insurance cover.

People with eating disorders are currently being treated through a variety of services. Significant volume of treatment occurs in the community, through general practitioners and paediatricians as well as through outpatient and day programs. The demand on inpatient services is significant. Data on impact varies considerably. NSW Health data on separations by eating disorder diagnostic categories for people treated in inpatient services in 2011/12 show that:

- ▶ There were 534 admission separations, of which 134 were from mental health services. Average length of stay (av. LOS) was 16.3 days in general units and 24.3 days for mental health units.
- ▶ Total eating disorder bed days for last year totalled 9,778 (of which 3,254 were in mental health). This equates to 8.91 average annual occupied beds days in mental health and 17.9 average annual occupied bed days in general medical.
(Note this does not include the more than 150 day program places)
- ▶ The Child and Adolescent (C&A) tertiary service through Sydney Children's Hospital Network (Westmead Children's and Sydney Children's Hospitals) had 148 admissions (50 through mental health and 98 through paediatric/general medical). The av. LOS through Sydney Children's Hospital Network varied between 16 and 25 days depending on where they were treated.
- ▶ Westmead Hospital [adult] had 29 admissions to mental health (av. LOS 27.7 days) and 91 admissions to general medical (av. LOS 18 days).
- ▶ The two (2) bed tertiary unit in Sydney Local Health District (Royal Prince Alfred Hospital) had sixteen (16) admissions through mental health and a further nine (9) admissions through general medicine. Av. LOS was 49 days.
- ▶ Mental-health admissions tend to be longer: The average LOS for non mental health units was 16.3, the average LOS in mental health was 24.3. These longer adult mental health stays are likely due to treatment complexity related to comorbidity and treatment complications related to having an enduring illness.
(source: Health Information Exchange tables [HIE], NSW Ministry of Health – InforMH)

Recovery is possible

The majority of people with an eating disorder who receive evidence-based treatment that can be delivered in a timely manner, make a full recovery. While the

treatment process can be challenging and may require prolonged treatment engagement, provision of care over extended periods can maintain or minimise deterioration in physical and psychosocial functioning, contain escalation and moderate demand on non specialist parts of the health system.

Large-scale public health promotion campaigns are not commonly available

Stigma surrounding people with eating disorders has also had an impact on treatment responses, with assumptions that the illnesses are related to contemporary western societies and cluster in certain socioeconomic groups. However, it is clear that eating disorders can now be identified in many cultures and across history (Morton, 1689; Lesegue, 1873; Makino, 2004; Becker, 2011). Males with eating disorders also encounter barriers to treatment due to these illnesses being primarily identified as a female disorder (Deloitte Access Economics, 2012). However, perceptions are shifting. The 2009 Mission Australia National Youth Survey canvassing 47,000 respondents aged 11-24, identified Body Image in the top three issues of concern, with 25.5% of young people identifying it as a major concern. Body Image concerns were rated more important by young people than depression, self-harm, bullying and abuse. Large scale public health promotion campaigns to prevent and target obesity have become common. Despite almost half (48%) of Australian School aged girls reporting engaging in dangerous dieting techniques (purging and/or complete fasting) (Wertheim et al. 1992), large-scale public health promotion campaigns for eating disorders are not common.

Evidence-based treatments are available

Research indicates that disseminating evidence-based treatments and developing local expertise within Child and Adolescent Mental Health Services (CAMHS) teams reduces the need for inpatient or intensive specialist outpatient services (Gowers et al., 2007).

Over the past ten years, several treatment models delivered in various settings have been demonstrated to deliver significant rates of full remission from eating disorders. These evidence-based interventions include, Maudsley Family Therapy (Eisler et al, 2000; Lock et al, 2006; Lock & el Grange et al, 2005, 2010) for Children and Adolescents with Anorexia Nervosa (data is building to support its use also in this age group for those with BN, and EDNOS of both AN and BN subtype), and CBT for

BED and BN in adults (Shapiro et al, 2007; Wilson et al, 2007), both of which have sufficient evidentiary support to be recommended as first-line treatments in the age groups and diagnostic categories where they have proven effective.

Day Programs are indicated as part of the continuum of care in eating disorders, offering a step up from evidence-based outpatient therapies (when they are not effective for the individual, or not of sufficient dose-strength to induce recovery), they should exist in addition to other intervention options. Evidence exists for their efficacy with adults who have eating disorders (Halimi, 2009).

Practitioner knowledge, competence and confidence can improve

A common problem exists within the health care system, where care of people presenting with an eating disorder is assumed to be the domain of experts in some *other* service. For example, this is evident that referrals of patients with mild illness are made to specialist tertiary services by health practitioners who have limited confidence and skill in the eating disorders area. If improvements to care and positive outcomes are to be achieved, all health practitioners need to know what their treatment responsibilities are and where to access advice and information regarding appropriate referral pathways. Health practitioners need to develop greater knowledge, competence and confidence in responding to the health needs of people with eating disorders, particularly in the mild to moderate stages of illness. Care needs to be sustained across age, sub-speciality and clinical settings, to reflect significant durations of illness (e.g. for AN the average is more than seven years).

In particular, this Plan identifies the need for the provision of prolonged multifaceted integrated care that addresses risks associated with gaps in access, difficulties in sustaining improved outcomes, and/or premature disengagement from treatment. It also recommends the following challenges are addressed:

- ▶ Improving access to services and monitoring of resource utilisation across the system
- ▶ Ensuring health practitioners across all subspecialties understand and accept clinical responsibility for people who have complex health needs
- ▶ Integrating the health care needs of people with eating disorders into the current generalist models of care, both within mental health and general health services

- ▶ Increasing support for health practitioners who feel unskilled or unsupported in managing the medical risk and challenging psychological and behavioural presentation, and those who have negative expectations for recovery

1.2 National and State Policy and Planning Context

People with eating disorders have significant health needs that are of sufficient complexity that a number of interventions will be required. These are complex and multi-causal disorders that necessitate flexible, individualised care solutions, provided across a range of settings and in a coordinated way that reflects best available evidence. In adopting a population health approach this Service Plan is informed by, and is consistent with, a number of national and state policy documents, including:

State

- ▶ NSW 2021: A plan to make NSW Number One
- ▶ NSW Youth Health Policy 2011-2016
- ▶ NSW Aboriginal Health Plan 2013-23

National

- ▶ The Roadmap for National Mental Health Reform
- ▶ Fourth National Mental Health Plan: an agenda for collaborative government action in mental health
- ▶ National Action Plan for Promotion, Prevention and Early Intervention for Mental Health

The National Eating Disorder Collaboration

In 2009 the Department of Health & Ageing funded a national collaboration to bring together Eating Disorder stakeholders and experts in mental health, public health, health promotion, education, research and the media to help to develop a nationally consistent approach to eating disorders in Australia. A national framework, communication strategy, resources review and evidence review were developed.

The National Eating Disorder Collaboration (NEDC) (2010-2012) is progressing activities relevant to ongoing service development in NSW including:

- ▶ A National Standards Schema
- ▶ A Revised National Framework (NEDC Framework)
- ▶ A Communication Strategy
- ▶ Professional Development Workshops and Resources
- ▶ Web-based Clearinghouse and Information Resources

- ▶ Further evidence-based information for specific aspects of the continuum of care
- ▶ A National Gap Analysis Report identifying and responding to gaps in services, approaches, research evidence and information resources
- ▶ A Prevention and Early Intervention Report providing an analysis of high risk groups; points for early intervention and options for evidence-based prevention and early intervention programs for Australia

The NEDC Framework and Communications Strategy outlines the following key principles:

1. Eating disorders are a priority mainstream health issue in Australia
2. A healthy, diverse and inclusive Australian society acts to prevent eating disorders
3. Every Australian at risk has access to an effective continuum of eating disorders prevention, care and ongoing recovery support

The NEDC Framework calls for integration and collaboration in multiple domains:

- ▶ Physical and mental health services
- ▶ Public and private health services
- ▶ Professional disciplines
- ▶ Treatment approaches for comorbid conditions
- ▶ Families and clinicians as essential members of the treatment team

The NEDC Framework concludes that a Continuum of Care model with multiple components and access to tertiary consultation is ideal for the treatment of people with eating disorders. The full continuum involves:

- ▶ Primary, secondary and tertiary prevention
- ▶ General outpatient support provided in both hospital and community settings with flexible access to a range of services delivered with variable frequency of access, with particular emphasis on relapse prevention / early intervention.
- ▶ Intensive outpatient support for people living with their family or other support structures who require intensive clinical support
- ▶ Day programs, providing a more structured program, including group therapy
- ▶ Residential programs, providing 24 hour support ideally located in the community
- ▶ Inpatient services for medical intervention and stabilisation; intensive, structured inpatient programs to address severity and co-morbidity

The NSW Eating Disorders Service Plan reflects and supports a number of these key components.

1.3 Evidence-Based Treatments

While research is equivocal as to best practice, evidence exists as a guide to management for the different diagnoses, for children, adolescents and adults, as follows:

Anorexia Nervosa (AN):

Current studies suggest that different approaches may be beneficial at different stages of illness and that a continuum of care model is needed (Halmi, 2009). This continuum includes community care to promote self-mastery and recovery, hospitalisation as an option for medical stabilisation or to provide a therapeutic and containing environment when behaviours indicate substantial risk and problems with treatment engagement exist. This will be followed by intensive outpatient, preferably day patient care, to restore weight to the healthy range and eliminate disordered eating behaviours, followed by ongoing outpatient care to maintain recovery and reduce risks for relapse.

Specialist hospital treatment reduces mortality, rectifying electrolyte and organ dysfunction, and induces partial weight restoration. Specialist hospital-based management involves dietetic assessment and management of refeeding risk and syndrome, close medical monitoring of organ and electrolyte parameters, intensive support with containing the drive to activity and disordered eating behaviours, and management of self-harm and suicide risk (please view Adult Inpatient Guidelines at Appendix C or at www.cedd.org.au).

Maudsley Family Therapy delivered on an outpatient basis is the optimal line of treatment for children and adolescents in most cases of short-moderate duration (less than 3 years) (Lock & le Grange, 2005; le Grange, Lock & Dymek, 2003; Eisler et al., 1997). The Maudsley Model supports parents to foster the young person's weight gain/stabilisation and nutritional restoration. Family and individual dynamics are addressed secondarily. This approach is usually conducted in conjunction with medical stabilisation and monitoring and nutritional counselling and five year follow-up studies demonstrate that success rates for adolescents in early stages of illness are between 50% and 90% (Le Grange and Lock, 2010). There is no evidence base to support this model in adults over the age of 18, although some U.S. trials delivered the treatment up to the age of 19.

In older people with AN, Cognitive-Behavioural Therapy (CBT) and its variants have been the treatment most commonly used on an outpatient basis, with mixed results, although supportive psychotherapy may be more effective than CBT and Interpersonal Psychotherapy (IPT) when used alone (Macintosh, et al 2005). In practice, a variety of therapeutic styles is usually required, as well as medical monitoring, anti-depressant and anti-anxiety medication and dietetic support.

While a majority of people who experience AN will recover or partially recover, the illness can persist into later life. Long term AN is associated with a myriad of medical complications and conditions including osteoporosis, growth retardation and infertility. The chronic condition may also require a different therapeutic approach, with less emphasis on restoration to a normal weight, and more on increasing to a more healthy body mass, remission of complications, and improving quality of life (Touyz et al, 2013).

People with long term AN are at significantly increased risk of poor social integration and occupational attainment and as such may require a range of psychosocial supports beyond health care services. The families and carers of persons with long term AN are often under significant stress and require support, information and strategies to cope with the illness, and the risk of death to the sufferer, over the long term. BN and BED can also be chronic conditions; the average duration of BN is 9 years. They tend to remain more hidden due to the decreased rate of medical compromise. However, they pose a significant burden to the individual and can result in a burden on the health system.

Bulimia Nervosa (BN) and Binge Eating Disorder (BED):

In general, treatment in the community, with involvement from psychologists, GPs, dieticians and other health/mental health professionals is appropriate for people with BN and BED.

For adolescents, family-based treatments are usually recommended, including Maudsley Family Based Therapy (Le Grange et al, 2003, 2007). Hospital admission may be required where BN is severe and medical complication arises from purging behaviours, or where a less restrictive environment is clinically insufficient to alter the severity of the symptoms. People with BED rarely require hospitalisation.

For older adolescents and adults with BN, the evidence supports Cognitive Behavioural Therapy (CBT) as the treatment of choice (National Institute for Clinical Excellence [NICE], 2004). CBT for BN and BED has been manualised and can be delivered on an outpatient basis of over 20 sessions for those who are moderately ill (more sessions will be required for those who are severely ill). People who experience suicidal thinking, comorbidity or where bingeing and purging behaviours are extreme, may benefit from psychotropic medication and/or one or more hospitalisations during the course of treatment to support the recovery process.

Eating Disorders not otherwise specified (EDNOS):

The most appropriate evidence-based treatment to be applied in EDNOS depends on the subtype of the presentation. People who present with an EDNOS best described as being similar to AN, but which lacks one or more criteria for full diagnosis, should have the same evidence-based treatment delivered as would be provided to someone with AN who experiences similar characteristics. People who present with an EDNOS best described as being similar to BN or BED, but lacking one or more criteria for full diagnosis, should be treated with the evidence-based treatment appropriate for someone with BN or BED.

1.4 Who Needs an Eating Disorder Service?

In the broadest sense, the target group for the *Service Plan* are people within the community with an eating disorder, those in the process of recovery from an eating disorder, or those at risk of developing an eating disorder. Persons caring for an individual with an eating disorder (be they parents, other carers or clinicians) also form part of the target group. A more comprehensive discussion of populations that may require a particular response is outlined in Appendix A.

Eating disorders affect a broad cross-section of the community; they have been identified in males and females as young as 6 years of age and have been documented in persons aged over 70 years. Eating disorders commonly occur concurrently with other psychiatric and medical conditions, in people already accessing the health and mental health system. This supports the need for greater awareness and competence in the identification and response to people at risk of developing an eating

disorder among branches of the health system and both structural and clinical links between services.

1.4.1 Risk factors associated with the development of an eating disorder

- ▶ Being aged 12 to 25 years old
- ▶ Being female
- ▶ Sporting, professional or health reason to be on a restrictive diet
- ▶ A personal or family history of psychiatric disorder, especially an eating disorder
- ▶ Social adversity: emotional, physical, sexual abuse, physical illness and immigration
- ▶ Personality factors such as high stress reactivity or perfectionist traits
- ▶ Girls who experience two developmental changes simultaneously (e.g. menstruating and dating) in addition to achievement threat (i.e. academic pressure) and slender body ideal are highly likely to display pathological eating behaviours

Children of families with a history of eating disorders

Available evidence suggests that children of families with a history of eating disorders may be at increased risk of disturbances in their development (Patel et al, 2002). A relatively recent study found that the children of mothers with eating disorders exhibit disturbed eating habits and attitudes compared with controls, and may be at risk of developing eating disorder psychopathology (Stein et al, 2006). The influence of maternal eating disorders appears to be related to growth, feeding, body shape and weight concerns (Patel et al, 2002). General parenting and genetics also appear to play a part. Research on this area is limited and relatively recent; for example at this stage there has been no investigation into fathers with an eating disorder.

1.4.2 Specific Needs Groups

Comorbidity/Dual Diagnosis

Children, adolescents and adults with eating disorders in clinical and community populations suffer high levels of comorbid psychiatric conditions (Bulik, Sullivan, Fear, & Joyce, 1997; Devaud, Jeannin, Narring, Ferron, & Michaud, 1998; Geist, Davis, & Heinman, 1998; Striegel-Moore, Garvin, Dohm, & Rosenheck, 1999; Zaider, Johnson, & Cockell, 2000; Blinder et al., 2006; McDermott et al., 2006).

Depression is very common, particularly in AN where it can be a consequence of starvation. Rates of comorbid anxiety disorders including OCD are also high. High proportions of general psychiatric populations exhibit high levels of disordered eating (Grilo et al., 1995; Zaider et al., 2002), suggesting the need for basic skills to address eating disorder behaviours across the mental health system. Complex treatment planning may need to be considered for those individuals who have an eating disorder as the primary diagnosis and other co-occurring conditions.

Rural and remote communities

Access to specialised health and mental health services can be limited for people living in rural and remote communities. There is a notable absence of health practitioners with eating disorder expertise or training in rural areas for appropriate assessment, diagnosis and treatment. Rural GPs are a key element of the service system and partnerships between health services and primary care practitioners are essential. Telepsychiatry and other mechanisms for consultation with specialist tertiary services are important in terms of supporting treatment of the person in their local community, identifying appropriate referral pathways and step-down care.

Aboriginal and Torres Strait Islander people

While accurate and reliable data on the mental health and social and emotional well being of Aboriginal and Torres Strait Islander people is limited, eating disorders are known to occur in this group. There are particular issues associated with service delivery for Aboriginal and Torres Strait Islander people and these issues need to be understood within a context which recognises the complex inter-relationship of individuals, historical, social, cultural, economic, environmental, mental and physical factors that affect the social and emotional well-being of people. Issues of poverty and marginalisation from resources are also significant factors.

The peak representative body, the Aboriginal Health and Medical Research Council of NSW and service providers such as the Aboriginal Community Controlled Health Services (e.g. AMSs) or culturally aligned NGO services should serve as the primary point of health contact for LHDs for the Aboriginal Community when available. Key partnerships across these representative bodies should provide better service access and service delivery.

Much prevention work for eating disorders has strong resonance to other community activity for the Aboriginal and Torres Strait Islander community including issues of self-esteem building, health nutrition and body image. Awareness and skills development should be progressed through both specialist Aboriginal community [mental] health workers and health services to ensure that generic services are responsive and sensitive to cultural issues in their engagement and treatment.

Persons from culturally and linguistically diverse (CALD) backgrounds

There is a common misconception that eating disorders are experienced only by Anglo-Saxon, middle class females. Both AN and BN and their sub-clinical presentations are commonly experienced by young people from CALD backgrounds. Dissonance between a culture that idealises the fuller female body and Western culture, in which the thin ideal is the norm, is thought to contribute to vulnerability in this group for the onset of eating disorders, as is the social adversity that can come with migration (Furnham & Alibhai, 1983; Di Nicola, 1990).

While the population from CALD backgrounds is heterogeneous in its composition and needs, there are some specific factors that may directly or indirectly impact on the mental well being of this population group and have implications for effective assessment, intervention and management strategies. Lack of awareness of eating disorders in CALD communities may inhibit early identification and referral; educational programmes may need to specifically target awareness in these communities. The Transcultural Mental Health Centre can assist in accessing and tailoring programs to suit individuals from CALD communities.

SECTION 2

The Service Delivery Framework

The following Framework outlines the key principles and processes to ensure the provision of appropriate care for people with eating disorders in NSW. While all LHDs have responsibility for assessing and delivering treatment to people with eating disorders, they are at different stages of readiness to provide more than short term non-specialist responses to acute presentations. Establishing local specialist eating disorder hubs or networks that support a significant degree of clinical expertise and self-sufficiency is a key goal of this Framework.

Services should be developmentally appropriate and flexible to reflect challenges in early engagement, ongoing treatment and fluctuations in risk. The range of eating disorder service options that are therefore needed across the health system can be conceptualised in four main delivery areas: community-based interventions; specialist outpatient treatment, hospital-based interventions; inpatient care and access to tertiary specialist advice and treatment.

Commonwealth funded primary care organisations, as well as the health and mental health services provided by private and NGO sectors, contribute towards the development of a comprehensive range of care/interventions for people with eating disorders. For the NSW public health system, LHDs need to provide leadership in service development strategies that enhance the assessment and treatment of people with eating disorders at all levels of need and link care across subspecialties, across public and private providers, across age groups and across clinical settings. The development of locally accessible models of care, consistent with this Framework, will need to be planned and progressed over time, and will depend on the level of local specialist clinical capacity, bed platform and demand.

Current capacity and gaps need to be identified across each LHD and the wider provider network, through a process of mapping care options and expertise. Building on existing mainstream services such as CAMHS, Child and Family, Paediatric and Adult mental health services as well as medical, allied health and other sub-specialities through workforce development and linkages to specialist supports, will assist in providing quality care and address

additional treatment complications arising from the high prevalence of physical and mental health comorbidities. Development of a local hub of clinical expertise in eating disorders will create a mechanism for development of local specialist competency.

2.1 Access, Coordination and Service Governance

This Service Plan requires and supports LHDs to build capacity to provide assessment and treatment for eating disorders and with pathways to options for more intense and specialist treatment to be established. Strong governance, linkages and structures to support clinicians and service access across the state are key features within the Plan.

In summary, service access and governance is provided through:

- ▶ service and funding agreements;
- ▶ the establishment of an oversight and coordination team that has strong links and accountabilities to ensure state-wide functioning of the system;
- ▶ local leadership;
- ▶ clinical support and networks; and
- ▶ data and performance monitoring with regular feedback to the system.

These elements, along with new investment in treatment capacity, will deliver the foundations for improved responses to eating disorders in NSW.

2.1.1 Service Plan Governance

Statewide access to treatment and support will be underwritten by service agreements that stipulate statewide access. Service access and the implementation of other aspects of this Plan will be supported by a Statewide Eating Disorder Service Coordinator that will operate within a Centre of Excellence – working with four Eating Disorder Service Coordinators and a network of identified LHD clinicians. These positions will operate as the specialist front line, supporting all LHDs to develop local capacity to treat more people where they live and

get access to more intensive specialist treatment for those who need it.

The four NSW Eating Disorder Service Coordinators currently supporting individual specialist services will take on a wider cross LHD/regional network role to further support LHD capacity building, clinical networks and facilitation of access to local and tertiary care options. These positions will report directly to the Statewide Eating Disorders Service Development Coordinator funded by the Ministry of Health and operating through the Centre for Eating and Dieting Disorders of the University of Sydney (see s.9). This statewide role will be integrated through a service partnership with the tertiary eating disorders service within Sydney LHD to support the ongoing patient flow and integrated care models across NSW.

A senior person will be identified within each LHD to be the contact person to support clinical pathways and networks and to support local capacity building. These positions will need to be able to work across age-specific services, subspecialty and service setting. The focus for these positions is to ensure people can access services: that there are mechanisms for internal referral, processes for specialist consultation and escalation of care options, as well as training and supervision.

These structures will be supported by data collection, service access monitoring and an annual service development forum to assist the implementation of the Plan. An annual NSW Eating Disorders Forum will strengthen implementation of the Plan by disseminating best practice, skills enhancement, support leadership roles, engagement and networking.

System monitoring and feedback is an element of the Service Plan that will guide implementation and quality care improvement. Data will be collected by the Ministry of Health, with six-monthly data reports indicating service utilisation for eating disorders. The NSW Chief Psychiatrist will be engaged in an oversight role, assisting to resolve clinical placement or other issues where necessary. ACI will ensure that clinicians from relevant ACI Clinical Networks provide input and support for the development of the processes by the Ministry of Health to enhance access to inpatient and community-based treatment services, build clinical capacity and support regional capability to better respond early and effectively to people with eating disorders.

2.1.2 Implementation and Reporting by LHDs

In adopting the Service Plan, all LHDs need to demonstrate and report to the Ministry of Health on an annual basis progress on building local capacity to respond to the treatment needs of people with an eating disorder and their family and carers. The relevant components include:

- ▶ Appointment of senior person within each LHD to be the lead officer for service advice and planning;
- ▶ Map local service delivery points, current clinical capabilities and capacities;
- ▶ Develop a local plan to maximise current capacity and identify gaps in consultation with stakeholders, including consumers and carers;
- ▶ Ensure local protocols allow access and treatment for medically compromised and high risk eating disorder presentations;
- ▶ Develop a local eating disorders clinical hub or network to support all models of care relevant to local resource, multi-specialty and multidisciplinary care planning;
- ▶ Target service development to address the four service levels outlined in the Framework;
- ▶ Develop the workforce – access to training and increase competence to reflect generalist and specialist care models;
- ▶ Develop strategies to address gaps in local service provision with the goal of ensuring access to all levels of care required.

2.2 Planning for the Service Spectrum

Eating Disorders vary in their level of severity and clinical complexity, age and gender. Service level is dependent on considerations and variances in the nature of the disorder and the level of risk associated with comorbidities as well as physical and mental health complications of the disorder.

2.2.1 Integrated regional care

The current Australian National Standards for Mental Health Services highlight the need for integrated health services to provide more comprehensive and effective health care to clients. Through service integration, diverse skills and resources can be combined to address community needs and provide effective care (Armstrong, 2010). Integration across public and private providers and a whole-of-hospital model of care supports:

1. Comprehensive services across the care continuum
2. Consumer focus to care planning
3. Geographic coverage and role delineation to reduce duplication and maximise access to care
4. Standardized care delivery through inter-professional teams
5. Performance management
6. Information systems shared across services
7. Organisational culture and leadership
8. Medical integration both in regard to primary care and secondary referral
9. Governance structure that promotes coordination
10. Financial management to maximise resources

2.2.2 Budgeting at the LHD/Hospital Network level

As noted in Section One, LHDs are currently admitting people with an eating disorder to paediatric, non specialised and non mental health inpatient care at almost double the rate (17.9 occupied bed days) compared to Child and Adolescent mental health, specialist and adult mental health (9.7 occupied bed days). Local admission rates and length of stay vary widely. Having an effective care model for local provision of coordinated and timely evidence-based eating disorder treatments will impact on unnecessary and costly presentations to emergency and intensive sectors of the health service. Efficient pathways through acute presentation at emergency departments to specialist interventions will impact on emergency access targets, admission length of stay, and readmission rates.

The Australian Health Reform Activity Based Funding model identifies eating disorders with a specific price weighting that recognises the multi-disciplinary, multi-speciality requirements of interventions and associated extended average length of an episode of care. There are different weighting scales for child and adolescent and adult care in specialist mental health units (Psych>0). This funding follows the person across hospital subspecialities in response to treatment need and is not attached to provision of a designated number of beds *per se*. Hospital substitution care, such as day program and outpatient services is also supported with funding models dependent on the service type. The funding model supports service growth based on identified activity against the annual base.

For LHDs this funding model helps resolve cost and bed capacity constraints within any single health subspecialty and assists LHDs to consider a whole of hospital and whole of treatment model of care that is responsive to clinical need and demand.

2.3 Key Principles underlying the Service Framework

All services should support:

- ▶ **Early identification and dissemination of evidence-based treatment:** Best Practice early intervention strategies have the strongest evidence for preventing or reducing the high levels of morbidity and mortality associated with eating disorders;
- ▶ **Flexible entry and care delivery options:** Service responses from entry point through to ongoing and multi levelled care requires a coordinated approach between professionals, options for re-entry at all levels, as well as systems support for quick transition between different levels of intensity of care when required. During times of rapid weight loss and/or life threatening situations, specialist inpatient or supported generalist inpatient treatment is indicated.
- ▶ **Targeted Services:** Services should be developmentally appropriate in terms of program design, risk assessment and health practitioner skills. These services should recognise particular cultural issues impacting on the recognition, engagement and family and carer participation in care;
- ▶ **Family and Carer Engagement and collaboration:** Parents, partners, carers, loved ones and friends can play a key role (Treasure, 2007 Lock & LeGrange, 2005) and should be involved as a matter of course, particularly with children and adolescents, but also with young people and adults wherever it is appropriate. Assessment of families' and carers' capacity, their engagement in treatment, their assistance in the application of evidence-based treatments and assessment of carers' own needs in caring for someone with an enduring illness are key components of comprehensive treatment and care;
- ▶ **Local capacity and access to specialist treatment:** Development of local eating disorder hubs or networks allow maximum care integration and skills transfer from tertiary supports provided through case review and supervision and, when treatment requires, coordinated admissions and planned discharge.

While all LHDs need to be able to assess and treat people with eating disorders it is recognised that tertiary support, including access to tertiary inpatient care, needs to be available when treatment and risk factors are beyond local capacity;

- ▶ **Comprehensive and integrated care:** A range of health subspecialties have key roles in treatment and recovery, with multi-disciplinary input into coordinated care planning usually essential. Public, private and NGO providers may be involved in care at stages or concurrently;
- ▶ **Continuity across setting and over time:** Transitions from child & adolescent to adult streams of health, from hospital to community, and from private to public provider need to be supported. Local protocols and referral pathways as well as local networking ensure that people are not lost to the system at pivotal times in care;
- ▶ **Partnerships for recovery:** Working with relevant local agencies such as schools, youth services and the health industry to increase support in personal health and social development is also recommended;
- ▶ **Consultation with consumers and carers:** Services will benefit from strategies to ensure and support consumer and carer participation in the development and implementation of LHD service development;
- ▶ **Evaluation and Monitoring:** Services need to understand demand and pathways to care. This requires clear and specific data collection and performance indicators to enable evaluation of their effectiveness, cost efficiency and feasibility.

2.3.1 Essential Service Capacities

Early engagement: Every health service point of entry for people who have, or are at risk of developing an eating disorder should have the capacity (e.g. policy, protocols, access, referral pathways, information resources) and capability (e.g. staff knowledge, and skill) to provide the following services:

- Screening
- Assessment
- Early intervention treatment
- Appropriate referral pathways to more intensive treatment
- Shared care during treatment and recovery support

Accessible and appropriate treatment: Every health service should have the capability to link with and be supported by specialist eating disorders expertise. Specialist services require the capacity (e.g. sufficient resources, referral pathways, communication technology) and capability (e.g. multidisciplinary expertise) to provide:

- Inpatient and outpatient treatment
- Telephone / telepsychiatry assessment
- Liaison and case management
- Consultation support
- Supervision and professional development support

Responsive and flexible care options: LHD service model needs to allow people to transition between general and intensive outpatient treatment and provide:

- Multidisciplinary treatment that addresses the physical, psychological, nutritional, and functional needs of patients
- Evidence-based behavioural learning and therapeutic approaches
- Family education and support
- Accessible and culturally appropriate locations for high risk groups

2.4 Service Spectrum to respond to levels of need

The range of eating disorder service options needed across the health system can be conceptualised in terms of increasing specialisation and intensity with flexible patient flows supported by collaborative care planning. Service configurations and linkages may vary on the basis of developmental considerations, geographic and resource constraints.

2.4.1 Primary and Community Based Interventions

Promote Healthy Body Image:

Community programs that promote positive body image, good nutrition and appropriate messages around dieting have potential to impact on population risk behaviours. Engagement with the wider community and the provision of education and consultation promotes opportunities for early identification. Access to care for people with emerging eating disorders will have long term impact.

Early identification and access to treatment:

General practitioners or other health professionals managing people with eating disorders are part of a network of providers and can be linked through referral pathways, consultation and liaison and shared care models.

Case management by generic community health and mental health services can reduce the need for more intense and costly services when health practitioners are supported by training and have access to clinical supervision and opportunities for multi-disciplinary clinical review.

Escalation and risk management:

Protocols and procedures should identify treatment roles and escalation of treatment level indicated by rapid weight loss, failure in treatment and need for medical stabilisation, or to contain behaviours that increase risk of serious harm.

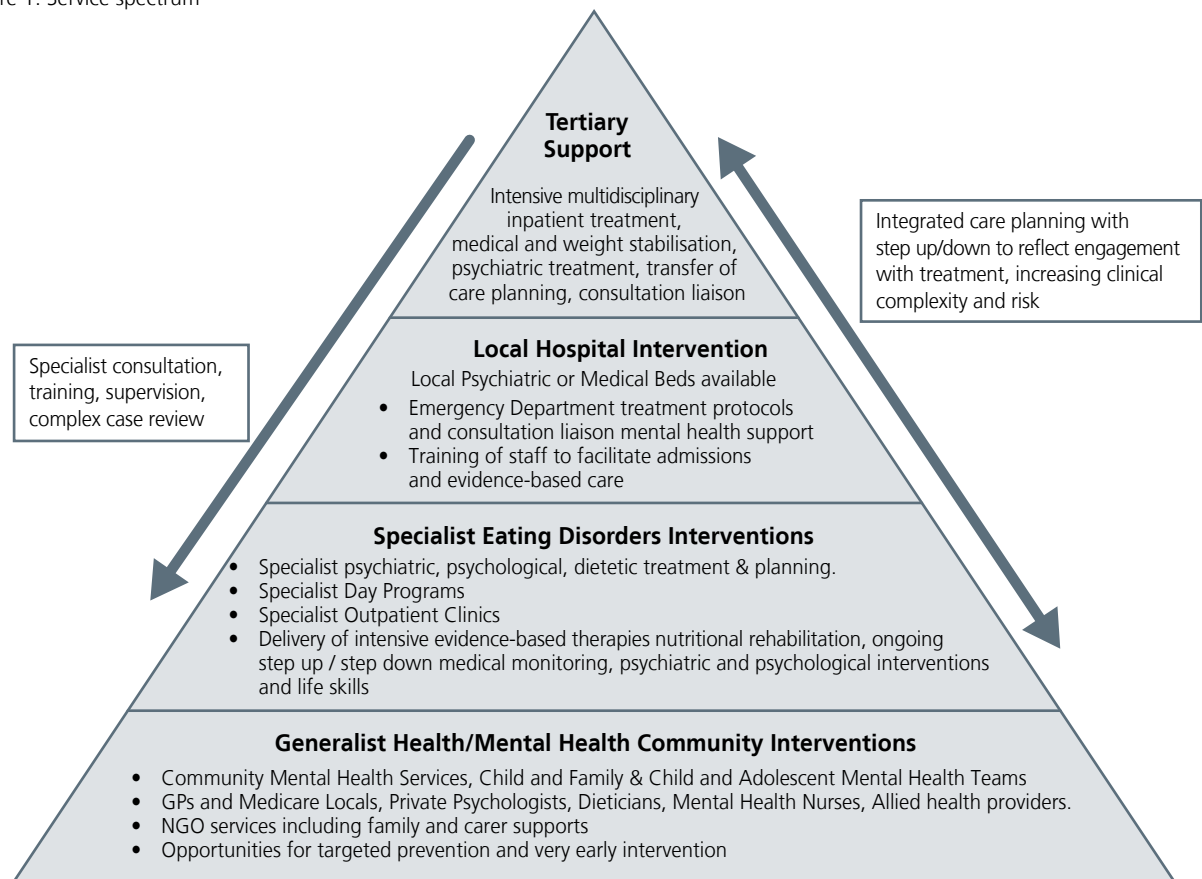
Health and wellness programs such as self-esteem and healthy body image programs in schools as well as specialist community supports such as The Butterfly Foundation counselling service can improve willingness to engage in treatment for the duration of the illness.

The majority of people with eating disorders can be managed through primary care with appropriate specialist support when required, or through outpatient services.

Medicare Locals and other generic health centre models such as headspace and youth health centres provide ideal structures for further education, ongoing consultation, primary care and escalation pathways for deteriorating conditions.

The significant contribution of primary health providers and the private health sector, as well as a range of public health subspecialty services across all levels of clinical need is recognised. Many health practitioners in primary health care, including GPs and allied health professionals, have an interest and developed expertise in treating existing disorders. The role of the GP is essential to manage possible

Figure 1: Service spectrum



medical complications (NICE, 2005; Beumont, Hay & Beumont, 2003). GPs may also be best placed to act as the clinical coordinator for the longer term management of people who have eating disorders. Medicare funded mental health treatment planning and linkage to allied health interventions provides significant opportunity for early intervention and shared care options. However, GPs can struggle to identify and manage eating disorders within a primary setting (Speilman & Steinbeck, 1995) due to complexities associated with the disorders themselves, challenges of multidisciplinary teamwork and lack of adequate training and support (Orman, 2005; Williams, 1998).

NSW has 20 Medicare Locals contracted by the Commonwealth Government to improve health services for communities in their regions by:

- ▶ Working closely with LHDs to provide seamless care for patients
- ▶ Identifying gaps in local health services and working to address these
- ▶ Linking local general practices, other primary care providers, hospitals, aged care facilities and Aboriginal and Torres Strait Islander health organisations
- ▶ Maintaining up-to-date local service directories
- ▶ Planning and supporting local after-hours general practice services
- ▶ Supporting local primary health care providers, including general practices, to adopt and meet quality standards and
- ▶ Being accountable to local communities to make sure that services are effective and of high quality (T.Usherwood 2013).

While primary care services can manage mild to moderate symptoms, LHD Boards, the mental health services and relevant service providers need to establish a networked model/pathways to care that incorporates from primary care to more intense and specialist treatment for people with moderate to severe levels of clinical need. An ideal care model provides for a seamless treatment and support journey, with referral pathways across these systems and services and clear roles and mechanisms for consultation, collaboration and review. To promote engagement and maximise support for the person with an eating disorder and their family/carers, the care model needs to outline opportunities for linkage and participation of relevant non-government agencies and the wider community, promoting engagement and providing recovery support.

2.4.2 Specialist Eating Disorders Interventions

Clinical hubs:

Clinical leadership and identification of health practitioners with an interest in the area is vital to establishing a viable model of care. Outpatient clinics and Day Programs provide an effective level of care for most people who have eating disorders. They also provide a clinical hub of gathered expertise in eating disorders to support informed and effective care as well as a mechanism for broader service capacity building. Establishing care pathways from such services to hospital care, through a consultation and liaison model, may provide a response capacity for smaller facilities and for LHDs at early stages of implementing this plan.

Best practice interventions:

Evidence-based treatment includes treatment for medical complications, refeeding and nutritional rehabilitation. In addition, health restitution and recovery can be promoted through undertaking person centred psychological therapy and/or family therapy and by developing life skills. Family and carer support and engagement are essential for maximising effectiveness of the treatment plan.

Coordinated care planning:

Transition between services and accessing continuing care are major points of treatment disengagement and pose significant risk for deterioration in health status of the individual. Issues include coordination of care between emergency responses, inpatient treatment and community follow up, across multiple specialist interventions and service subspecialties, and at points of transition including between paediatric/adolescent/adult services is a key capability and capacity of specialist hubs.

Case consultation, education, supervision and advice:

Supporting nonspecialist services to manage mild to moderate severity of symptoms.

For those patients who do not require containment to support treatment engagement or whose risk status does not require life saving interventions, comprehensive outpatient or day-patient treatments have been shown to have both financial and clinical advantages over traditional inpatient care (Zipfel et. al (2002). To be

successful, such treatment will require access to multidisciplinary care planning including psychiatry, psychologists, mental health nurses and dieticians, linked to shared care GP community teams. For many people with an eating disorder, outpatient care may be sufficient (Fairburn & Bohn, 2005).

Specific strategies should be developed to support involvement of carers and families and the provision of family support. For younger adolescents particularly, training of carers and families to help them fully participate as important members of the treatment/care team is important. This support may be delivered effectively as part of a hospital or community-based treatment program or an NGO support service.

Day Programs based in the community offering early intervention and sub acute alternative to hospital care, where that is clinically indicated, show evidence of capacity for good clinical and personal recovery outcomes. Day Programs allow intensive group and individual treatment to occur, while allowing the patient to continue some degree of educational, vocational and family life, resulting in reduced dependency, control issues and the stigma associated with psychiatric hospitalisation. Day Programs have been shown to result in significant remission rates, maintained for up to 18 months (Fittig et al, 2008) and a reduction in inpatient bed days and overall costs of treatment (Birchall et al, 2002). Day programs aim to contain eating disorder behaviour and facilitate weight gain and psychological development while developing psychosocial skills. These programs can be used as step-up when progress in less intensive outpatient therapy is insufficient or step-down following an inpatient admission. Day programs are less restrictive and more cost-effective than inpatient programs and are an important component of a comprehensive service. Partnerships with the community managed sector or other service providers should be considered, as they may be the most cost-effective way to deliver high quality day care.

Where community mental health services have a level of expertise in assessment and case management of eating disorders, the evidence suggests reduced demand on specialist outpatient and day programs. Small clinical hubs of expertise based at community teams can effectively manage moderate symptoms with evidence-based interventions and access to specialist support. LHDs should ensure that systems are in place to facilitate

structured case management, “shared care” or a team approach to support effective coordination of care.

Specialist services should ensure there are strong community linkages with the community managed sector, youth and women’s health services and schools to provide education and information exchange. Many services that engage groups at risk can provide important opportunities for identification of risk behaviours and early illness, facilitate help-seeking, promote positive health messages and challenge stigma. Existing partnership programs such as *School-link* and other community networks provide mechanisms for education and trust building that support access and engagement in care.

The Statewide Eating Disorder Service Coordinator and four LHD-based Eating Disorder Service Coordinators will support a network of identified LHD clinicians. These positions will operate as the specialist front-line, supporting all LHDs to develop local capacity to treat more people where they live, and facilitate access to more intensive specialist treatment when needed.

To support the expansion of specialist eating disorders services the NSW Government will:

- ▶ Enhance capacity of existing Adult Eating Disorder Day Programs
Two current Day Programs offer statewide intensive community treatment services: A stand-alone community early intervention service located within Central Coast LHD and a step up, step down service linked to the eating disorders services provided at Royal Prince Alfred Hospital in Sydney LHD. Additional funding will be provided to each service to support access to medical review to strengthen the provision of care in the community.
- ▶ Establish a new Adult Eating Disorder Day Program
Building on local capacity and networks, additional funds will be allocated to establish a new adult Day Program in the Hunter Region, to provide 8 adult specialist eating disorder clinical places.

2.4.3 Local Hospital Interventions

Acute and emergency responsiveness:

Local Emergency Departments, medical, psychiatric or paediatric wards need to be able to identify illness or significant risk and be equipped to provide medical stabilisation and/or acute intervention.

People with anorexia nervosa should be able to access medical beds where their BMI is 14 or under. Earlier admission is desirable to halt the illness trajectory, reduce length of stay and disease impact.

Model of Care to support essential treatment

Liaison and interface between medical and mental health care, to treat aspects of the illness and prevent mortality, is essential.

Involuntary admission and treatment through the application of the NSW *Mental Health Act* is appropriate and may be required when there is significant risk of harm. However, voluntary engagement of the person in recovery planning is necessary and imposed treatment should be applied judiciously and reflect individual stage of readiness for change.

Access to specialist consultation and care planning:

Local Hospitals/ District Hospitals need access to specialist advice and consultation in developing care plans including for safe refeeding, psychiatric and mental health care, nursing management, dietetic and behavioural interventions.

Emergency Departments have a key responsibility in facilitating entry into treatment.

Health practitioners working in Emergency Departments need training in the triage, risk identification and medical management of people with eating disorders. Procedures need to be established to ensure there is a locally supported admission pathway for patients presenting with severe illness and to prevent premature discharge or inappropriate treatment.

People with eating disorders can present to Emergency Departments with acute metabolic crisis and/or acute behavioural and psychosocial deterioration, including food refusal or self harm behaviours. The clinical picture can

deteriorate rapidly, particularly in children and adolescents. As such, a clinically informed assessment is essential and where an internal treatment pathway is not indicated, referral to appropriate follow-up should be facilitated. People with eating disorders may have poor or fluctuating engagement with treatment and health services. This can be further negatively impacted by difficulties in accessing appropriate care when they *do* present to services.

Inpatient services may be general medical or mental health beds or specialist units/pods. This Framework generally adopts the recommendations of the United Kingdom Royal College of Psychiatrists and Royal College of Physicians (MARSIPAN, 2010) for specialist inpatient eating disorders units to treat people with severe anorexia nervosa. However, where this is not viable or until specialist inpatient eating disorders units are established, generalist inpatient care needs to include input from a senior psychiatrist, physician and dietician. At a minimum, inpatient care needs to provide the capacity for nasogastric insertion and feeding with daily biochemistry, as well as nursing care to support medical and dietary stabilisation as well as stabilisation of problem weight control behaviours such as purging and excessive exercise. (Please refer to Adult Inpatient Guidelines at Appendix C or at www.cedd.org.au)

While varying from site to site, it is likely that there will be limitations in treatments and interventions able to be delivered by generalist units. Medical units will have greater options for invasive interventions such as intravenous infusions, artificial ventilation, cardiac monitoring, and treatment for serious medical complications. Responsive transfer options between medical and mental health units are required to deal with medical compromise as it arises. Consultation liaison and telemedicine support from specialist services can help to develop care plans for patients who require more intensive treatment and/or link to agreed referral pathways to specialist services when treatment fails or becomes too complex.

Consultation pathways with CAMHS and adult Mental Health services should be available during admission particularly to address comorbidities.

The effective management of a patient with an eating disorder involves collaborative multidisciplinary care. A joint care plan should be agreed upon including goals, non-negotiables, daily group programs and regular

individual consultations. Clinical roles and responsibilities should be outlined. Regular meetings should be held to review treatment plans. The patient and family/carers have an important role in developing and reviewing the plan. Support should be offered to families and carers who experience high rates of anxiety, depression and other mental health issues (Kyriacou et al, 2007).

For people who lack motivation to engage in treatment, short admissions for stabilisation of medical compromise, followed by supportive follow-up or more intensive counselling-based on a motivational approach, may be offered. It is never too late to recover from an eating disorder, so offering the opportunity to engage with treatment opportunities wherever these exist is always recommended.

For people who are medically compromised as a result of malnutrition, vomiting and purging or who have significant suicidal ideation, involuntary admission under the *Mental Health Act* may be necessary, particularly as a short term life saving intervention. However, involuntary care and intense behavioural remediation plans can reinforce conflict between the treating team and the person and are unlikely to assist in a person's journey to self mastery of the condition and decisions about when to enact compulsory treatment is best guided by a longitudinal perspective and in consultation with the person and their carer network.

Engagement in a community recovery or maintenance plan needs to commence in hospital. Models of care currently used in inpatient services need to limit the risk of institutionalised and iatrogenic problems.

This Service Plan supports increased specialist skills at local sites and access to consultation and supervision, and flexible treatment options to enable greater and ongoing involvement of local services.

The Service Plan includes Guidelines for the Inpatient Management of Adult Eating Disorders in General Medical and Psychiatric Settings in NSW (Appendix C) to provide local health staff with information about when to admit an adult with an eating disorder who presents to the hospital setting either through Emergency Departments or other service access points, and advice on how to treat the person once admitted until specialised advice or service can be accessed.

2.4.4 Tertiary Supports

Across the age spectrum:

Statewide services support local inpatient and specialist community programs by providing clinical consultation and supervision as well as access to highly specialised care where local services are unable to achieve weight gain and stabilisation for those with highest medical risk. This may be due to complexity of treatment or containment of behaviours that compromise these goals.

Capacity in NSW:

The Child and Adolescent tertiary service of Sydney Children's Hospital Network provides statewide inpatient admission and outpatient care as well as consultation support and training to regional services. Adult statewide services are less developed and need to expand activity to support the recommended development of LHD capacity to provide the majority of care needs to its catchment.

Development of expertise:

Opportunities to further develop training and innovation in care options will improve outcomes for individuals and support local capacity to minimise numbers needing highly specialist care and those with severe symptoms persisting through to adulthood. A statewide clinical pool of highly trained and experienced clinicians to manage the complex issues of refeeding syndrome, underfeeding syndrome and management of treatment failure and challenging behaviours is a priority for the NSW Ministry of Health.

The Statewide Eating Disorders Service Development Coordinator at the Centre for Eating and Dieting Disorders of the University of Sydney will be integrated through a service partnership with the tertiary eating disorders service within Sydney LHD to support ongoing statewide access and integrated care models across NSW. The four NSW Eating Disorder Service Coordinators currently funded by the Ministry of Health to support individual specialist services will, under this plan, take on a wider cross LHD/regional network role to further support LHD capacity building, clinical networks and facilitation of access to local and tertiary care options.

There will always be a significant number of patients (mainly those with serious anorexia nervosa) who require specialist inpatient care. For patients who are especially emaciated or have been at extreme low BMI for extended periods, the illness can pose difficult problems for medical management including risk of refeeding syndrome or underfeeding syndrome. Treatment intensity should be reduced as soon as clinically appropriate to promote self mastery and recovery.

Support to LHD services includes clinical case review, supervision and advice to prevent unnecessary deterioration and reliance on limited tertiary admission capacity and promote local treatment efficacy. Reasons for referral to tertiary admission should be based on clear goals that are beyond local service provision and with clear transition of care planning back to local services.

Those with particular complexities may require more specialist or intensive treatments than can be provided at local sites. Acute Inpatient Specialist Services for children and adolescents (Sydney Children's Hospital Network – Randwick and Westmead) and adults (Royal Prince Alfred Hospital, Camperdown and Westmead Hospital) have a limited number of statewide specialist beds for eating disorders.

Staff in tertiary specialist inpatient services require ongoing education and supervision to provide care to those with the most complex care needs and develop skills of consultation and supervision to others.

To support the development of tertiary eating disorders services the NSW Government will fund:

A Pilot Child and Adolescent Day Program delivered through Sydney Children's Hospital Network in partnership with The Butterfly Foundation will be trialled over the life of the Service Plan to test the efficacy and appropriateness for a younger cohort. The new service will operate five days a week for people aged 10-18 and their families. To provide greater clinical support and care integration to families from across the state, Day Program staff will provide consultation and education through telehealth and abridged residential treatment programs that will reduce the duration young people and their families need to be away from home.

Expand Adult Tertiary Eating Disorder Services

Over the life of this Service Plan the NSW Government will expand the statewide adult specialist eating disorders bed base from five (5) to nine (9) beds. Royal Prince Alfred Hospital adult eating disorder unit will be expanded to six (6) beds; Westmead's three (3) adult beds will become statewide accessible; mechanisms to link tertiary care options to subacute private eating disorder beds will be strengthened.

Royal Prince Alfred Hospital located within Sydney LHD will build to a six bed statewide adult eating disorders unit linked to the existing day clinic and day program. The expanded tertiary model will deliver best practice care to the most complex cases referred from across the state. The service will provide support to LHDs through consultation and supervision to minimise demand on limited tertiary beds and improve outcomes through ongoing local care delivery. The NSW Government will also provide funds to allow some additional access to private eating disorders beds to allow maximum access to tertiary beds and flexible care options for those requiring extended inpatient care.

2.5 Workforce Development and Competency supports

Centre for Eating & Dieting Disorders

The Centre for Eating and Dieting Disorders (CEDD) is funded by the Mental Health and Drug & Alcohol Office, NSW Department of Health. It is an academic and service support centre based in Sydney, Australia resulting from a collaboration between Sydney LHD and The Boden Institute of Obesity, Nutrition, Exercise & Eating Disorders in the Faculty of Medicine at the University of Sydney

The Centre has a number of key functions:-

- ▶ to promote awareness of eating disorders as serious mental illnesses, that require treatment and in many cases can be cured
- ▶ to contribute to policy development for the treatment, prevention and cure of eating disorders
- ▶ to improve access to services for people in NSW who have an eating disorder, and their carers
- ▶ to provide support to clinicians in NSW who have taken on the care of people who have an eating disorder
- ▶ to conduct and foster research into the eating disorders, their aetiology, treatment and cure
- ▶ to educate and train the health workforce in evidence-based medicines and treatments for people with eating disorders
- ▶ to support other organisations working for the betterment of those afflicted by these mental illnesses
- ▶ to contribute to the development of prevention and early intervention policy and interventions to reduce the incidence, duration and burden of eating disorders
- ▶ to collaborate and cross-fertilise ideas with experts in the fields of obesity, body image and other related disciplines to promote broad spectrum Public Health.

NSW Resources can be found at www.cedd.org.au

An online training program for health professionals has been developed by the NSW Eating Disorder Coordinator and the Centre for Eating and Dieting Disorders (CEDD). It has 5 modules and is highly interactive involving text-based learning, videos, role-plays, quizzes and interactive games. First year evaluation results reveal the program significantly increases confidence to treat, knowledge and skill level in eating disorders and significantly reduces stigma and bias against treating these illnesses. Over 600 NSW clinicians have accessed the program which is registered for CPD points with all relevant national

professional group bodies. Please visit CEDD website for information and to register – www.cedd.org.au.

The Guidelines for the Inpatient Management of Adult Eating Disorders in General Medical and Psychiatric Settings in NSW (**Appendix C**).

Other programs being developed include a GP handbook and electronic practice guide.

The Eating Disorder Toolkit developed by NSW Ministry of Health MH-Kids is a practice-based guide to the Inpatient Management of Adolescents with Eating Disorders, with special reference to Regional & Rural areas.

The CEDD website has professional sections with practice aides for daily use in treating eating disorder cases.

The *Mental Health for Emergency Departments: A Reference Guide 2009* provides advice on managing Eating Disorder emergencies, designed to guide initial mental health assessment and interventions for patients presenting to the Emergency Department or medical clinics' staff.

A guide for the management of patients in psychiatric settings has been developed and is available on the Centre for Eating & Dieting Disorders website.

Guidelines and a training program for gyms and personal trainers in the detection, management and support of people with body image, eating disorder, over-training and supplement abuse issues is available.

Several resources published across Australia are being used in NSW. These include Australian and New Zealand clinical practice guidelines for the treatment of anorexia nervosa (Beumont et al, 2004), Practice recommendation for the dietetic treatment of anorexia in adults (Wakefield & Williams, 2009), Eating Disorder First Aid guidelines (Oryen Health, 2009), Queensland Health: Eating Disorders Outreach Service Model, eating disorder information sheets and worksheets produced by the Centre for Clinical Interventions in Perth and a position statement on inpatient care by the Australia New Zealand Academy for Eating Disorders.

Background Information

What are Eating Disorders?

Anorexia nervosa (AN) is a serious mental and physical disorder with a lifetime prevalence in one Australian community sample of 1.9% for full syndrome anorexia nervosa and 2.4% partial syndrome (Wade et al., 2006), resulting in overall lifetime prevalence of approximately 4.3%. In females, within the child and adolescent age range point, prevalence has been estimated to fall at approximately 0.84% (Rastam et al, 1989). The disorder can result in life-long physical and psychiatric morbidity and risk of suicide. The disorder has an average length of 5 to 7 years. Persons with AN may require high levels of inpatient care, multiple hospitalisations, and several years of outpatient and/or community-based care to bring about recovery. Full recovery is possible in AN; research shows that 50% will make a full recovery and a further 20-30% will make a partial recovery (Ben Tovim et al., 2000; Wentz, 2009). The disorder has a high mortality rate; best estimates put it at more than 5% per decade of illness (Sullivan, 1995).

Bulimia nervosa (BN) is a moderate to severe mental illness with a lifetime prevalence between 1.1% to 5% among young females (Ben Tovim et al., 1989; Hoek & Hoeken, 2003; Favaro et al., 2003; Garfinkel & Goering, 1996; Lewinsohn et al., 2000; Striegel-Moore et al., 2003; Wade et al., 2004). Partial-syndrome BN is thought to have prevalence of about 5.4% among young females (Hoek & Hoeken, 2003). Comorbidity in this group is common. People with BN are trapped in a vicious cycle of dietary restriction, binge eating and purging behaviour.

Binge eating disorder (BED) is a moderate to severe disorder with a lifetime prevalence of at least 2.9% (Wade et al., 2006). BED is similar to BN except that these individuals do not purge after they binge on food, hence they are at higher risk of becoming obese (Yanovski, 1993; Johnson et al, 2001). While still associated with significant levels of psychiatric morbidity (Yanovski, 1993; Grilo et al 2001; Johnson et al 2001), there is some evidence to suggest that BED has lower rates of comorbidity than does BN (Fontenelle et al., 2005). Within the diagnostic

group of BED is Night Eating Syndrome (NES). NES is an eating disorder characterised by morning anorexia (loss of appetite), evening hyperphagia, and insomnia with awakenings followed by nocturnal food ingestion. NES can be distinguished from BN and BED by the lack of associated compensatory behaviours, the timing of food intake and the fact that the quantities of food are small, amounting to repeated snacks rather than true binges. NES is of importance clinically because of its association with obesity. Its prevalence rises with increasing weight, and about half of those diagnosed with NES report a normal weight status before the onset of the syndrome.

Eating disorders otherwise not specified (EDNOS) is a term used to describe atypical presentations of eating disorder, or eating disorders that do not meet the strict criteria for anorexia or bulimia nervosa. Included in this group are those with emerging or recovering eating disorders, or may include those whose eating problems relate to other psychiatric illness (e.g. depression, anxiety, schizophrenia).. Recent research suggests that EDNOS can be just as severe as anorexia nervosa and has a similar mortality rate (Franko et al., 2004; Garfinkel & Goering, 1996). Persons with EDNOS comprise the largest number of individuals with eating disorders. Although the true incidence of EDNOS is unknown, research suggests that they are the diagnostic group that presents most often for outpatient therapies (Fairburn & Bohn, 2005).

Feeding disorders of infancy and early childhood are of significant concern and may be associated with considerable physical and psychological sequelae and may place an individual at increased risk of an eating disorder in later life. They may include conditions such as pica, rumination, picky and fussy eating, food faddiness, food avoidant emotional disorder, selective eating, restrictive eating, functional dysphagia and pervasive refusal syndrome (Lask et al, 2000 and Kedesdy et al, 1998).

Disordered eating is relatively common. It is a behavioural disorder that may be related to the onset of an eating disorder. It includes eating too much, too little or having a markedly imbalanced diet. It is generally estimated that

up to 60% of girls and young women regularly engage in unhealthy weight loss behaviours. Of 15-year-old females, 68% are on a diet and of these 8% are severely dieting. Disordered eating behaviours put an individual at significantly increased risk of developing a full-blown eating disorder and hence represent an important indicator for early intervention services.

Obesity is a condition that may be related to disordered eating. It is a condition of increasing concern to society, due to its association with many of the chronic diseases that comprise much of the burden of disease impacting upon the public health system. However, as it is not defined as a mental disorder, or included in the DSM IV classification of 'eating disorders', it is considered outside the scope of this report, except in relation to primary prevention and health promotion.

Current Status of Services

In NSW, specialist outpatient and inpatient services are largely centred in metropolitan Sydney. Many people with eating disorders receive treatment from community-based services such as general practitioners, community dietitians, community-based mental health staff such as generalist psychologists or psychiatrists, and medical and nursing staff in general hospitals. However, many of these workers report a reluctance to treat eating disorders, citing lack of skill and expertise, lack of time, degree of difficulty, and concerns about medical risk associated with treating the client group (HAHS, 2000).

Specialist and Tertiary Services

There are several tertiary teaching hospitals in NSW that currently offer treatment and consultation for Eating Disorders: one for Children & Adolescents at the Children's Hospital at Westmead (CHW) in partnership with the Department of Adolescent Medicine, Westmead Hospital, and a corresponding service for adults at Royal Prince Alfred Hospital (RPAH), Camperdown.

- ▶ Children's Hospital Westmead has approximately six (6) non-dedicated but specialist beds available for admissions to treat children with eating disorders. Due to medical imperative the number of eating disorder admissions frequently exceeds this number. These beds are supported by significant outpatient care options.
 - SCHN eating disorders team works in collaboration with the Department of Adolescent Medicine in Westmead Hospital, which provides an additional 8 non-dedicated but specialist eating disorder beds for older adolescents.
 - Through the Child and Adolescent Psychiatry Telemedicine Outreach Service (CAPTOS), the Westmead Eating Disorder Team provide limited case coordination, clinical consultation and outreach support for children and adolescents managed in other health services throughout NSW.
- ▶ Sydney Children's Hospital offers four (4) beds for local children and adolescents, as well as for children across NSW.

- ▶ John Hunter Hospital has previously admitted children and adolescents with eating disorders from the Hunter New England region and beyond into the psychiatric unit (Nexus) and adolescents medical ward. In 2011, an integrated program commenced at the hospital, based in the adolescent unit, under the dual care of mental health and paediatrics, with community CAMHS inter-linkages. It provides four (4) beds.
- ▶ RPAH at Camperdown has two (2) adult beds currently operational from the four (4) adult beds allocated to eating disorders. This service offers limited consultation and outreach support via tele-psychiatry for adults with eating disorders in NSW. Staffed by a multidisciplinary team and attached to an academic unit they consult to all LHDs in NSW.
- ▶ Westmead hospital provided three (3) adult inpatient beds
- ▶ In 2008/09 the Ministry of Health funded two (2) pilot day programs which have been very successful in engaging and treating older adolescents and young adults with moderately severe eating disorders:
 - Alongside RPAH mental health inpatient unit to provide step down care and alternative community support and treatment to adults with eating disorders. This multi-disciplinary service provides statewide support where appropriate.
 - Central Coast Eating Disorder Early Intervention Service (EDEIOS). Based at Wyong a small team of clinicians including a dietician, clinical psychologist and social worker offers outpatient individual and family therapy to patients in early stages of an eating disorder.

Newcastle Centre for Psychotherapy

- ▶ An outpatient service staffed by clinical psychologists, dietitians, and occupational therapists based at James Fletcher Hospital in Newcastle offers individual and group therapy services to patients in the Newcastle area.

Other public eating disorder services

- ▶ A few individual clinicians and small clinics exist in both hospital and community settings around NSW.

These include clinics in Sutherland, Campbelltown, Wollongong, Nowra and individual practitioners in Bathurst, Bowral and Tamworth. In addition, a NSW Health funded assessment and referral service is provided from the Women's Community Health Centre in Lismore, where limited inpatient facilities also exist.

Specialist service roles

Eating Disorder Service Officers

To support the expansion of care options for existing specialist ED services, the Ministry of Health funded four service development officers based in SCHN, SWSLHD, WSLHD, SESLHD and HNELHD. These officers have been working to:

- ▶ identify local capacity to treat in the community, involving a mapping of existing ED specialist services, generalist health and mental health services with capacity to treat patients with eating disorders, and assisting to develop the capacity within these services with education and local networking.
- ▶ fortify patient transition arrangements, including community-inpatient-community, and child-adult care pathways.
- ▶ network with the other LHDs and existing eating disorder specialist services and with the statewide Eating Disorder Service Development Coordinator to maximise training and service development resources.
- ▶ provide limited direct outpatient services where this is seen as having significant impact on identified gaps in comprehensive services.
- ▶ establish data-collection and reporting processes in collaboration with ESDSC's including those for enhanced service capacity.
- ▶ facilitate rural and regional outreach and coordination, both to rural zones within networks and via tertiary/rural support frameworks/telehealth (e.g. GESCHN, CAPTOS).
- ▶ provide annual reporting of activity to the Mental Health and Drug and Alcohol Office of NSW Ministry for Health demonstrating:
 - Numbers of eating disorders client seen (inpatient and outpatient)
 - Service development/capacity building
 - Any impact on hospital admission rates

Eating Disorder Service Development Coordinator NSW

The Eating Disorder Service Development Coordinator (EDSDC) funded by MHS and based at RPAH plays a key role in engaging and supporting LHDs in progressing treatment options available to persons with eating disorders across the state. The ESDSC acts as the clinical coordination point for developing services for persons with eating disorders and the broader health service provider system. Key functions of the position are policy development, consultation and liaison, assistance in the provision of education and other supports for both existing and developing services and capacity building at the LHD level and facilitate ongoing partnership with relevant service user and community organisations.

Non Specialist Eating Disorder Health Service Responses

▶ Paediatric services

Children and adolescents with eating disorders often present to paediatricians and paediatric wards, where the range of expertise, interest and availability of treating teams is mixed. Support is often provided by Children's Hospital Westmead and Westmead Hospital adolescent units.

▶ Headspace

This program was established and funded by the Commonwealth Government in 2006, and provides a number of services in nine locations across NSW for youth aged 12-25. Some eating disorder services are offered by Headspace.

Community organisations

▶ Butterfly Foundation

The Butterfly Foundation is the peak consumer organisation in Australia supporting those people affected by an eating disorder. It has an office in Sydney, staffed by qualified allied health practitioners and provides a wide range of services to assist consumers, their families, health and education practitioners and the general public. It is a key point of access to the health system for consumers and carers, enabling people to be informed about the illness and providing them with triage and referral options. The Butterfly Foundation operates the Butterfly National Support Line and an online information service, runs support groups and

publishes up-to-date information about the disorders and treatment alternatives. The Butterfly Foundation provides support and counselling to people in rural and remote areas. It is a registered charity with all income raised through memberships, donations and fundraising activities by volunteers.

Private Sector

A range of support and treatment options are available in NSW through private hospital services and private clinicians working under Medicare funding arrangements.

In 2013, there are at least thirty two (32) eating disorder beds available for adolescents and adults in the private health system, providing inpatient and outpatient and day program support for people with mild to moderate severity of symptoms. These are located through North Side Clinic at Greenwich in Sydney and Wesley Private Hospital at Ashfield in Sydney.



Guidelines for the Inpatient Management of Adult Eating Disorders in General Medical and Psychiatric Settings in NSW

This document is designed to be used by Nurses, Doctors, Allied Health and general health staff located in hospitals or wards without specialist eating disorder facilities, to guide in the assessment of eating disorders, indicators for admission, and management strategies.

The document is divided into three sections:

- **Background**
- **Assessing for an Eating Disorder and**
- **Management of the Eating Disorder Inpatient Admission**

each of which is colour coded and designed to stand-alone. So, for example, section 3 can be separated from the others and distributed to inpatient staff involved in the care of the admitted patient.

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Royal Prince Alfred Hospital Eating Disorder Specialist Team: Elizabeth Frig (Dietitian), Professor Janice Russell (Psychiatrist), Brooke Adam (Clinical Psychologist)

Westmead Hospital Adult Eating Disorder Specialist Team: Elizabeth Parker (Dietitian), Dr Frances Wilson (Psychiatrist).

Local District Eating Disorder Coordinators: Dr Mel Hart (Dietitian), Juliet Elsegood (Clinical Psychologist), Dr Helen Rydge (Clinical Psychologist), Joanne Titterton (Clinical Nurse Consultant), Brooke Adam (Clinical Psychologist)

CEDD Eating Disorder Expert Network Members: Gail Anderson (Clinical Nurse Consultant), Peta Marks (Credentialed Mental Health Nurse), Deanne Harris (Dietitian)

NSW District Health Managers: Dr Mim Webber (NCLHD), Dr Nick O'Conner (NSLHD), Judith Leahy (CCLHD), Dr Susan Hart (SLHD), Alison Latta (CCLHD), Kerry England, (NS&CCLHD)

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Background

Eating Disorders

Eating disorders comprise a group of illnesses that range from moderately-severe through to critical and life threatening, including anorexia nervosa, bulimia nervosa, binge eating disorder, as well as sub-threshold, mixed and atypical cases (known as eating disorders not otherwise specified - EDNOS). Incidence of these disorders begins in childhood, peaks in the adolescent years and can occur in later life. Australian epidemiological data shows lifetime prevalence of eating disorders to be approximately 8% and almost double this in females. Research indicates that the overall prevalence of eating disorders is increasing.

Eating disorders are associated with significant psychiatric and medical morbidity. Effective management of patients requires close collaboration between clinicians working in psychiatric and medical settings. The overarching principle that guides the management of persons with eating disorders within NSW is that they have access to the level of health service they require as determined by their medical and mental health needs. In practical terms this means that patients have a right to access medical and mental health services across the continuum of care including community, inpatient and specialist services.

Management Guidelines

These Management Guidelines were developed following a review of the relevant literature by the Centre for Eating and Dieting Disorders (CEDD) and in consultation with three expert reference groups; an eating disorder specialist clinician reference group, a NSW Health Management reference group comprising local district medical and mental health managers as well as representatives from key health oversight organisations, and a Consumer and Carers reference group facilitated by the Butterfly Foundation.

Individuals with eating disorders are often at risk of not being admitted to hospital despite requiring urgent medical attention. Specifically, a person with an eating disorder maybe acutely medically compromised without necessarily presenting as underweight. Similarly, severely ill individuals requiring urgent nutritional rehabilitation can present without obvious medical abnormality. These guidelines offer indicators for admission to hospital and subsequent management to address these risks.

Purpose of the Guidelines

To provide local health staff with information about when to admit an adult with an eating disorder who presents to the hospital setting either through A&E or other pathways, and how to treat the person once admitted until specialised advice or service can be accessed.

Scope of the Guidelines

These guidelines pertain to adult individuals suffering from a DSM V eating disorder diagnosis. Child and Adolescent management is beyond the scope of this document however comprehensive guidelines and a toolkit for this subset of patients are available on the CEDD website (www.cedd.org.au). As this set of guidelines are for inpatient admissions, they largely refer to eating disorder diagnoses associated with severe medical compromise or emaciation. These are typically AN, BN along with mixed and atypical presentations classed in EDNOS. Guidelines for the management of Binge Eating Disorder are beyond the scope of this document, as are guidelines for outpatient, intensive outpatient or day program or care of the eating disorder.

Assessing for an Eating Disorder

People with an eating disorder may feel uncomfortable disclosing information about their behaviours making the detection of disordered eating symptoms difficult.

Although the incidence of Eating Disorders tend to peak between the ages of 13-25, they can affect people of all ages. While AN and the other eating disorders are always more common in females, childhood AN occurs in males at a higher rate than after puberty. The ratio of AN in females to males is 3:1 before puberty and 10:1 after. Some individuals with an eating disorder will deny their symptoms (see Table 1). It is therefore important to keep objective measures such as weight and physical markers under review if an eating disorder is suspected.

Parents or carers should be included in the assessment process wherever possible. Endeavour to interview family members and carers of adults as part of the assessment procedure, with prior consent from the patient.

A thorough medical examination of the person is mandatory. Persons with an eating disorder will often not disclose eating disorder symptoms at presentation but will present for treatment for a variety of other often related physical signs and symptoms (as listed below). Comorbid psychiatric illnesses are seen in up to 80% of patients with an eating disorder and therefore should be examined in addition to the physical manifestations of the disorder.

Table 1: Indicators for an Eating Disorder Assessment

| Hallmark Signs of an Eating Disorder | Physical Signs of an Eating Disorder | Comorbid Presentations |
|---|---|--|
| <ul style="list-style-type: none"> ▶ Low body weight or failure to achieve expected weight gains ▶ Fear of weight gain ▶ Body image disturbances ▶ Severe body dissatisfaction and drive for thinness ▶ Preoccupation with food, weight and shape ▶ Restricted dietary intake ▶ Self-induced vomiting ▶ Misuse of laxatives, diuretics or appetite suppressants ▶ Excessive exercise ▶ Amenorrhoea, Oligomenorrhoea or failure to reach menarche ▶ Loss of sexual interest ▶ Binge eating episodes involving loss of control over eating and eating unusually large amounts of food | <ul style="list-style-type: none"> ▶ Dehydration ▶ Hypothermia ▶ Syncope (e.g. low BP, postural drop) ▶ Cardiac arrhythmias (Bradycardia) ▶ Suicide attempts ▶ Overwhelming infection ▶ Renal failure (e.g. elevated creatinine) ▶ Bone marrow suppression ▶ GIT dysfunction ▶ Acute massive gastric dilatation from bingeing ▶ Enlarged Parotid Glands from purging ▶ Electrolyte imbalance (e.g. potassium, sodium) ▶ Dorsal hand calluses from inducing purging | <ul style="list-style-type: none"> ▶ Major Depressive Disorder ▶ Anxiety Disorders ▶ Obsessive Compulsive Disorder ▶ Substance abuse / dependence ▶ Self-harm and suicidal ideation |

Screening for a likely Eating Disorder

If 1 or more of the above hallmark or physical signs, or a comorbid condition is present, an eating disorder diagnosis should be screened for. The SCOFF Questionnaire is an evidenced-based screening tool for determining the likelihood of an eating disorder.

Ask the following 5 questions:

1. Do you ever make yourself sick (S) because you feel uncomfortably full?
2. Do you worry you have lost control (C) over how much you eat?
3. Have you recently lost (O) more than 6kg in a three month period?
4. Do you believe yourself to be fat (F) when others say you are too thin?
5. Would you say that food (F) dominates your life?

One or two positive answers should raise your index of suspicion and indicate full assessment for an eating disorder and consultation with an eating disorder expert or mental health clinician is needed.

Morgan JF, Reid, F, Lacey JH. (1999), The SCOFF Questionnaire: assessment of a new screening tool for eating disorders, *British Medical Journal*, 319, 1467-1468)

Emergency Department Triage

The tests outlined below in Table 2 should be conducted for all patients presenting to the Emergency Department with an eating disorder. Seek consultation if there are any concerns or signs indicating admission.

While every endeavour has been made to recommend the most suitable hospital setting for admission (i.e. medical versus psychiatric), options at the local health district are often limited, therefore **when the indicators below are present, admitting the patient to hospital (regardless of setting) is the recommended policy**. Clinical judgment regarding best available setting should always be exercised.

Indicators for Community Referral

If the patient is medically and psychologically stable and does not require a hospital admission, it is recommended that the patient be referred to their GP and considered for referral to, an eating disorder specialist or service (in districts where an Eating Disorder Coordinator is available they should be contacted to assist with referral options), the local dietitian and or the local Mental Health Team. The recommended approach for community care for people with an eating disorder is multidisciplinary coordinated care, involving the GP and including other medical specialists, psychological and dietetic health professionals, and others as indicated.

Table 2: Indicators for Admission

| | Psychiatric or Medical admission is indicated (level of acuity can usually be managed in either setting) | Acute Medical admission is required (level of acuity usually requires a medical ward) |
|-----------------------------------|--|---|
| Re-feeding risk | High (if markers below present) | Extreme (if markers below present) |
| Weight | Body Mass Index (BMI) < 16 | BMI < 14 |
| Weight Loss | Rapid weight loss (i.e. 1kg/wk over several weeks) or grossly inadequate nutritional intake (<1000kCal daily) or continued weight loss despite adequate community treatment. | |
| Systolic BP | < 90mmHg | < 80mmHg |
| Postural BP | > 10mmHg drop with standing | > 20 mmHg drop with standing |
| Heart rate | | < 40bpm or > 110 bpm or significant postural tachycardia (increase in more than 10bpm on standing) |
| Temp | <35.5°C Or extremities are cold and blue | <35.°c Or extremities are cold and blue |
| 12-lead ECG | | Any arrhythmia including QTc prolongation, or non-specific ST or T-wave changes including inversion or biphasic waves |
| Blood sugar | < 3.5mmol/L | < 2.5mmol/L |
| Sodium | < 130 mmol/L* | < 125mmol/L |
| Potassium | < 3.5 mmol/L* | < 3.0mmol/L |
| Magnesium | 0.7 – 1.0 mmol/L* | < 0.7 mmol.L |
| Phosphate | 0.8 mmol/L* | < 0.8 mmol/L |
| Albumin | < 35/L | < 30 g/L |
| Liver enzymes | Mildly elevated | Markedly elevated (AST or ALT >500) |
| Neutropils | < 2.0 x 10 ⁹ /L | < 1.0 x 10 ⁹ /L |
| Severity Eating Disorder Symptoms | – BN without control of vomiting – Vomiting more than 4 times a day – BN with hypokalaemia – Excessive daily laxative use | |
| Risk Assessment | – Suicidal ideation – Active self-harm – Moderate to high agitation and distress – Other psychiatric condition requiring hospitalisation | |
| Other | – Not responding to outpatient treatment – Aversive family relationships or severe family stress or strain | |

* Please note, any biochemical abnormality that has not responded to adequate replacement within the first 24 hours of admission should be reviewed by a Medical Registrar urgently.

Indicators for Admission

If any of the signs listed in Table 2. are present the patient should be admitted to hospital immediately. There is a level of illness acuity where the purpose of admission is purely medical and the psychiatric setting is no longer ideal (as outlined in the 2nd column of table 2). Thresholds for both types of admissions in this document are high, however it should be noted that deterioration is the norm rather than exception, **lower admission thresholds should be employed across the district wherever possible, including on medical wards.**

Patient Refusal of Care

Unfortunately this will occur reasonably frequently. In the situation where the patient has an acute and potentially life threatening illness then a decision must be made regarding the degree to which the patient should be involved in the medical decision making process (i.e. their decision making capacity). A psychiatrist should be involved at this point. If a patient refuses medical care, please consider the following criteria:

1. Do they **understand** the information and do they understand the consequence of non-treatment?
2. Do they **believe** the information?
3. Are they able to **weigh-up** the information and arrive at a choice?
4. Are they **cognitively impaired** by severe starvation?
5. Are they **delusional** about the necessity of adequate nutrition, threat to life, and the need for medical intervention?

If they do not satisfy all criteria they do not have the ability to make a medical decision.

It may become necessary to utilise the *Mental Health Act* (<http://www.legislation.nsw.gov.au>) to enable ongoing enforced medical care (AN is a serious mental disorder, inpatient re-feeding is at times an essential and direct treatment for this illness and in rare situations, where there is a life threatening physical risk and an unwillingness or inability to agree to treatment, compulsory treatment can and should be initiated).

Patients can be detained under the *Mental Health Act* as mentally disordered.

Under the *Mental Health Act* mental illness is:

- ▶ a condition that seriously impairs, either temporarily or permanently, the mental functioning of a person and is characterised by the presence in the person of **any one** or more of the following symptoms:
 - (a) delusions,
 - (b) hallucinations,
 - (c) serious disorder of thought form,
 - (d) a severe disturbance of mood,
 - (e) sustained or repeated irrational behaviour indicating the presence of any one or more of the symptoms referred to in paragraphs (a)-(d).

A person (whether or not the person is suffering from mental illness) is a **mentally disordered** person if the person's behaviour for the time being is so irrational as to justify a conclusion on reasonable grounds that temporary care, treatment or control of the person is necessary:

- (a) for the person's own protection from serious physical harm, or
- (b) for the protection of others from serious physical harm.

Severely underweight persons with an eating disorder very often meet criteria as mentally disordered and therefore meet the criteria for treatment under the *Mental Health Act*. This process should be well documented in the medical records. Psychiatric services should be involved in the care of this patient as soon as practical (e.g. Consultation Liaison Psychiatry).

Management of the Inpatient Admission

Multi-disciplinary management of the patient should commence immediately. The following set of guidelines address medical, nutritional, and nursing management in the early stages of admission.

The in-patient medical team should be supported by a psychiatrist, preferably one with an expertise in eating disorders. If an expert is unavailable, consultation would involve a consultation liaison or adult general psychiatrist.

The in-patient medical team should contain a physician and a dietitian with specialist knowledge in eating disorders, preferably within a nutrition support team, and have ready access to advice from an eating disorders psychiatrist or expert. If specialist knowledge is unavailable then consultation with tertiary services with outreach support will be necessary and is recommended.

It is important to remember that the majority of patients to which these guidelines refer will be critically ill upon admission, and hence the admission needs to be considered as **medical** as well as psychiatric regardless of the ward to which the patient is admitted.

Who to call when processing an admission

If consultation liaison has not already been contacted they should be

- Local clinical dietitian.
- Royal Prince Alfred Tertiary Eating Disorder Service (Ph 02 9515 8165) requesting the Eating Disorder Coordinator or Psychiatric Registrar.
- Centre for Eating and Dieting Disorders for supporting documentation and telemedicine support if needed (www.cedd.org.au).

The key tasks of the in-patient medical team are to:

- safely re-feed the patient
- avoid re-feeding syndrome caused by too rapid re-feeding
- avoid underfeeding syndrome caused by too cautious rates of refeeding
- manage, with the help of psychiatric staff, the behavioural problems common in patients with anorexia nervosa, such as resisting nutrition
- occasionally to treat patients under compulsion (using the *Mental Health Act*), with the support of psychiatric staff
- manage family concerns
- arrange transfer of the patient to next step in staged care

Goals of an Admission

It is important to establish the goals of the admission from the outset. If a patient presents with a low BMI, restoration of a normal weight is unlikely within one admission. If a medical or psychiatric inpatient admission is indicated (refer to Table 2), the likely goals of the admission include:

- Treat medical complications and restore medical stability
- Begin the process of nutritional rehabilitation and increase the patients BMI to a safer level
- Halt weight loss and stabilise body weight
- Reduce acute purging or other eating disorder behaviours sufficient to restore medical and behavioural stability
- Assist in the development of appropriate eating behaviour to allow for continued medical stability in the community

Ward Management

1. A consistent multi-disciplinary team approach is essential to minimise the potential for splitting between patient and individual members of the team.
2. A clear plan for the purpose of admission and what medical risk factors are present will assist to identify restrictions that may be put in place e.g. physical activity.
3. Collaborative and non-judgmental application of the care plan involving the patient, and wherever possible and appropriate the family and carers, will be most successful.
4. Patients with eating disorders require a firm, but understanding, non-judgmental, and non-punitive approach to management. They often illicit an intense countertransference and negative reactions from staff. Opportunities for debriefing, discussing adherence to the care plan, discussing strategies for distress tolerance techniques for staff and patient need to be frequently available.
5. Limiting physical activity on the ward is important from time of admission as it is harder to enforce as admission progresses.
6. The amount of physical activity will be determined by the medical team dependent on the medical stability of the patient.
7. The amount and frequency of activity should be clearly identified and timed e.g. 10 min walk in ward 3x per day.
8. The amount of exercise can be increased with weight gain, and should be reduced if there is weight loss or lack of progress.
9. If medically stable, the patient may be granted leave from the ward. Leave should be for a set period of time, in a wheel chair (if medically necessary or activity is to be reduced) and accompanied by family, a carer or friends. Those accompanying the patient should be informed and clear about the patient's care plan.
10. Supervision is a priority, at all times, as any unobserved time can be used for purging food or exercise (including excessive fidgeting or moving about whilst on bed rest; sit-ups) including time in bathroom and shower. When supervision is limited, locating the patient as close to the nurses station as possible is ideal (supervision and bed rest is strongly advised post-meal as outlined in nursing management).
11. On admission search belongings for laxatives, diuretics, diet pills, chewing gum, water bottles, small weights and do so again after any leave from the ward.
12. A behavioural management plan for each patient may be created outlining specific guidelines regarding activity, supervision, access to bathroom, challenging behaviours (purging, tampering with naso-gastric feeds, splitting staff etc), meal support, helpful/unhelpful phrases, leave arrangements etc.
13. It is important for staff to be aware and sensitive to families and carers, as this is a highly stressful and distressing experience for all involved. Families will require large amounts of information, and frequent updates, and it needs to be established who in the team will deliver this.

Medical Management

- ▶ Commence prophylactic supplementation immediately for patients at high and extreme risk of refeeding syndrome (as defined in Table 2: Indicators for Admission above): supplemental thiamine 100mg twice daily orally, or if unable to take orally, then IMI or via naso-gastric tube for first 3 days, then oral administration thereafter.
- ▶ And 1 tablet of multivitamins bd.
- ▶ And 1 tablet zinc sulphate 50mg daily.
- ▶ And commence 1 tablet Phosphate-Sandoz 500mg bd (or equivalent) (some may require this IMI)
- ▶ It is required that the patient receive daily medical monitoring for at least the first 7–10 days of re-feeding, and serum levels of EUC, CMP be monitored for at least 2 weeks following, even if normal.
- ▶ Immediately — FBC, EUC, LFTs, phosphate, Mg, ECG, B12/folate, TFTS and other investigations as indicated by clinical findings.
- ▶ Daily EUC, CMP, LFTs, K, ECG are necessary in the first week and then second daily until goal energy intake is reached. Immediately replace K, PO₄, Mg if these are found to be deficient as required.
- ▶ BGL QID — early morning, and 1 – 2 hrs after meals, as low glycogen stores and an abnormal insulin response may lead to post-meal low BSLs, and low BGLs in the morning/overnight.
- ▶ Hypoglycaemic episodes often occur in the early re-feeding stage of severely malnourished clients. Low BGLs (<4.0mmol/l) should be managed with appropriate simple oral CHO (e.g. sugar in orange juice) and MUST be accompanied by a slow acting carbohydrate with protein (e.g. one of the following: Tetrapak or Resource Plus/Ensure Plus Fortisip/glass milk and crackers), to be given at the same time.
- ▶ IV Dextrose should not be necessary. If it becomes necessary it must be accompanied by IV phosphate and thiamine administered simultaneously.

Managing Refeeding Syndrome

Every LHD has access to a clinical dietitian with expertise in managing malnutrition and refeeding syndrome, and most districts will have a local policy relating to its management. Reference to the local policy should be made, and prompt referral to the clinical dietitian should be made before beginning a refeeding regime. The dietitian can assist in determining whether oral or NG feeding is recommended.

- ▶ Re-feeding Syndrome is the term used to describe the adverse metabolic effects and clinical complications when a starved or seriously malnourished individual commences refeeding. If nutrition is not managed carefully, a variety of detrimental effects can occur including:
 - sensory disturbances, confusion, depression, irritability
 - glucose intolerance, hyperglycaemia, polyuria
 - impaired muscle contraction (including heart, respiratory and gastrointestinal muscles)
 - neuromuscular weakness
 - reduced oxygenation of tissues, ventilation difficulties
 - cardiac arrhythmias
 - cardiac arrest.
- ▶ Confusion (delirium) is often the first sign, accompanied by chest pains, muscle weakness, and then heart failure.
- ▶ Avoidance of the syndrome can be achieved by **prophylactic supplementation of phosphate, thiamine and multivitamins** along with **gradually increasing nutritional intake beginning with a nutritionally balanced diet, adequate in protein and fat content.**
- ▶ **Managing risk of refeeding syndrome must be balanced against risk of underfeeding the patient**, adequate nutritional supplements along with fat and protein in the diet, should mitigate the risk of refeeding syndrome so as not to have to slow the feeding rate too much.
- ▶ Monitor markers of possible refeeding syndrome via **clinical observations twice daily and biochemical review daily (EUC, CMP, ECG).**
- ▶ Avoidance of refeeding syndrome can also be assisted by reducing carbohydrate calories and increasing supplementation of phosphate.
- ▶ **Feeding rates: (Risk defined above in Table 2: Indicators for Admission).**

These rates are guidelines only, and prioritise avoiding re-feeding syndrome. A specified feeding rate devised with a clinical dietitian (ideally with eating disorder expertise), is always preferable. With all of the above mentioned strategies in place to avoid re-feeding syndrome much faster feeding rates can be tolerated by numbers of patients, and are advisable to avoid under-feeding.

| Extreme risk patients (defined in Table 2) | High risk patients (defined in Table 2) |
|---|---|
| ▶ Start with 0.5 x estimated BEE (Basal Energy Expenditure) i.e. approximately 20mL/h | ▶ Commence with between 0.8 – 1.0 x estimated BEE i.e. approximately 1000Cal/day or 40mL/h |
| ▶ Increase by 200-300Cal every two to three days if tolerated and biochem is stabilised. | ▶ Increase rate daily or second-daily, 20 – 40mL/h at a time, if tolerated and biochem is stabilised. |
| ▶ Feeding rate can be increased faster if electrolytes are stable and prophylactic supplementation continues. | ▶ Feeding rate can be increased faster if electrolytes are stable and prophylactic supplementation continues. |
| ▶ May take many weeks to reach goal rate | ▶ May reach goal rate in 2 weeks |

- ▶ Minor or even moderate abnormalities in liver function (e.g. alanine transaminase up to four times the upper limit of the normal range) should not delay gradual increases in feeding.

Nutritional Management

- ▶ The ideal feeding method is oral, however many patients at this level of severity require N/G feeding for optimal treatment. Some patients may opt for N/G tube when this unwell as it reduces demands and guilt, for others oral feeding will fail (this needs to be reviewed daily and at this severity of illness moved to N/G tube feeding sooner rather than later. The *Mental Health Act* or Guardianship may be required).
- ▶ N/G Feeding is often the safest way of reintroducing nutrition; by the time the patient reaches a medical bed they are usually critically ill. If the patient is hypoglycaemic or bradycardic, delivering a constant and controlled supply of carbohydrate is less likely to cause reactive hypoglycaemia, and feeding patients overnight can help keep their low heart rate and blood sugar level at a safer level.
- ▶ Your local clinical dietitian can provide you with an individualised nutrition management plan for either oral or N/G delivery. **Feeding rates provided are a GUIDE ONLY, a personalised plan with regular monitoring and adjustment is always preferable.**
- ▶ For patients not at high or extreme risk of refeeding syndrome, orally delivered nutrition of approximately 1800 calories per day is an appropriate starting point for a period then gradual increases titrated to the patients weight gain and level of physical activity (e.g. 200 calorie increases twice per week as long as clinical and biochem markers are stable). For most adult patients a final level of 2400-2600 calories per day is sufficient to induce weight gain (with the occasional person requiring more).
- ▶ Ensure the current meal plan, with feeding method is clearly written and copies available for staff and patient.
- ▶ It is essential that only food on the meal plan is consumed i.e. **NO food to be brought in from outside**, and NO diet foods/lollies/chewing gum as these can be used to diminish appetite and/or may have a laxative effect.
- ▶ See below guidelines for managing NG tube feeding if this is how the nutrition is to be delivered (or if oral feeding fails), and guidelines for managing the delivery and consumption of food and meal times if to be orally administered.
- ▶ If a patient is struggling to adhere to the feeding regime it is likely a 1:1 nursing special will be initially required. Ideally this will comprise a psychiatrically trained nurse. Consultation Liason Psychiatry in most districts needs be contacted to conduct the assessment for a Individual Patient Special (IPS) and make referral.

Managing Enteral Nutrition via Naso-Gastric (NG) Feeding

1. Refer to your local policy regarding naso-gastric tube insertion.
2. 1:1 nursing is the only way to ensure that there is no sabotaging of N/G feeding.
3. A lockable pump is preferred to prevent patients from switching off the device or altering the settings.
4. The N/G tubing should be visible to nursing staff at all times, not covered by clothing or bed linen; this will prevent kinking or holes being put into the tube.
5. N/G feeding and resultant weight gain will likely be a source of great anxiety for the patient and may result in sabotaging behaviour as weight increases.
6. Offer PRN medication to assist with anxiety or encourage distraction.
7. Inspect tube at the start and end of the feed.
8. Make sure no syringes are left in the room unattended, even if in other patient's cubicle.
9. Access to bathroom/ sinks should be limited or supervised (bathrooms locked and patient requests to use facilities as needed, door kept open whilst toileting) to prevent syphoning off feeds down drains.
10. Access to bathroom to be restricted 1 hour post bolus feed.
11. Feed times are often highly anxiety provoking and distressing for the patient and therefore encouragement, understanding, firm management of boundaries and assistance with distress tolerance will be needed.

Meal Management

1. Only food prescribed by the dietitian is to be consumed.
2. Meals to be delivered to nursing staff and not the patient directly.
3. Patient is not to be left alone with food.
4. All food eaten (type and portion) is to be recorded by supervising nursing staff.
5. Time allowed to complete meals/ snacks is to be decided by the care team and enforced by supervising staff, and documented clearly.
6. Uneaten food to be replaced with a supplement (as directed by dietician).
7. Bed rest or supervised quiet time for 1 hour after meals and snacks is required.
8. No bathroom access for 1 hour post meals. **Direct patients to use bathroom before meal.**
9. As eating is often highly distressing for the patient, distraction methods (e.g. conversation), gentle encouragement, and enforcement of boundaries during the meal, and distress tolerance assistance post-meals is almost always needed.

Nursing Management

1. Engage with the patient, build a trusting relationship, provide information as often as required (memory/cognition are both affected by starvation). Provide support and encouragement to the patient during the difficult process of early nutritional rehabilitation. Enforce care plan with compassion and be firm without being punitive.
2. Distress in eating disorder patients in this stage of treatment is the norm rather than the exception, they have severe weight and food phobia and are being exposed to both multiple times a day in quantities they have avoided for a long time. Skills in tolerating and managing distress will be required by the nursing staff, and need to be taught to the patient.
3. The management of the family and carers is very important during this often stressful and distressing time. Families may require detailed information, and frequent updates, establish in the team who will deliver this. It will be natural for the family to be sympathetic to the appeals from their loved one for an alteration in treatment plan. It can be helpful to involve the family as much as possible in understanding the care plan, the rationale for it, and the clinical milestones needed. Give families a copy of the care plan, or appropriate version of the care plan, wherever possible. It can be helpful to arrange for a family member to attend a portion of ward round each week to reduce splitting.
4. In general leave from the ward is not granted due to medical risk, and when appropriate monitor leave as per care plan carefully
5. Observations should be taken 4th hourly until stable for a minimum of 72 hours. Only then should they be changed to QID.
6. QID lying & standing blood pressure. Staff should call for a clinical review or activate a local rapid response if:
 - Pulse is below 60bpm
 - Temp below 35.5c
 - Systolic BP below 90
 - Significant postural drop of more than 10mmHg
7. BGL QID – 1–2 hrs after meals, as low glycogen stores and an abnormal insulin response may lead to post-meal low BGLs, and low BGLs in the morning/overnight.
Suggested times are 0400, and 1 – 2 hrs post each main meal. Treat blood glucose levels of <4.0mmol/l as per Medical Management discussed earlier
8. Daily ECG initially and at least until medical stability maintained for a minimum of 72 hours.
9. Patient may require full bed rest if medically unstable
10. Accurate assessment of the patient's nutritional status and eating behaviours:
Weight: Measure and record, weight, height & urine specific gravity the morning after admission at 6.30am after voiding, and repeat each Monday and Thursday (Guidelines for Weighing below)

Height: Should be measured in early morning, check patient is standing at full height.

Bowel chart: record bowel activity (or lack of) daily as patient may have reduced gut motility (they may find this distressing and want to reduce eating and will need encouragement, and support, explaining continued eating is the only way to resolve discomfort)

Intake: Record all offered intake as well as all consumed food & fluids

Check all meals against the meal plan, patient should not be allowed to choose meal from the meal plan at this stage see nutritional management plan)

11. Request family members to assist with the management plan, by NOT bringing in food and medications (e.g. laxatives) from home or allowing patient to exercise.
12. Monitor and contain eating disorder behaviours:
 - Visually observe the patient at a minimum frequency of 15 minute intervals
 - It is often more effective particularly on medical wards to provide 1:1 constant supervision
 - Shared room (rather than single room)
 - Exercise
 - Vomiting /chewing spitting
13. Limit physical activity (the patient may require bed rest to reduce energy expenditure)
14. Support at meals and post meals e.g. crosswords, puzzles for distraction
15. Access to toilets needs to occur prior to meals (encourage patients to use bathroom before meals as access after will be denied for one hour). When risk is high supervision is required during toileting and shower use to reduce opportunities for purging behavior(s) and or laxatives/diuretics use. Lock any bathroom en-suites and restrict the patient to using the ward toilet.
16. Manage constipation with psychoeducation regarding the biological factors that influence this including inadequate food intake, lack of dietary fibre and fluid restriction. Use stool softeners with caution and only when clinically indicated. Do not allow laxatives to be brought from home.
17. Inappropriate fluid intake:
 - Monitor fluid intake for under or over drinking
 - Restriction
 - If possible provide supervision during and after meals to observe and record intake.

Managing Weighing

1. Weighing is non-negotiable
2. Patients should be weighed wearing a hospital gown with underwear only and hair accessories removed, on consistent predetermined days
3. Ideally patients are weighed in the morning prior to breakfast
4. Patient should be instructed to empty their bladder prior to being weighed
5. If you suspect the weight has been falsified (water loading, salt loading, secreting weights in underwear, and/or bra) share concerns with team and document. In this instance a 'spot weigh' should be conducted. This involves weighing the patient at a random time, when they are not expecting to be weighed.
6. As weighing is often extremely anxiety provoking for the patient, distraction and distress tolerance methods should be utilized (e.g. engaging the patient in light conversation during the weight, encouraging them to do crosswords or knitting etc. afterwards).
7. In some cases 'blind weighing' or deciding collaboratively with the patient that it may be best for them to not know their weight can be helpful in these early stages of recovery where immediate weight restoration is essential (later exposure to weight and shape as an outpatient will be important). Discussing its advantages with the patients may be important. The team should agree on the weight approach and it be clearly outlined in the progress notes and treatment plan to avoid confusion and splitting.

Goals of Longer Admissions

- Medical and physical stability
- Continue to improve nutritional status and weight restoration towards healthy levels
- Sufficient normalisation of eating disorder behaviours that criteria for admission to a less restrictive treatment environment (day program, intensive outpatient) are met and transition can be effected.
- There may be limited utility in trying to engage the patient in psychological therapy while severely undernourished. Brain function is effected and engagement in psychological work can be difficult. Nonetheless psychologists can play a pivotal role in assisting the treatment team throughout the admission e.g. administering debriefing sessions, assisting the patient with distress tolerance especially around meal and weight times and speaking with families and assisting with any associated distress.

Discharge Planning and Transition

- Discharge needs to be carefully planned with the patient, family and carers, preferably from the outset of admission.
- These critically ill patients will require a long treatment trajectory involving numerous treatment settings, of which the inpatient medical admission is only one.
- Preparing families or carers and the patient will be important to contain anxiety and set realistic expectations about likely readmissions, the need for ongoing treatment, and realistic treatment outcomes.
- Ascertain the local treatment options outside of the inpatient setting and begin referral processes early in the admission. Follow-up with a GP and local dietitian and psychologist will be needed at minimum.
- Wherever possible transfer of the patient from the inpatient environment to an intensive day program environment should be arranged to prevent weight loss and rapid readmission, and to consolidate change once outside of hospital.
- Discharge is best avoided on Friday or Saturday when continuity of care in community within the 24-36 hours post-discharge is limited. It is ideal if discharge can occur earlier in the week to allow for follow-up appointments with a GP and/or outpatient team for later the same week.
- A multidisciplinary meeting should be facilitated to ensure appropriate referrals for community-based care have been made with follow-up appointments scheduled; if transferring to a different medical or psychiatric setting ensure the team is aware of who is responsible for organising the transfer and writing the discharge summary.
- With the permission of the patient, family, carers or support can be invited to the discharge planning meeting.

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