

PAYING THE PRICE

The economic and social impact
of eating disorders in Australia



ACKNOWLEDGEMENT

The Butterfly Foundation acknowledges the valuable input of so many people to this economic and social impact report. Butterfly is committed to an evidence based approach in all its work and convened an Experts Panel to have oversight of the research and development of the report. Each member of that Experts Panel has generously provided their experience, expertise and time. On behalf of all those who will learn and benefit from this report – thank you to our Expert Panel members.

We have also relied on the results of a consultation survey with those with a lived experience. We wish to thank all those who helped in its distribution including members of the National Eating Disorders Collaboration and Richard Kerr from bulimiahelp.org.

Most importantly, our thanks go to each of you with a lived experience of eating disorders. You have provided invaluable insights into the difficult and often very lengthy battle with an eating disorder from the perspective of the individual, the carer, the partner, the family member and the friend.

Thank you for your voice.

Foreword :: Professor Pat McGorry

PAYING THE PRICE - The economic and social impact of eating disorders in Australia

29 November 2012

I welcome this report which, for the first time quantifies the extensive costs of eating disorders in Australia, for both the individual and the wider community.

It reinforces the prevalence and seriousness of these mental illnesses. I believe their debilitating effects are comparable to psychosis and schizophrenia.

The suffering of the individual, their families and the community is greatly magnified by the difficulty many people face in accessing timely and appropriate treatment.

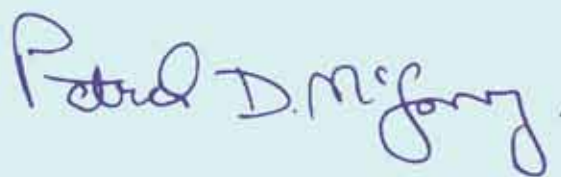
Delays in diagnosis and access to care, exacerbate and prolong the illnesses, costing the community and affected individuals very dearly. The burden of these diseases is at least equal to those of anxiety and depression.

Many eating disorders peak in the teenage years. We are witnessing a tragic waste of personal and economic potential. This report cries out for urgent action. We desperately need a coordinated, government led comprehensive response to this emerging crisis.

I endorse the recommendations of this report including the need for better data monitoring to improve our understanding of eating disorders and new strategies to train our health professionals and provide accessible effective treatment.

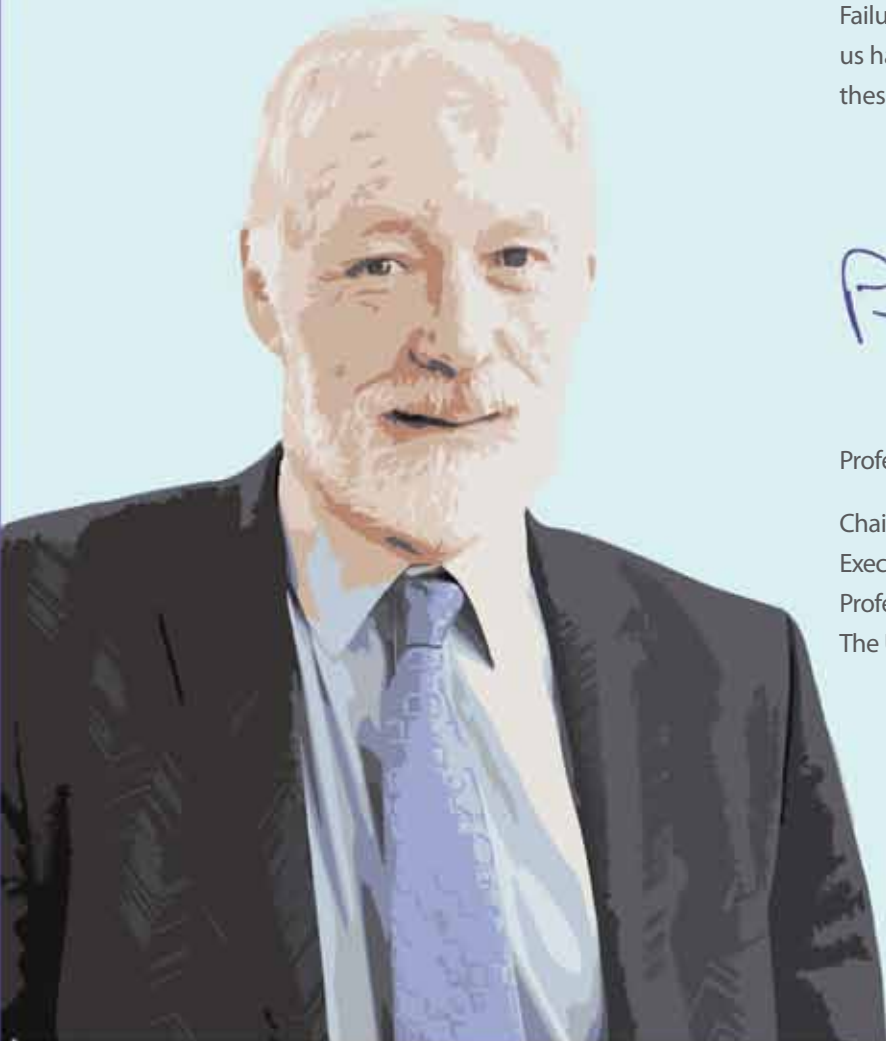
There remains a missing piece - how to prevent eating disorders in the first place? Early intervention is crucial and is dependent on clinicians and services being equipped to recognise and treat an eating disorder before it becomes entrenched and potentially chronic.

Failure to deal with addressing these urgent needs risks us handing to the next generation the full burden of these dreadful illnesses.



Professor Pat McGorry AO

Chair of the National Eating Disorders Collaboration
Executive Director, Orygen Youth Health Research Centre
Professor, Centre for Youth Mental Health,
The University of Melbourne



Christine Morgan
CEO
The Butterfly Foundation
103 Alexander Street
Crows Nest NSW 2005

30 November 2012

Dear Christine

Economic and social costs of eating disorders in Australia

Deloitte Access Economics welcomes the opportunity to provide this report on the economic and social costs of eating disorders (EDs) in Australia.

2

In undertaking the analysis for this study, our personnel have been moved by the experiences of people with eating disorders and by the substantial impacts of these conditions. The extent of impacts was found to be larger than expected, although our methods were conservative.

- We used a combination of international sources for prevalence estimates rather than relying only on the most recent Australian study, which would have provided larger estimates of the number of people with eating disorders had we relied on that source.
- We used the Australian Institute of Health and Welfare (AIHW) estimates of the health system costs of EDs, although these are incomplete (e.g. excluding allied health expenditure) and some ED costs may be coded to other conditions (e.g. anxiety) as EDs are not well understood and there are primary care data coding issues.
- Productivity costs and other financial cost estimates were also conservatively based on the median rather than mean cost reported in survey responses to the community consultation process fielded in October 2012.

We recommend that larger studies are undertaken to triangulate these findings, particularly for productivity and burden of disease impacts, which are based on literature that suggests the severity of impacts from binge eating disorder (BED) and eating disorders not otherwise specified (EDNOS) are similar to the impacts from anorexia nervosa (AN) and bulimia nervosa (BN). That said, comparisons with other conditions such as youth mental illness, anxiety and depression, and obesity, suggest the costs per case of EDs are comparable, which is not unexpected.

We hope that the report assists in raising awareness, prevention and treatment options for people with these serious illnesses.

Yours sincerely,



Lynne Pezzullo
Director, Deloitte Access Economics Pty Ltd
Lead Partner, Health Economics and Social Policy, Deloitte Touche Tohmatsu

:: Contents

Foreword Professor Pat McGorry	1
List of acronyms	4
Experts Panel	5
About Butterfly Foundation	7
Executive Summary	8
Chapter 1: Eating Disorders	12
1.1 Definitions.....	14
1.2 Aetiology	15
1.3 Risk factors and trends.....	15
1.4 Morbidity and mortality	16
1.5 Treatment	16
Chapter 2 : Prevalence.....	18
2.1 Lifetime prevalence	20
2.2 One-year prevalence	21
2.3 Mortality	37
Chapter 3 : Case studies.....	42
3.1 "Julie".....	44
3.2 "Irene"	46
3.3 "Allison's mother"	48
Chapter 4: Financial costs.....	50
4.1 Methodological overview.....	52
4.2 Health costs	55
4.3 Productivity costs.....	61
4.4 Carer costs.....	64
4.5 Other financial costs	65
4.6 Deadweight losses	66
4.7 Summary of financial costs	67
Chapter 5: Burden of disease costs	68
Chapter 6: The personal experience	72
Chapter 7: Conclusions	88
7.1 Findings	90
7.2 Recommendations	93
Charts	96
Tables	97
References	98
Appendix A : Survey form	100
Appendix B : Survey information	122

:: List of acronyms

ABS	<i>Australian Bureau of Statistics</i>
AN	<i>anorexia nervosa</i>
AIHW	<i>Australian Institute of Health and Welfare</i>
AWE	<i>average weekly earnings</i>
BMI	<i>body mass index</i>
BN	<i>bulimia nervosa</i>
BOD	<i>Burden of Disease</i>
BEACH	<i>Bettering the Evaluation and Care of Health</i>
BED	<i>binge eating disorder</i>
COAG	<i>Council of Australian Governments</i>
DAE	<i>Deloitte Access Economics</i>
DALY	<i>disability adjusted life year</i>
DCIS	<i>Disease Costs and Impact Study</i>
DSM	<i>Diagnostic and Statistical Manual of Mental Disorders</i>
DWL	<i>deadweight loss</i>
ED	<i>eating disorder</i>
EDNOS	<i>eating disorder not otherwise specified</i>
GP	<i>general practitioner</i>
HOS	<i>Health Omnibus Survey (South Australia)</i>
ICD-10	<i>International Classification of Diseases (Tenth Revision)</i>
ICPC	<i>International Classification of Primary Care</i>
MCPF	<i>marginal cost of public funds</i>
NEDC	<i>National Eating Disorders Collaboration</i>
NHMD	<i>(AIHW) National Hospital Morbidity Database</i>
PIR	<i>Partners In Recovery (program)</i>
PTSD	<i>post traumatic stress disorder</i>
VSL(Y)	<i>value of a statistical life (year)</i>
YLD	<i>years of life lost due to disability</i>
YLL	<i>years of life lost due to premature death</i>

Experts :: Panel

The Experts Panel provided oversight of the research and development of this report contributing their expertise in eating disorders, mental health and population health.

PROFESSOR SUSAN PAXTON (CHAIR)

Professor Paxton is currently Professor and Director of Postgraduate Teaching and Learning in the School of Psychological Science at La Trobe University. She is Past President of the Academy for Eating Disorders and of the Australian and New Zealand Academy for Eating Disorders. Professor Paxton is a clinical psychologist and researcher engaged in projects that focus on understanding risk factors of body image and eating problems, evaluating prevention and early intervention strategies and exploring stigma and mental health literacy related to eating disorders in the community.

PROFESSOR PHILLIPA HAY

Professor Hay is Foundation Chair of Mental Health at the School of Medicine, University of Western Sydney and Adjunct Professor of Psychiatry at the School of Medicine, James Cook University and Senior Consultant in Psychiatry at Campbelltown Hospital. She has over 20 years of experience in the field of eating disorders as a clinician, researcher and educator. She is immediate Past-President of the Australian and New Zealand Academy for Eating Disorders (ANZAED) and holds senior committee positions in the Royal Australian and New Zealand College of Psychiatrists (RANZCP) and the International Academy for Eating Disorders (AED). She is regularly invited to give plenary, keynote and other addresses at scientific meetings in Australasia, the Americas and Asia. She is also regularly invited to submit articles and commentaries to Australasian and International journals, publications and books.

PROFESSOR STEPHEN TOUYZ

Professor Touyz is Professor of Clinical Psychology and Honorary Professor in the Discipline of Psychiatry at the University of Sydney. He has written/edited 6 books and over 240 research articles and book chapters on

dieting, eating and eating disorders. He is a fellow of the Academy of Eating Disorders (AED) and the Australian Psychological Society (APS). Professor Touyz is a past president of the Eating Disorders Research Society (EDRS). He was the inaugural treasurer of the Australian and New Zealand Academy of Eating Disorders (ANZAED). He has also served on the Executive of the Eating Disorder Foundation of New South Wales and is a member of the Editorial Board of the European Eating Disorders Review. He is the co-editor of the Journal of Eating Disorders and was recently presented with a Leadership Award in Research by the Academy of Eating Disorders.

PROFESSOR DAVID FORBES

Professor Forbes is an academic paediatrician with training in clinical nutrition and gastroenterology. He is based in the School of Paediatrics and Child Health at the University of Western Australia, and at Princess Margaret Hospital for Children in Perth, where he has been part of the Eating Disorders Program since 1996, and provides clinical leadership in the care of young people with eating disorders. He has a strong interest in health advocacy and policy development

DR SLOANE MADDEN

Dr Madden is nationally and internationally recognised for his expertise in the treatment and management of eating disorders. He is co-director of The Eating Disorder Service of the Sydney Children's Hospital Network, the largest public eating disorder service in NSW and one of the two largest adolescent eating disorder services in Australia. Dr Madden's research has three major foci, early onset eating disorders, the treatment of anorexia nervosa and the neurobiology of eating disorders. Dr Madden was the lead investigator in an Australia wide study exploring the eating disorders in children under the age of 13 years and is a chief investigator and the clinical coordinator of a current, NHMRC funded, inpatient treatment trial of adolescent anorexia nervosa. Dr Madden is the chair of the neuroimaging special interest group in the Academy of Eating Disorders

Experts :: Panel cont.

(AED). He has been invited to present keynote addresses symposia and discussion panels on this subject at both local and international meetings. Dr Madden is the author of over 30 peer reviewed journal articles and book chapters on eating disorders.

PROFESSOR FEDERICO GIROSI

Federico Girosi has been an Associate Professor in Population Health at the School of Medicine, University of Western Sydney, since late 2011. He is currently an investigator in a project that utilizes linked data to investigate geographic variations in primary care and he is developing a microsimulation model to predict the health and health care utilization trajectories of the New South Wales population of age 45 and older. Dr. Girosi earned a Ph.D. in Health Policy from Harvard University in June 2003, and worked 8 years at the RAND Corporation (Santa Monica, U.S.A.) as a health economist and modeller. At RAND he was the leader of the modelling team that developed the COMPARE microsimulation for the analysis of health insurance reform. He was also involved in the development of the Future of the Elderly Model (FEM), a model that can be used to study the costs and benefits of prevention for the U.S. population over age 51. Dr. Girosi also led the modelling effort for a Gates Foundation project aiming to evaluate the benefits of introducing new diagnostic tools in the developing world. In addition, he was part of a RAND team that quantified the cost and benefits of widespread adoption of electronic medical records systems in health care. He also holds a Ph.D. in Physics from the University of Genoa, Italy, and conducted research for 10 years at the Artificial Intelligence Laboratory, at the Massachusetts Institute of Technology, in the fields of statistical data analysis and computer vision.

ANNE DOHERTY

Anne has over thirty years experience in health, the majority spent in mental health. Anne spent 12 years in forensic mental health in New South Wales. She is committed to improving patient/consumer care and the patient/consumer and carer experience. Anne currently holds the position of Executive Director Mental Health, Southern Health Victoria.

LESLEY COOK

Lesley established Partners in Practice as the health and welfare arm of Blackboro Associates Pty Ltd consulting services in 2007 after a career that has encompassed all areas of community welfare. With over 30 years experience working in and with community organisations, Lesley's areas of expertise include knowledge management, partnership brokerage, social inquiry and stakeholder consultation, project design, and evaluation. Her area of specialisation is the facilitation of collaboration and she has worked with the National Eating Disorders Collaboration since its inception in 2009.

CHRISTINE MORGAN

Christine is the CEO of the Butterfly Foundation and National Director of the National Eating Disorders Collaboration. Prior to her role with Butterfly, Christine was General Manager with Wesley Mission, responsible for the Community Services and Corporate Services portfolios. Christine has qualifications in law and business and prior to entering the not for profit sector in 2005 served in senior executive corporate roles for over 20 years, holding the positions of General Counsel / Company Secretary for a number of listed public companies on the ASX 200.

About :: Butterfly Foundation

The Butterfly Foundation represents all people affected by eating disorders – sufferers, their families and their friends. As a leading national voice in supporting their needs, Butterfly highlights the realities of seeking treatment for recovery, and advocates for improved services from both government and independent sources.

Butterfly operates a national helpline, which is staffed by counselors experienced in assisting with eating disorders. It also provides a wide range of facilities for service providers and recovery groups.

Because Butterfly recognises that eating disorders often arise from poor body image, it delivers a range of Positive Body Image workshops to schools and workplaces through its education program. It has a strong media presence to raise awareness of Butterfly's perspective in community debates about body image and eating disorders.

Throughout its work Butterfly emphasises the critical importance of prevention and early intervention strategies in limiting the development of, and suffering from, negative body image and eating disorders. To expand knowledge in this field. The Butterfly Research Institute supports academic research projects and funds PhD research scholarships.

Butterfly is committed to collaboration across the sector and works with allied medical and mental health providers as well as with clinicians and academics. Butterfly has been appointed to co-ordinate the National Eating Disorder Collaboration (NEDC) for the Australian Department of Health and Ageing.

For help and information please call the national support-line on 1800 33 4673 (ED HOPE)

www.thebutterflyfoundation.org.au

Executive :: Summary

Unfortunately, as this illness often presents itself in the teen years, the behaviour can be mistaken with 'puberty blues'. And then one day you realise that it is not puberty - there is something very wrong.

By then your child is very ill.



There are more than 913,000 people in Australia with eating disorders in 2012. The total socio economic cost of eating disorders in 2012 is \$69.7 billion.

In 2012 Deloitte Access Economics was commissioned by the Butterfly Foundation to examine the economic and social costs of eating disorders in Australia. This review was supported by an advisory panel of experts in eating disorders, mental health, and population health.

Prevalence of eating disorders and associated mortality

The last official estimate by the Australian Institute for Health and Welfare (AIHW) suggested that there were 23,464 people with eating disorders in Australia in 2003 (Begg et al, 2007).

- This estimate was not based on Australian data, but mainly on a relatively small survey of Swiss schoolgirls in the mid-1990s.
- The AIHW estimate also only covers two eating disorders, anorexia nervosa (AN) (male and female) and bulimia nervosa (BN) (only female estimates). No estimates were made for Binge Eating Disorder (BED) or Eating Disorder Not Otherwise Specified (EDNOS), which have higher prevalence than AN and BN.
- As the Australian Bureau of Statistics (ABS) does not appear to have ever collected data on eating disorders, the AIHW figure remains the only official Australian estimate.

Recent population based surveys in South Australia, New Zealand and the United States yield far higher (although widely varying) estimates. Taking an average

of these studies, Deloitte Access Economics estimates that there are 913,986 people in Australia with eating disorders in 2012, or around 4% of the population (Table i). Of these people, 3% have AN, 12% BN, 47% binge eating disorder and 38% other eating disorders. Females comprise around 64% of the total.

- This estimate may be conservative, as it is lower than the only Australian study (Hay et al, 2008), which also found that the rate of disordered eating behaviour had doubled in the ten years to 2005.

The imbalance between reported estimates of mortality from eating disorders and evidence from scientific studies is also substantial. The ABS (2012) indicates a total of 14 deaths from eating disorders in 2010. However, the latest meta-analysis of epidemiological studies from the published literature (the gold standard of health research) indicates that mortality rates are almost twice as high for people with eating disorders and 5.86 times higher for people with AN (Arcelus et al, 2011), compared to those without the conditions. On this basis there were an estimated 1,829 deaths from eating disorders in 2012.

Cost impacts of eating disorders

The AIHW reports health system expenditure for eating disorders of \$80.4 million in 2008-09. Inflating this to allow for subsequent prevalence increase and health cost inflation suggest expenditure of \$99.9 million by 2012.

Table i : Estimated prevalence of eating disorders, 2012

	Anorexia	Bulimia	BED	EDNOS	Total
Females	18,284	78,154	264,516	219,667	580,621
Male	7,469	29,761	164,317	131,818	333,365
Total	25,753	107,915	428,833	351,485	913,986

Executive Summary

Table ii : Total ED costs, by type and bearer, 2012 (\$m)

	Individual	Family /Friends	Federal Govt	State Govt	Employers	Society /Other	Total
Health system costs	10.4	7.9	42.6	26.4	0.0	12.6	99.9
Productivity costs	9,378.1	0.0	4,841.9	0.0	843.0	0.0	15,063.0
Carer costs	0.0	5.7	2.8	0.0	0.0	0.0	8.5
Other financial costs	585.2	8.8	0.0	0.0	0.0	0.0	594.0
Deadweight losses (DWLs)*	0.0	0.0	0.0	0.0	0.0	1,414.8	1,414.8
Transfers	0.0	-7.2	7.2	0.0	0.0	0.0	0.0
Total financial	9,973.8	15.2	4,894.6	26.4	843.0	1,427.4	17,180.2
BoD	52,554.9	0.0	0.0	0.0	0.0	0.0	52,554.9
Total with BoD	62,528.7	15.2	4,894.6	26.4	843.0	1,427.4	69,735.2

* DWLs measure the administrative and efficiency impacts of levying taxation to fund government payments.

10

The productivity impacts of eating disorders were estimated as \$15.1 billion in 2012, similar to the productivity impacts of anxiety and depression which were \$17.9 billion in 2010 (Access Economics, 2010). Of this cost, \$2.0 billion is due to lost lifetime earnings for young people who die. Eating disorders also have lengthy duration – an average of around 15 years in survey respondents – which can mean long lasting productivity impacts for those living with eating disorders, such as lower employment participation (costing \$6.0 billion) and greater absenteeism (\$1.8 billion) and presenteeism (\$5.3 billion). Productivity costs are borne largely by individuals, but also by Federal Government (in the form of less taxation revenue) and by employers (sick leave and lower productivity from presenteeism). Table ii also provides estimates of the cost of informal care for people with eating disorders, totalling \$8.5 million, based on data from the Federal Department of Human Services, and other financial costs of \$594 million, based on survey data for out-of-pocket expenses borne by people with eating disorders and their families and carers.

The “burden of disease” from eating disorders is estimated as \$52.6 billion, calculated by multiplying the years of healthy life lost (measured in disability adjusted life years or DALYS), by the value of a statistical life year (VSLY) as recommended by the Department of Finance

and Deregulation. The estimate is comparable, although slightly larger, than the estimated value of the burden of disease for anxiety and depression of \$41.2 billion (Access Economics, 2010).

Recommendations – data and monitoring

A pressing need in relation to eating disorders is collecting better information, particularly in relation to tracking prevalence, mortality and health system costs, and better defining less well known eating disorders. While AN and BN are well defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM IV), EDNOS is composed of disparate criteria. One of these – BED – is the most common single ED, and in early 2013 will be classified independently in the DSM 5. Almost half (44%) of people with BED are severely obese (Spitzer et al, 1993), and it is probable that many of these people may currently have their treatment classified as “consequences of obesity” rather than BED.

Deloitte Access Economics makes the following recommendations regarding information.

- **Include eating disorder questions in the Australian Health Survey.** New Zealand and the United States include validated questions about eating disorders in their equivalent to our Australian Health Survey. It would be relatively simple and

inexpensive to do the same. However, self-reported data are not as reliable as epidemiological data, and an Australian epidemiological study would be very valuable to better understand eating disorders and their impacts nationally. EDs should be recognised as a serious psychiatric disorder.

- **Reassess mortality data.** The AIHW (2012) notes that most people have three causes of death, and as many have five causes of death (20%) as have only one. If eating disorders have the mortality rates that the literature suggests it is important to verify this, which would also be assisted by funding a national epidemiological study.
- **Include BED as a condition in the International Classification of Primary Care.** The ICPC 2 Plus is an Australian categorisation system used by the AIHW to measure non-hospital treatment by disease type. At present, it contains categories for AN and BN, but not for BED. Once the DSM 5 has been released, there may be merit in reviewing the inclusion of BED in the ICPC2. It is possible that the small reported non-hospital costs for eating disorders other than AN and BN may be partly due to general practitioners (GPs) having limited awareness of BED and classify it by its frequent impact (overweight and obesity) instead.
- **Include eating disorders in welfare data.** At present, there is no information on eating disorders as a cause for unemployment benefits, sickness benefits or disability support pension. Given the high prevalence of eating disorders, this should be revisited.

Treatment recommendations

Relative to prevalence, there appears a lack of focus on treatment for eating disorders across acute and community care settings. The reports from survey participants of not being able to access appropriate treatment when needed are harrowing.

- **Make eating disorders a priority for Medicare Locals.** Medicare Locals are a commendable recent

initiative by Council of Australian Governments (COAG) to better coordinate primary health care. They have been explicitly tasked with improving the patient journey, mapping population health needs and identifying services gaps. Medicare Locals have somewhat of an initial focus on preventative health and diabetes, which is relevant given the interface between BED, obesity and diabetes. Early intervention for people with eating disorders is paramount. Medicare Locals may be able to help primary providers enhance identification of people with early symptoms of eating disorders, and conduits for appropriate care.

- **Increase Medicare psychology coverage and/or Partners In Recovery (PIR) referral.** Many survey respondents noted that they often require psychiatric visits on a weekly basis, but noted that Medicare coverage is capped at ten visits per year, when the literature suggests a minimum of twenty visits per annum is required to be effective. Given the high productivity costs of eating disorders – and thus lost taxation revenue – it is possible that increasing the visit cap may have little adverse impact on the net Commonwealth budget position. Alternatively, if the cap is approached, referral into the PIR program may be appropriate for those where symptoms are severe and persistent.
- **Increase private health insurance coverage.** Judging from survey participant feedback, private health insurance appeared to be necessary but insufficient. Participants were grateful that their insurance covered most of their hospital costs, but also noted that it failed to cover a majority of their other costs, or left large out-of-pocket ‘cost gaps’ between what was reimbursed and actual fees (GPs, counselling, dietitians, etc). Given eating disorders are long-lasting and complex to treat, it would help people if such multidisciplinary costs could be covered by insurance, although it is acknowledged premiums may have to increase to cover this.

Deloitte Access Economics

¹ Deloitte Access Economics ran a small survey designed to measure out of pocket costs for people with eating disorders, which suggested higher health system costs. However, in the interests of conservatism and using official estimates where robust, the AIHW figures were adopted in this report.

Chapter 1 :: Eating Disorders

Everyone should have access to support - I was lucky enough to be able to beg and borrow enough.





Chapter 1 :: Eating disorders

Eating disorders can be fatal. One in 10 people with anorexia nervosa do not live more than 10 years after the onset of the disorder. Early diagnosis and effective treatment is essential.

1.1 Definitions

1.1.1 DSM-IV

Eating disorders are a group of serious mental illnesses that bring about significant physical and psychological impairment. The group comprises anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED) and eating disorder not otherwise specified (EDNOS). These

are defined in Table 1.1. Currently BED is listed under EDNOS although is expected to be defined separately (in its own category) when the American Psychiatric Association releases the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* in 2013.

1.1.2 ICD-10 definitions

The International Classification of Diseases, version 10,

Table 1.1 : Eating disorders definitions (DSM IV)

Eating disorder	Definition
Anorexia Nervosa (AN)	<ul style="list-style-type: none"> refusal to maintain body weight at or above a minimally normal weight for age and height intense fear of gaining weight or becoming fat, even though underweight. disturbance in the way one's body weight or shape is experienced, undue influence of body weight or shape on self evaluation, or denial of the seriousness of the current low body weight. in postmenarcheal females, amenorrhea
Bulimia Nervosa (BN)	<ul style="list-style-type: none"> recurrent episodes of binge eating characterised by both: <ol style="list-style-type: none"> eating, in a discrete period of time an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances. a sense of lack of control over eating during the episode recurrent inappropriate compensatory behaviour to prevent weight gain, such as self-induced vomiting, misuse of laxatives, diuretics, enemas, or other medications, fasting, or excessive exercise. the binge eating and inappropriate compensatory behaviour both occur, on average, at least twice a week for 3 months. self evaluation is unduly influenced by body shape and weight.
Binge Eating Disorder (BED)	<ul style="list-style-type: none"> binge-eating disorder: recurrent episodes of binge eating in the absence of regular inappropriate compensatory behaviour characteristic of BN. In the current DSM-IV, BED is a subset of EDNOS, but will be recognised as a separate disorder in the DSM-V (expected release in Q2 2013). Accordingly, it is treated as a separate disorder in this report.
Eating Disorder Not Otherwise Specified (EDNOS)	<p>This diagnosis includes disorders of eating that do not meet the criteria for the Otherwise Specified above eating disorder diagnoses. Examples include:</p> <ul style="list-style-type: none"> for female patients, all of the criteria for AN are met except that the patient has regular menses OR despite significant weight loss, the patient's current weight is in the normal range. all of the criteria for BN are met except that the binge eating and inappropriate compensatory mechanisms occur less than twice a week or for less than 3 months. the patient has normal body weight and regularly uses inappropriate compensatory behaviour after eating small amounts of food (e.g., self-induced vomiting after consuming two cookies). the patient engages in repeatedly chewing and spitting out, but not swallowing, large amounts of food.

Source: American Psychiatric Association (2000)²

provides the following definitions of eating disorders, under Chapter V Mental and Behavioural Disorders³.

F50.0 Anorexia nervosa

A disorder characterised by deliberate weight loss, induced and sustained by the patient. It occurs most commonly in adolescent girls and young women, but adolescent boys and young men may also be affected, as may children approaching puberty and older women up to the menopause. The disorder is associated with a specific psychopathology whereby a dread of fatness and flabbiness of body contour persists as an intrusive overvalued idea, and the patients impose a low weight threshold on themselves. There is usually under-nutrition of varying severity with secondary endocrine and metabolic changes and disturbances of bodily function. The symptoms include restricted dietary choice, excessive exercise, induced vomiting and purgation, and use of appetite suppressants and diuretics.

F50.1 Atypical anorexia nervosa

Disorders that fulfil some of the features of anorexia nervosa but in which the overall clinical picture does not justify that diagnosis. For instance, one of the key symptoms, such as amenorrhoea or marked dread of being fat, may be absent in the presence of marked weight loss and weight-reducing behaviour. This diagnosis should not be made in the presence of known physical disorders associated with weight loss.

F50.2 Bulimia nervosa

A syndrome characterised by repeated bouts of overeating and an excessive preoccupation with the control of body weight, leading to a pattern of overeating followed by vomiting or use of purgatives. This disorder shares many psychological features with anorexia nervosa, including an over concern with body shape and weight. Repeated vomiting is likely to give rise to disturbances of body electrolytes and physical complications. There is often, but not always, a history of an earlier episode of anorexia nervosa, the interval ranging from a few months to several years.

F50.3 Atypical bulimia nervosa

Disorders that fulfil some of the features of bulimia nervosa, but in which the overall clinical picture does

not justify that diagnosis. For instance, there may be recurrent bouts of overeating and overuse of purgatives without significant weight change, or the typical over-concern about body shape and weight may be absent.

F50.4 Overeating associated with other psychological disturbances

Overeating due to stressful events, such as bereavement, accident, childbirth, etc.

F50.5 Vomiting associated with other psychological disturbances

Repeated vomiting that occurs in dissociative disorders (F44.-) and hypochondriacal disorder (F45.2), and that is not solely due to conditions classified outside this chapter. This subcategory may also be used in addition to O21 (excessive vomiting in pregnancy) when emotional factors are predominant in the causation of recurrent nausea and vomiting in pregnancy.

F50.8 Other eating disorders

Includes Pica in adults and Psychogenic loss of appetite.

F50.9 Eating disorder, unspecified

1.2 Aetiology

There is no one cause of eating disorders, rather they are a complex combination of genetic, cultural, social, physical and personality factors.

Common personality traits have however been observed amongst those with an eating disorder (National Eating Disorders Collaboration (NEDC) 2011) including perfectionism, obsessive-compulsiveness and neuroticism. Individuals with AN often are skilled in constraint and persistence whereas those with BN are more likely to be impulsive and exhibit sensation seeking behaviour.

1.3 Risk factors and trends

Risk factors are disordered eating, dieting, and body dissatisfaction. Unfortunately these behaviours are common today in western societies, with body dissatisfaction or the desire to lose weight reported by 74% of adult women and 70% of adolescent girls (Hay et al., 2008). According to the NEDC (2010), Australian adolescent females who diet at a severe level are 18 times more likely to develop an eating disorder within six

Chapter 1 :: Eating disorders

months and have a 20% chance of developing an eating disorder after 12 months of extreme dieting.

The prevalence of eating disorders may be on the rise. A South Australian study observed a two fold increase in the prevalence of disordered eating behaviours in the community over a ten year period (Hay et al., 2008)⁴. Greater awareness and new strategies are needed to combat this insidious group of illnesses. This report serves to estimate the economic and social impacts of eating disorders in 2012 and to provide projections for the future should swift and adequate action not be implemented soon.

1.4 Morbidity and mortality

Comorbidities are common for eating disorders, including other mental illnesses such as obsessive compulsive disorder and bipolar disorder. Illicit drug use and alcohol abuse is also significantly higher amongst those with an eating disorder. Columbia University (2003) found that half of individuals with eating disorders abuse alcohol or illicit drugs compared with 9% of the general population. Long term complications of AN and EDNOS include kidney failure, heart failure, osteoporosis and infertility. Adult growth and development can also be inhibited if AN is experienced as a child, or young adolescent. BN is linked to dental, gum and other mouth problems.

Not surprisingly, one of the main comorbidities from BED is obesity. Spitzer et al (1993) estimate that 44% of people with BED have a history of severe obesity (BMI>35). Petersen et al (2012) note that recognising and treating underlying BED where it exists is important in the management of obesity.

Eating disorders can be fatal. About one in ten individuals with AN do not live a further ten years after the onset of the disorder (Sullivan, 2002). Of these deaths, about 20% are suicides. The mortality rate of females aged 15 to 24 years with AN is 6 to 12 times higher than the annual death rate from all causes (AED 2011, Arcelus et al 2011).

1.5 Treatment

Early diagnosis and intervention with effective therapy is critical; although, due to the secretive nature of the illnesses, a large proportion of people with eating

disorders do not seek help, or struggle for many years before doing so (NEDC, 2010). Specifically, a median ten year delay from onset to treatment has been observed for those with BN and 15 years for individuals with AN (Hart et al, 2009).

Early treatment is significantly more effective. Eisler et al (1997) performed a randomised controlled trial which showed 90% of patients given an effective treatment (family therapy) for AN within three years of illness onset had a positive outcome at five years. This compared to 20% of people with eating disorders reporting a positive outcome when treatment was commenced after three years.

Treatments are varied and multi modal including nutritional supplementation, cognitive behaviour therapy, medication and family counselling. The multidisciplinary approach means a variety of health care professionals can be involved including dietitians, counsellors, general practitioners (GPs), paediatricians, psychologists, psychiatrists and specialist physicians. Treatment is commonly delivered in an outpatient setting with only severe cases requiring hospitalisation. Comorbidities also require attention.

A minority of individuals with an Eating Disorder are hospitalised. Such patients are acutely unwell and require 24 hour medical stabilisation which may involve re-feeding and weight restoration. Hospitalisation can occur at a public hospital or private clinic.

A GP visit is often the first step taken by those suffering from an eating disorder and mild cases may only require GP intervention. GPs can assess symptoms, perform physical examinations, and provide referrals to other health care professionals who specialise in eating disorders.

Treatment for eating disorders is most frequently conducted in an outpatient setting by one or more specialists including a psychologist, psychiatrist, dietitian or social worker.

Some individuals with an eating disorder are managed by a psychiatrist, mostly in an outpatient setting. Psychiatrists can prescribe medications and monitor both psychological and physical symptoms. Paediatricians also help manage serious eating disorders in children and adolescents.

Dietitians perform assessments of dietary intake and can provide eating plans and nutritional advice in an effort to stimulate healthier eating patterns. They can also help individuals recognise feelings associated with hunger and satiety and discuss appropriate behavioural responses.

There is no single treatment approach, such as a pharmacological solution, to eating disorders. The complexities of eating disorders require a multi disciplinary team and a supportive environment with the capacity to provide collaborative intervention for an extended period of time (NEDC, 2012). Anti-depressant and anti-psychotic medications are sometimes used as a component of treatment. Medicines prescribed for eating disorders should be available on PBS for patients with a diagnosed eating disorder. Anti-depressant medications such as fluoxetine (Prozac[®]) and sertraline (Zoloft[®]) are sometimes used for treating eating disorders. They work by restoring neurotransmitter imbalances in the brain (anti-depressants and binge eating both involve the neuro-transmitter serotonin). Co-morbidities such as depression and anxiety can also be abated. The evidence of benefit of psychopharmacology in eating disorders is quite limited.

Being an adult male it was very difficult to be taken seriously.

I had three GP's and a nutritionist all fail to diagnose the condition.

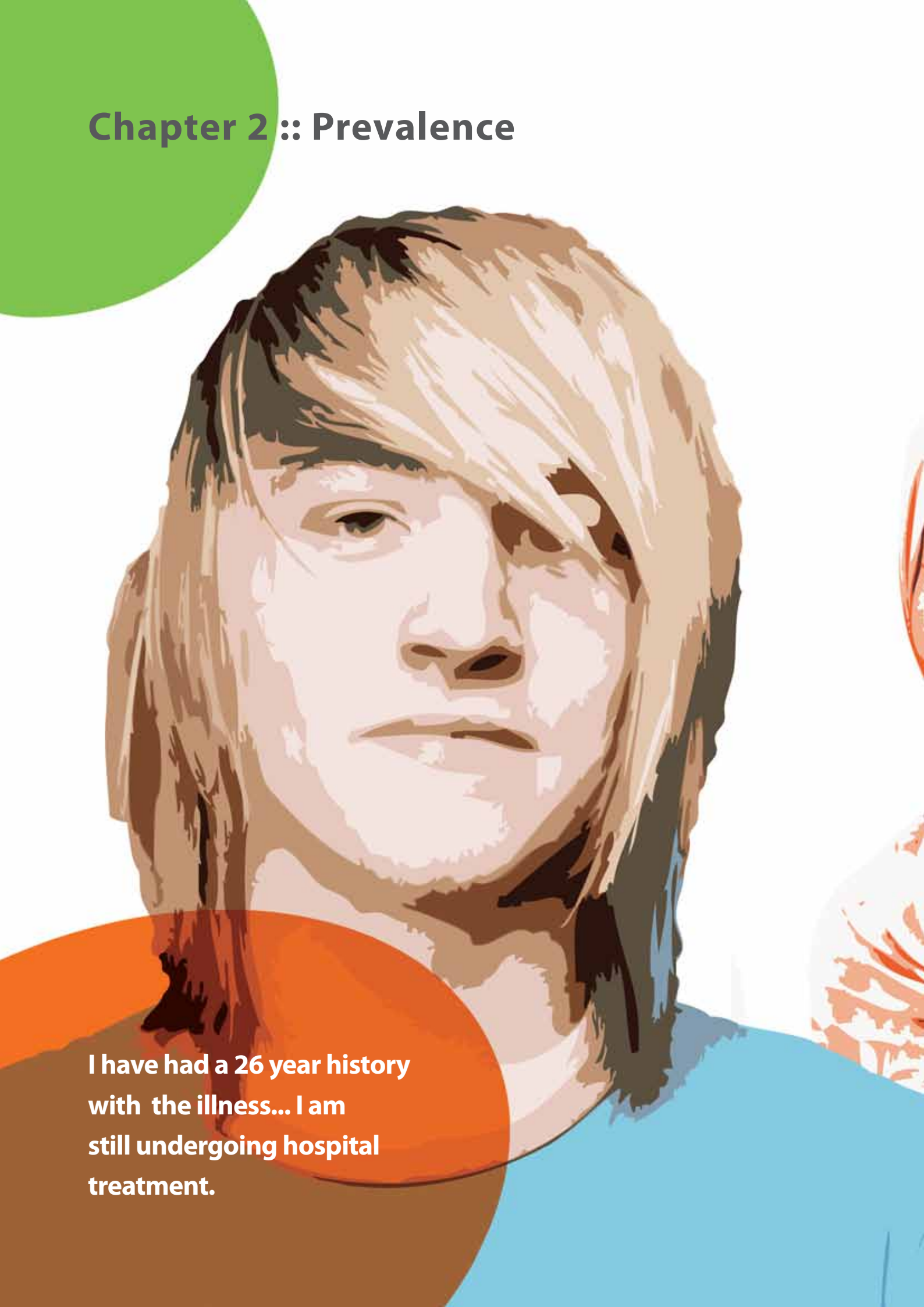
² http://casat.unr.edu/docs/eatingdisorders_criteria.pdf

³ <http://apps.who.int/classifications/icd10/browse/2010/en#V>

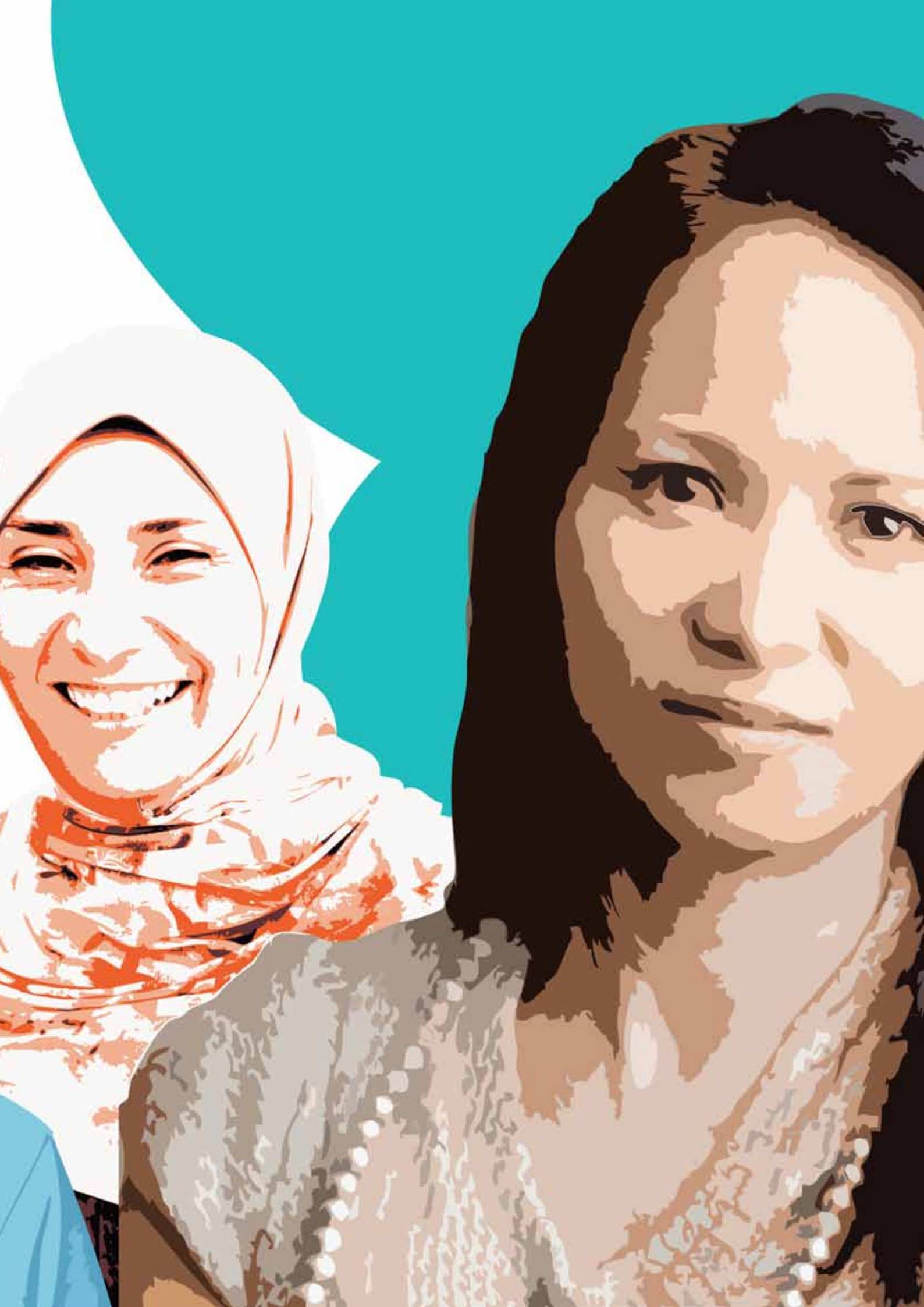
⁴ Disordered eating behaviour is not the same thing as an eating disorder, but is often a precursor to an eating disorder.



Chapter 2 :: Prevalence



**I have had a 26 year history
with the illness... I am
still undergoing hospital
treatment.**



Chapter 2 :: Prevalence

On current projections, there will be more than a million people with eating disorders in 2022.

AN can begin at any age, although the years 13 to 18 pose the highest risk of onset. In fact, AN is the third most common chronic disease (after asthma and obesity) amongst females aged 15 to 24 years (Matthews et al, 2011). BN usually occurs later, most commonly between 16 and 18 years. The occurrence of eating disorders at this life stage means people with eating disorders can also experience impaired educational and social development.

These disorders are much more prevalent in the female population, about 90% of people with AN and BN are female, although for BED, each gender is represented roughly equally (American Psychiatric Association, 2000). Males are, however, more represented in childhood (pre-pubertal) AN, where a 3:1 female to male ratio has been estimated (Madden et al, 2009).

The reported prevalence of eating disorders, based on hospital admissions or outpatient clinic attendances significantly underestimates the actual prevalence of disease. Under diagnosis (in part owing to the secretive nature of the disorders) and treatment by various health care professionals contributes to underreporting as information is recorded in disparate sources, or not at all. Up to 65% of people with BN and BED do not seek treatment specifically for their eating disorder (Keski-Rahkonen et al, 2009). In particular, males are less likely to seek treatment.

Overseas prevalence rates have historically been applied locally due to insufficient Australian data. There have been two major Australian community studies to estimate prevalence although generally overseas data is used. Two independent, cross-sectional epidemiological surveys were conducted in 1995 and 2005 in South Australia, with over 3,000 participants, to assess the prevalence of disordered eating and to compare these rates against international findings.

- This report measures prevalence of EDs – that is, in any given year, how many Australians will currently

have an ED. An alternative approach is to use incidence, which in any given year measures how many people will contract an ED for the first time. This is problematic with EDs, as many people are not aware they have an ED when the condition first begins.

One of the reasons for the paucity of prevalence data is that EDs can tend to be a hidden problem. Hart et al (2011), in a systematic review of the literature, found that on average only 23% of people with an ED seek treatment for their disorder per se (although around half of them will seek treatment for weight management instead). The authors note that people with EDs actually have above average health service utilisation, but that despite this, many either fail to be diagnosed – or fail to engage with treatment once referred.

2.1 Lifetime prevalence

According to the NEDC (2010), the lifetime prevalence of AN in women is up to 1.5%, BN up to 2.1%, and BED, up to 4.5%. The addition of people with 'partial' AN (where amenorrhoea is not present) and 'partial' BN increases the prevalence substantially, tripling AN to up to 4.6% (Wade et al 2011).

In total, the NEDC (2012) reports that Australian lifetime prevalence for EDs is “approximately 9% of the total population (males and females of all ages). ... For women, the risk is even higher with an estimated 15% of Australian women experiencing an eating disorder requiring clinical intervention during their lifetime”.

Lifetime prevalence is always higher than point (one-year) prevalence, except for diseases that are lifelong. For example, most people suffer from childhood diseases such as measles and mumps at some point in their lifetimes. But in 2012, the point prevalence will mostly be confined to that fraction of the population who are currently in their childhood.

Table 2.1: NEDC estimates of the lifetime prevalence of eating disorders in Australia

Disorder	Males	Females
AN	0.1 to 0.5%	0.3% to 1.5%
BN	<0.1% to 1.1%	0.9% to 2.1%
BED	1.0% to 3.0%	2.5% to 4.5%

Note: Lifetime prevalence of EDNOS was not estimated. NEDC figures are "based on large international studies, in the absence of Australian data."

Source: NEDC 2010.

2.2 One-year prevalence

There is a serious lack of official statistics on one-year ED prevalence in Australia. The Australian Bureau of Statistics (ABS) provides no figures at all. The Australian Institute of Health and Welfare (AIHW) publishes prevalence figures for AN in males and females, and BN in females only. However, based on international evidence, these two disorders only account for a minority of total ED prevalence.

- Moreover, AIHW figures (Begg et al, 2007) are based on an old, small, foreign study. However, this study was the midpoint of what the AIHW considered the best available studies at the time of writing.

Hay et al (2008) noted that studies with point prevalence rates for multiple eating disorders across whole populations are rare. Deloitte Access Economics' literature search was only able to uncover four such sources with data less than 15 years old (Table 2.2). And such studies as there are tend not to support each other. Hay et al (2008) also noted that point prevalence estimates conducted in the last 15 years in English speaking countries vary by more than four fold.

Accordingly, in this analysis, averages across the four following sources are used to derive point prevalence. Because Hay et al (2008) is the only Australian study, it is given a double weighting in the averaging. (It is also worth noting that this study uses definitions similar to the forthcoming DSM 5, which will shortly become the standard benchmark.)

- Hay et al (2008) is also the most recent study, which may be important if prevalence is rising. The authors examined data from two iterations of a South Australian community study (2005 and 1995) and

found that there was an over two-fold increase in the prevalence of disordered eating behaviour (binge eating, purging and strict dieting).

- Conversely, the only other Australian longitudinal data, national hospital admissions for EDs shows a fall of over a third (37%) during the ten years to 2007-08 (Chart 2.1). However, while total admissions, AN and BN fell, admissions for other eating disorders increased.
- In the absence of unequivocal data regarding trends in rates, and since the future may not be the same as the past in any case, projections in this report assume prevalence rates for each age-gender group are constant.

For BED and EDNOS, in the absence of AIHW figures, estimates from the South Australian Health Omnibus Survey (HOS)⁵ (Hay et al, 2008) are used (n=3047). In addition to being Australian, this study has the advantage of reporting all four kinds of ED. On the other hand, it does suffer from small numbers (there is only one male with AN). For a variety of reasons, its estimated prevalence rates are much higher than the AIHW's (more than twice as high, for female AN, five times as high for male AN, and nearly ten times higher for female BN).

Table 2.2: Sources of ED point prevalence estimates

Author	Country of studies	Subjects	Date of studies
AIHW (Begg et al, 2007)*	Switzerland	1,064	1995
Wells et al (2006)	New Zealand	12,992	2004
Hudson et al (2007)	United States	9,282	2003
Hay et al (2008)	Australia	3,047	2005

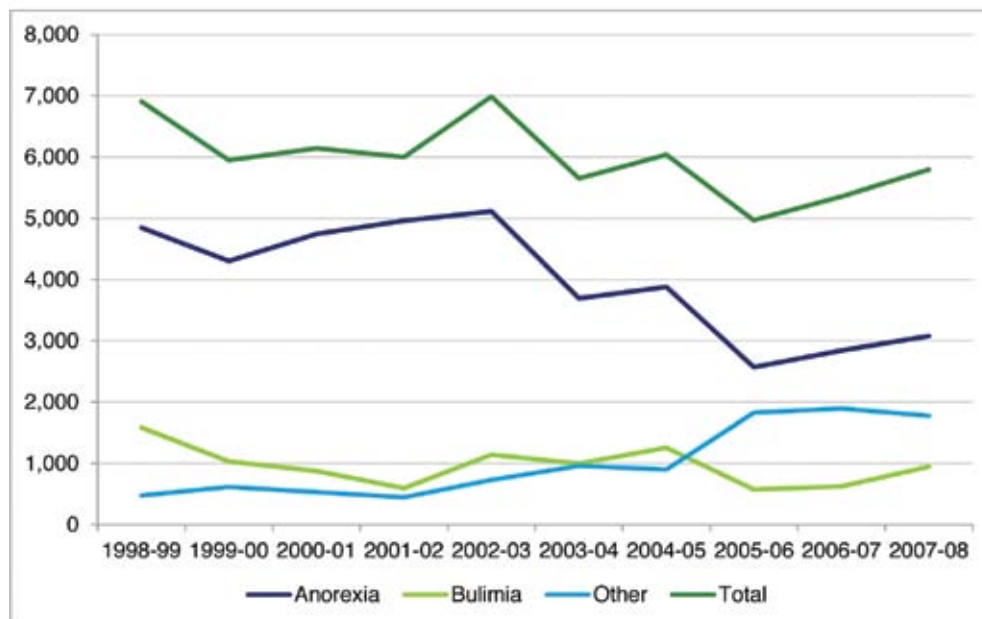
Note*. Begg et al sourced from Steinhausen et al (1997) as being the "mid point ... of more rigorous epidemiological studies".

Table 2.3: Average ED point prevalence estimates, by disease and gender

	AIHW	Wells et al	Hudson et al	Hay et al	Average
Anorexia (F)	0.10%	0.10%		0.23%	0.16%
Anorexia (M)	0.02%	0.10%		0.08%	0.07%
Bulimia (F)	0.12%	0.60%	0.50%	1.14%	0.70%
Bulimia (M)		0.30%	0.10%	0.31%	0.26%
BED (F)			1.60%	2.68%	2.32%
BED (M)			0.80%	1.78%	1.46%
EDNOS (F)				1.94%	1.94%
EDNOS (M)				1.16%	1.16%

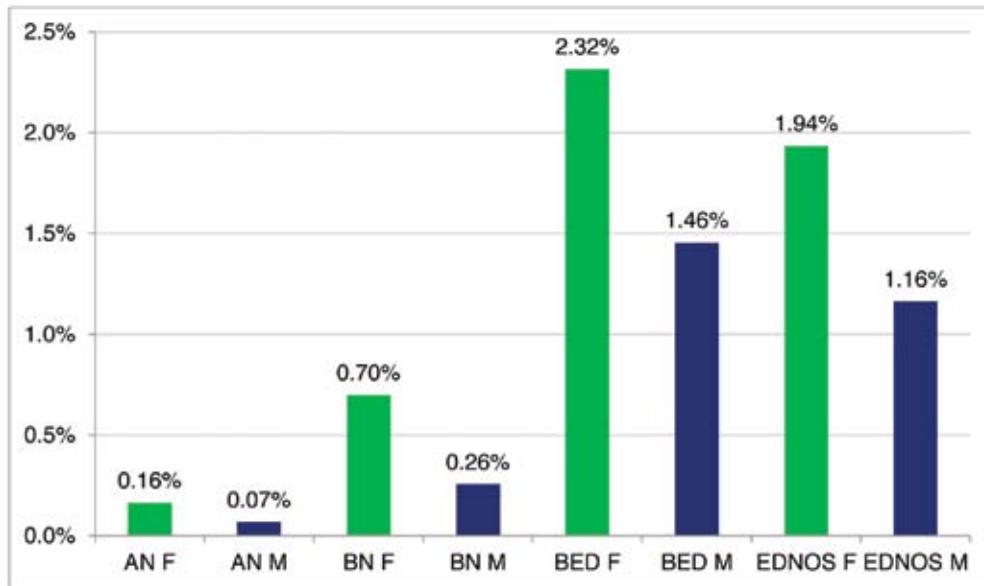
Sources as per Table 2.2.

Chart 2.1: Hospital admissions for eating disorders, Australia, 1998-99 to 2007-08



Source: AIHW NHMD.

Chart 2.2: Estimated Australian ED one-year prevalence, by disease and gender, 2012



Source: Table 2.3.

Table 2.4: Disease prevalence rates from HOS, 2005

	Male	Female
Survey participants	1,290	1,757
Anorexia	1	4
Bulimia	4	20
BED	23	47
EDNOS	15	34
Total ED	43	105
Prevalence rates		
Anorexia	0.1%	0.2%
Bulimia	0.3%	1.1%
BED	1.8%	2.7%
EDNOS	1.2%	1.9%
Total ED	3.3%	6.0%

Note: Total ED was not provided by source authors, so total here assumes no comorbidity.
Source: Hay et al (2008).

Chapter 2 :: Prevalence

2.2.1 Prevalence by disorder

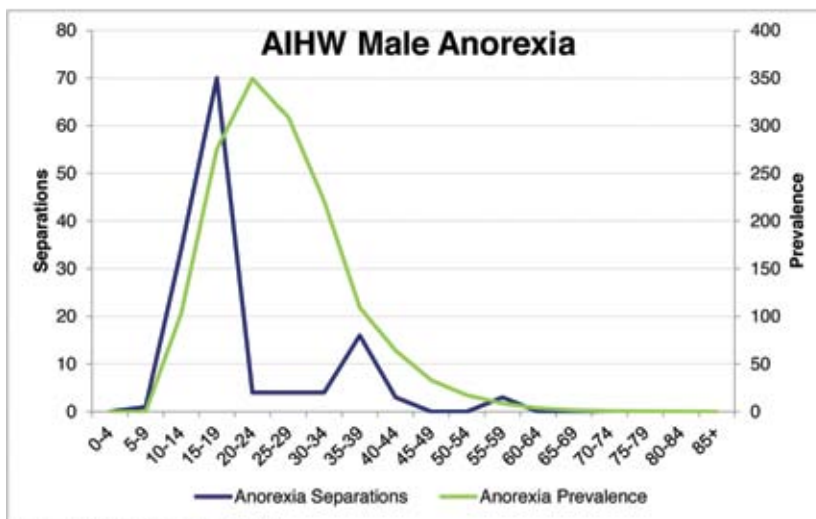
Anorexia Nervosa

The AIHW prevalence distribution for AN and BN by age and gender in 2003 very closely matches the AIHW hospital age gender separation distribution in the same year (Chart 2.3, Chart 2.4 and Chart 2.6)⁶. Accordingly, it is assumed that the AIHW age-gender prevalence distribution patterns for these diseases can be applied to the total population prevalence estimates that were derived by averaging across studies⁷. That is, if for example

the average total male population prevalence rate estimate is three times that of the AIHW figure for AN, then the rates for each male age cohort are also three times greater.

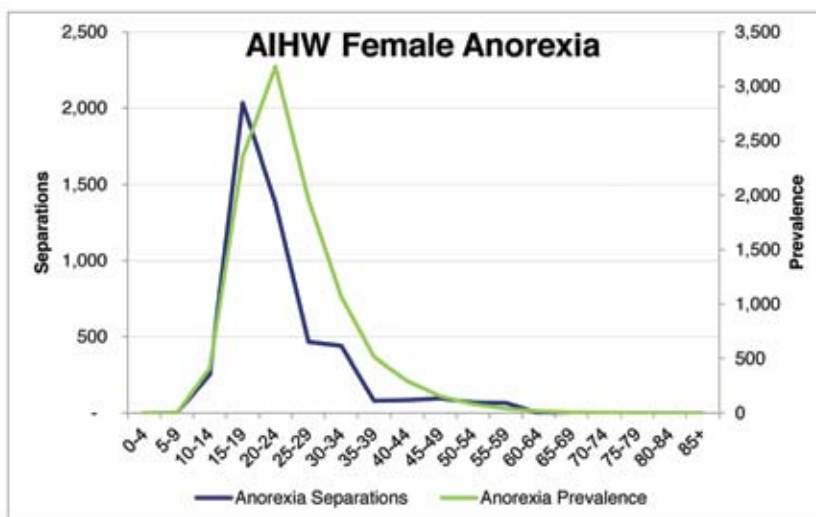
Applying AIHW age-gender distribution patterns to estimated total prevalence rates, the following AN estimates for Australia are derived.

Chart 2.3: Male AN prevalence and separations (2003)



Source: NHMD and Begg et al (2007).

Chart 2.4: Female AN prevalence and separations (2003)



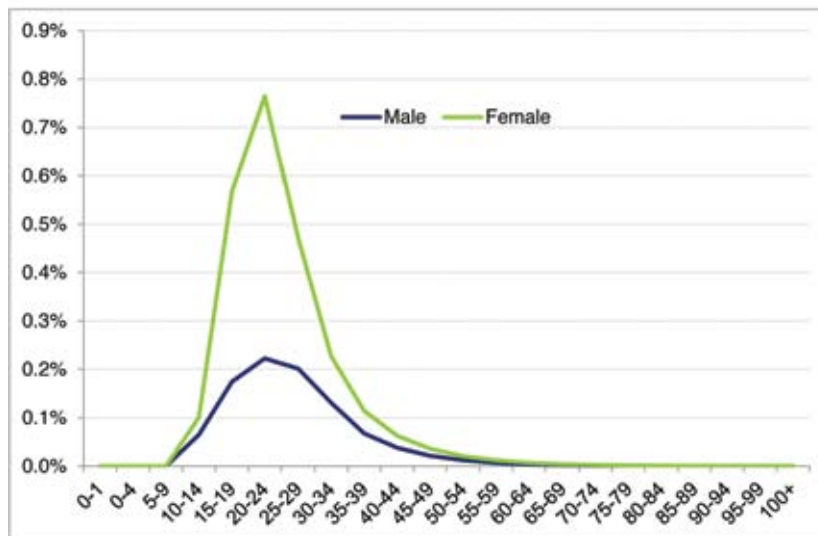
Source: NHMD and Begg et al (2007).

⁵ The HOS is a face-to-face survey conducted annually since 1991 for government and non-government organisations responsible for servicing the health needs of the South Australian community. Methodological aspects of the survey are overseen by the University of Adelaide.

Table 2.5: Estimated age-gender prevalence of anorexia in Australia

	Males	Females
0-1	0.00%	0.00%
0-4	0.00%	0.00%
5-9	0.00%	0.00%
10-14	0.06%	0.10%
15-19	0.17%	0.57%
20-24	0.22%	0.76%
25-29	0.20%	0.47%
30-34	0.13%	0.23%
35-39	0.07%	0.11%
40-44	0.04%	0.06%
45-49	0.02%	0.04%
50-54	0.01%	0.02%
55-59	0.01%	0.01%
60-64	0.00%	0.01%
65-69	0.00%	0.00%
70-74	0.00%	0.00%
75-79	0.00%	0.00%
80-84	0.00%	0.00%
85-89	0.00%	0.00%
90-94	0.00%	0.00%
95-99	0.00%	0.00%
100+	0.00%	0.00%
Total	0.07%	0.16%

Chart 2.5: Estimated age-gender prevalence of anorexia in Australia



⁶ The correlation in distribution is less pronounced for male anorexia, but that could be due to lumpiness in the small number of separations. (Note: hospitals generally measure patient numbers as separations rather than admissions, as full treatment records can only be compiled after the patient is discharged.)

⁷ As the AIHW figures were the lowest among the studies, this implies a lower proportion of people with eating disorders are hospitalised than using only AIHW data would indicate.

Chapter 2 :: Prevalence

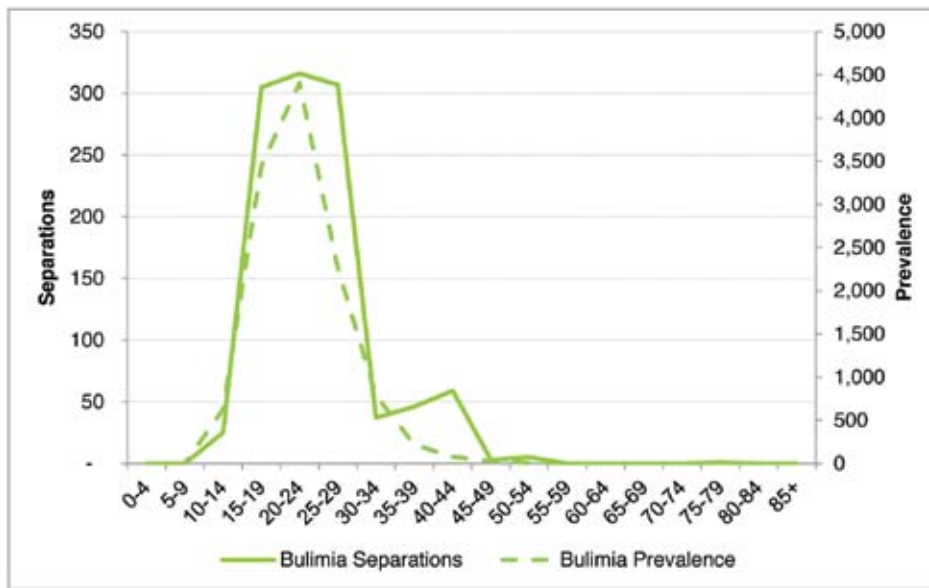
Bulimia Nervosa

The AIHW does not report on age prevalence patterns for BN in males. Thus, there are two possible patterns from which to choose – same disorder (BN in females) or same gender (males with AN). AIHW prevalence estimates for female BN are a closer fit to male BN

separation distributions than are (AIHW) prevalence estimates for male AN. Accordingly, the relative distribution by ages across female BN was applied to male total population prevalence rates.

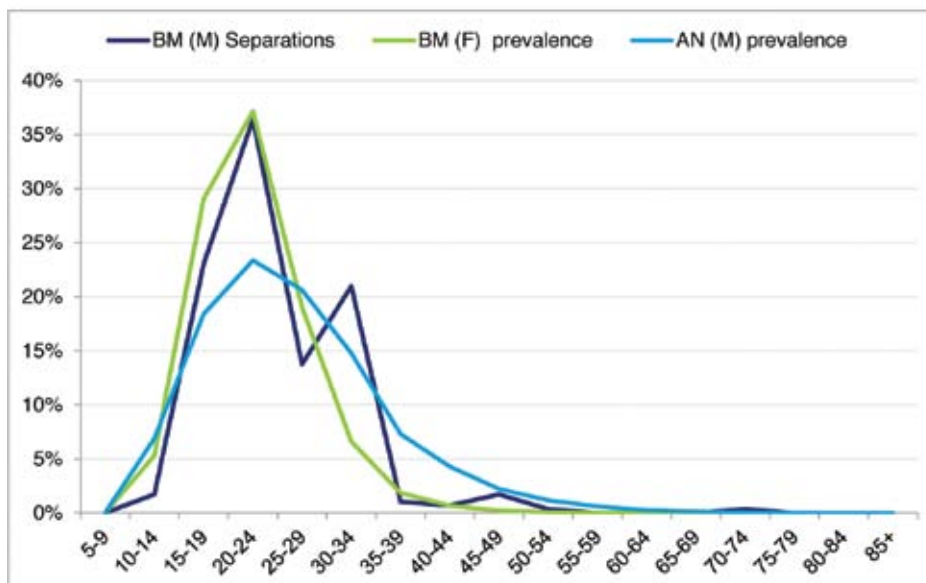
Bulimia Nervosa

Chart 2.6: Female BN prevalence and separations (2003)



Source: NHMD and Begg et al (2007).

Chart 2.7: Distribution of male bulimia separations, female bulimia prevalence and male anorexia prevalence (2003)

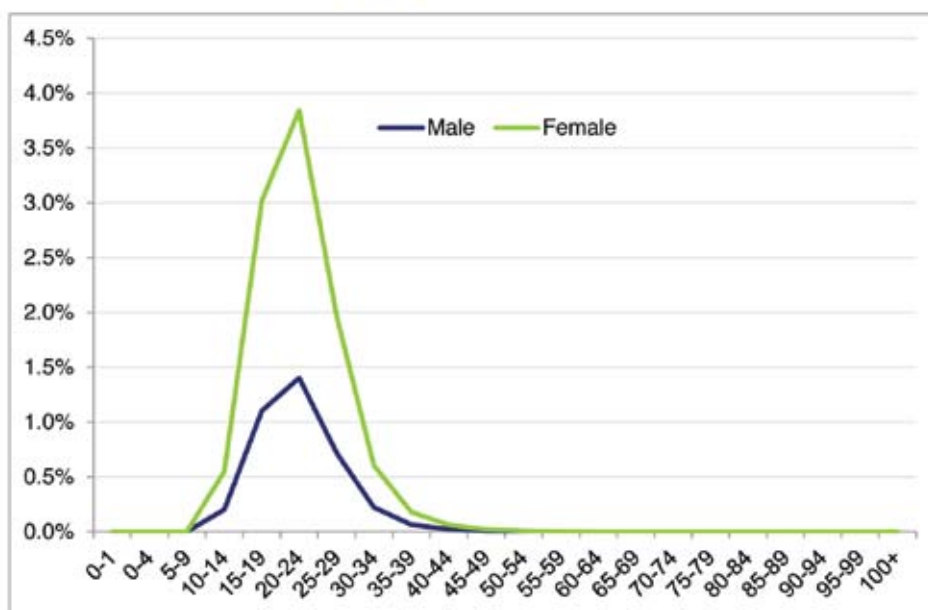


Source: Separations AIHW (NHMD), prevalence AIHW (Begg et al, 2007).

Table 2.6: Estimated age-gender prevalence of bulimia in Australia

	Males	Females
0-1	0.00%	0.00%
0-4	0.00%	0.00%
5-9	0.00%	0.00%
10-14	0.20%	0.55%
15-19	1.10%	3.02%
20-24	1.40%	3.84%
25-29	0.72%	1.97%
30-34	0.22%	0.60%
35-39	0.06%	0.18%
40-44	0.02%	0.06%
45-49	0.01%	0.02%
50-54	0.00%	0.01%
55-59	0.00%	0.00%
60-64	0.00%	0.00%
65-69	0.00%	0.00%
70-74	0.00%	0.00%
75-79	0.00%	0.00%
80-84	0.00%	0.00%
85-89	0.00%	0.00%
90-94	0.00%	0.00%
95-99	0.00%	0.00%
100+	0.00%	0.00%
Total	0.26%	0.70%

Chart 2.8: Estimated age-gender prevalence of bulimia in Australia



Chapter 2 :: Prevalence

Binge Eating Disorder

AIHW separation data are not helpful in determining age spreads for BED, mainly because there are almost no reported admissions. The AIHW uses the International Classification of Diseases (ICD) Tenth Revision categorisation for admissions which does not specifically recognise BED or EDNOS (unlike the DSM IV). The closest ICD-10 category is F50.4 "Overeating associated with other psychological disturbances". But between 1999 and 2008, there were only 22 recorded admissions under this category.

- As a broad generalisation, BED is BN without the purging. Hence, it is possible that many patients have their reason for admission listed as being for obesity consequences, rather than for BED. (Especially as BED is not a separately recognised disorder at this stage).

One possibility might be to use AIHW separations for eating disorders other than AN or BN. But there are problems with this approach.

- First, other disorders represent a small minority of ED admissions (around 10% in females), whereas prevalence studies point to AN and BN being a small minority in total prevalence.

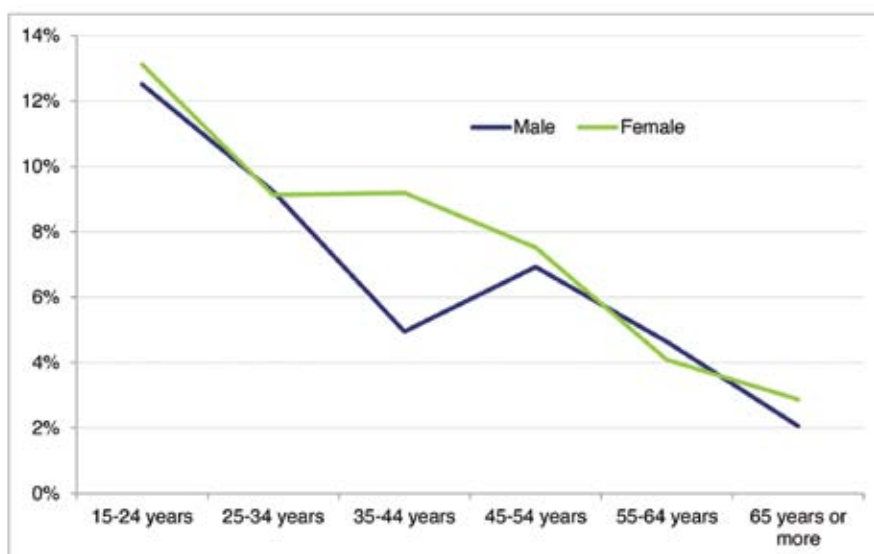
- Secondly, hospital separations show a similar pattern for these conditions as for BN and AN – that is a distinct peak in the early twenties and rapidly tailing off thereafter. But data from Hay et al (2008) show that the prevalence of binge eating behaviour, (as opposed to BED) remains relatively high over the age of 30 in both genders (Chart 2.9).

Hudson et al (2006) shows BED prevalence rates only slowly reducing in females over 25, and actually peaking for males in their 40s (Chart 2.10).

This prevalence pattern is used in the model in this report (Table 2.7). As Hudson et al (2006) only present four age points, relative prevalence patterns for those aged under 20 are modelled similar to the patterns reported by the AIHW for AN and BN.

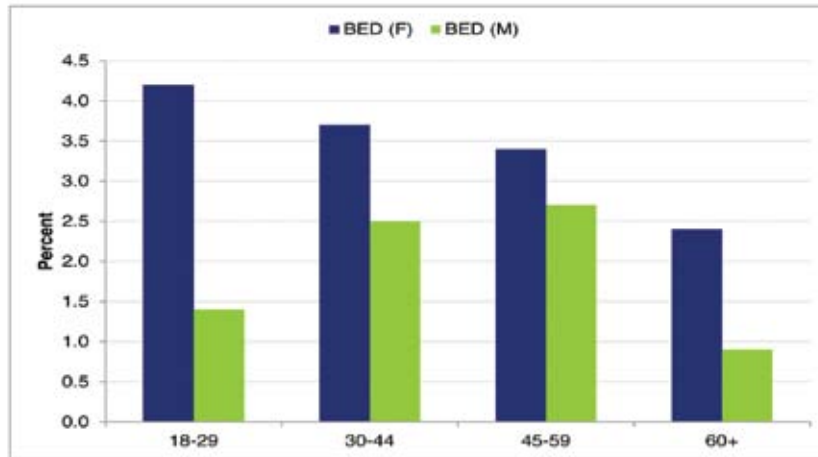
Patterns for those age over 60 are assumed to follow those for disordered eating behaviour – bingeing, purging or strict dieting – reported by Hilbert et al (2012), on the observation that eating disorders in this age group are mostly BED / EDNOS (Table 2.9). Prevalence patterns for 5 year cohorts with the 15 year cohorts reported by Hudson et al have been fitted to lines drawn between midpoints.

Chart 2.9: Prevalence of binge eating behaviour, Australia, 2005



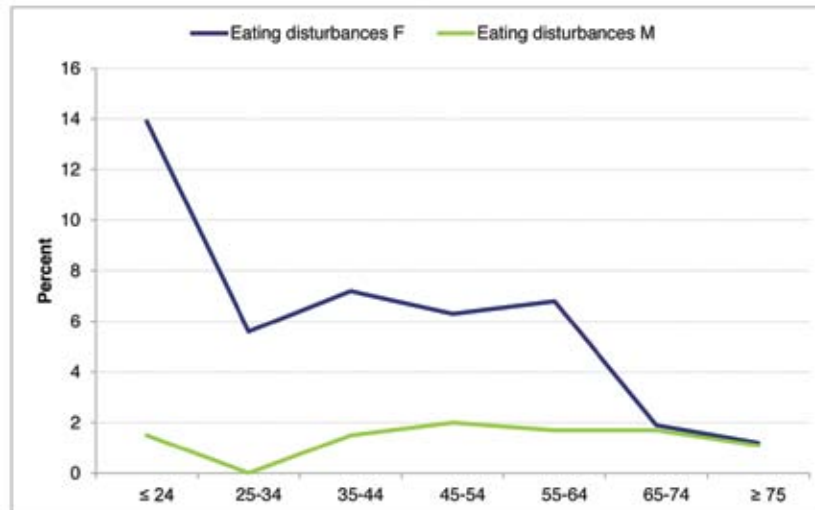
Source: Professor Hay, pers comm, 26/10/12.

Chart 2.10: Reported prevalence of BED in the United States in 2003



Source: Hudson et al (2006).

Chart 2.11: Prevalence of disordered eating behaviour in Germany in 2009



Note: Disordered eating behaviour consists of bingeing, purging or strict dieting.
Source: Hilbert et al (2012).

Chart 2.12: Estimated age-gender prevalence of BED in Australia

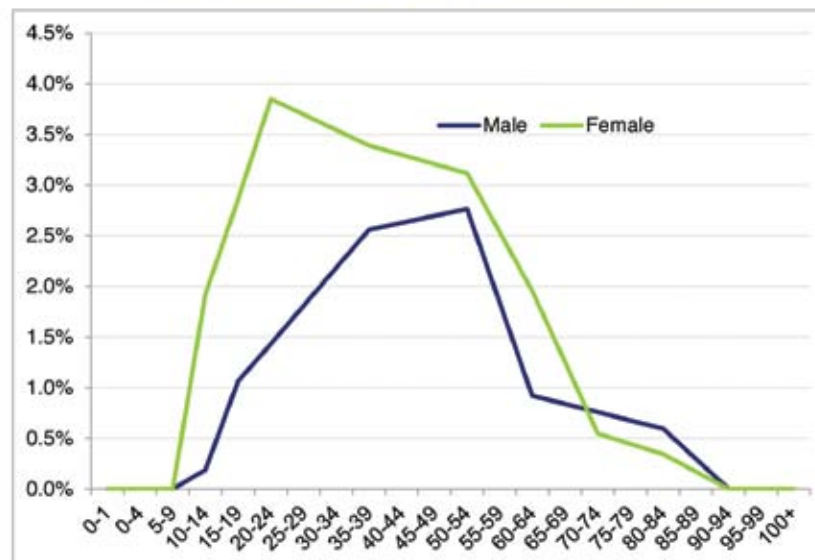
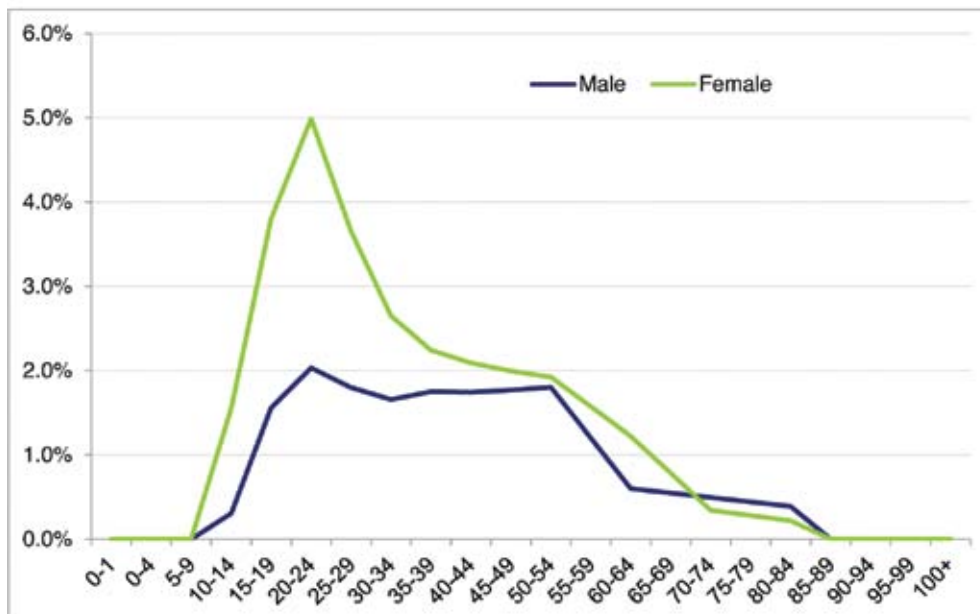


Table 2.7: Estimated age-gender prevalence of BED in Australia

Age	Males	Females
0-1	0.00%	0.00%
0-4	0.00%	0.00%
5-9	0.00%	0.00%
10-14	0.19%	1.92%
15-19	1.06%	2.86%
20-24	1.43%	3.85%
25-29	1.81%	3.70%
30-34	2.18%	3.54%
35-39	2.56%	3.39%
40-44	2.63%	3.30%
45-49	2.70%	3.21%
50-54	2.76%	3.12%
55-59	1.84%	2.54%
60-64	0.92%	1.96%
65-69	0.84%	1.25%
70-74	0.76%	0.55%
75-79	0.68%	0.45%
80-84	0.60%	0.35%
85-89	0.30%	0.17%
90-94	0.00%	0.00%
95-99	0.00%	0.00%
100+	0.00%	0.00%
Total	1.46%	2.32%

Chart 2.13: Estimated age-gender prevalence of EDNOS in Australia



Eating Disorders Not Otherwise Specified

Milos et al (2005) report that 40% of people with ENDOS go on to develop AN or BN within two years. Accordingly, in this report EDNOS is assumed to mostly be sub-clinical manifestations of one of the other three diseases (AN, BN and BED), and its prevalence patterns are assumed to be a weighted average of those three diseases.

EDNOS is the only disorder in this report where prevalence is not based on an average of more than one study. Apart from Hay et al (2008), the only other point prevalence

estimate obtained for EDNOS was 1.51% from Vardar and Erzenjin (2011). This dovetails neatly between the Hay et al estimates of 1.16% for males and 1.94% for females. However, Vardar and Erzenjin only included high school students, who could be expected to have higher prevalence than the general population. On the other hand, the Vardar and Erzenjin was carried out in Turkey, and eating disorders are reported to be lower in non-Western countries (Lee, 2000). So it is possible these two effects may balance out.

Table 2.8: Estimated age-gender prevalence of EDNOS in Australia

Age	Males	Females
0-1	0.00%	0.00%
0-4	0.00%	0.00%
5-9	0.00%	0.00%
10-14	0.30%	1.55%
15-19	1.56%	3.80%
20-24	2.03%	4.99%
25-29	1.80%	3.66%
30-34	1.66%	2.65%
35-39	1.75%	2.24%
40-44	1.74%	2.09%
45-49	1.77%	2.00%
50-54	1.80%	1.92%
55-59	1.20%	1.57%
60-64	0.60%	1.22%
65-69	0.55%	0.78%
70-74	0.49%	0.34%
75-79	0.44%	0.28%
80-84	0.39%	0.22%
85-89	0.00%	0.00%
90-94	0.00%	0.00%
95-99	0.00%	0.00%
100+	0.00%	0.00%
Total	1.16%	1.94%

Chapter 2 :: Prevalence

Total eating disorders

Combining the above estimated age gender prevalence rates by disease yields a combined total ED prevalence estimate of 2.94% in males and 5.11% in females.

- These estimates do not allow for comorbidity.

However, while there is reported comorbidity between EDs, this appears to be over time, rather than simultaneous as the DSM IV definitions are mutually exclusive.

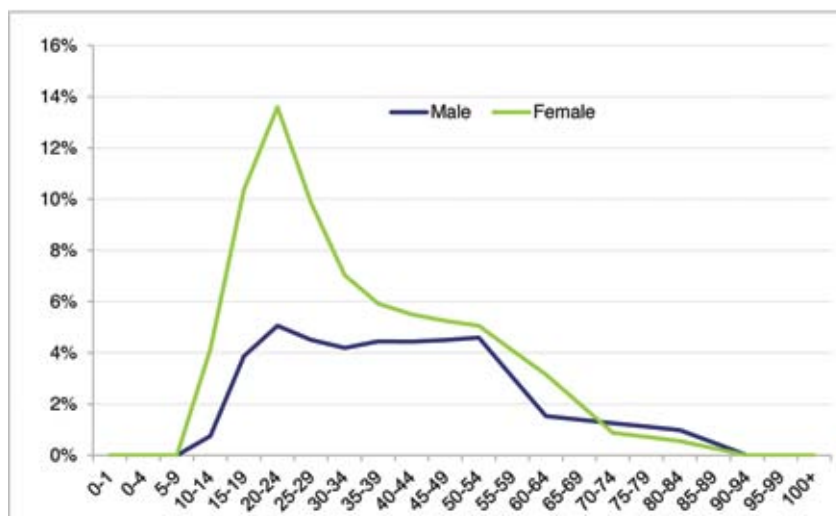
Table 2.9: Estimated ED prevalence by age and disease in males

Age	AN	BM	BED	EDNOS	Total
0-1	0.00%	0.00%	0.00%	0.00%	0.00%
0-4	0.00%	0.00%	0.00%	0.00%	0.00%
5-9	0.00%	0.00%	0.00%	0.00%	0.00%
10-14	0.06%	0.20%	0.19%	0.30%	0.75%
15-19	0.17%	1.10%	1.06%	1.53%	3.87%
20-24	0.22%	1.40%	1.43%	2.00%	5.06%
25-29	0.20%	0.72%	1.81%	1.78%	4.51%
30-34	0.13%	0.22%	2.18%	1.66%	4.19%
35-39	0.07%	0.06%	2.56%	1.76%	4.45%
40-44	0.04%	0.02%	2.63%	1.76%	4.44%
45-49	0.02%	0.01%	2.70%	1.78%	4.51%
50-54	0.01%	0.00%	2.76%	1.82%	4.59%
55-59	0.01%	0.00%	1.84%	1.21%	3.06%
60-64	0.00%	0.00%	0.92%	0.61%	1.53%
65-69	0.00%	0.00%	0.84%	0.55%	1.39%
70-74	0.00%	0.00%	0.76%	0.50%	1.26%
75-79	0.00%	0.00%	0.68%	0.44%	1.12%
80-84	0.00%	0.00%	0.60%	0.39%	0.99%
85-89	0.00%	0.00%	0.30%	0.20%	0.49%
90-94	0.00%	0.00%	0.00%	0.00%	0.00%
95-99	0.00%	0.00%	0.00%	0.00%	0.00%
100+	0.00%	0.00%	0.00%	0.00%	0.00%
Total	0.07%	0.26%	1.46%	1.16%	2.94%

Table 2.10: Estimated ED prevalence by age and disease in females

Age	AN	BM	BED	EDNOS	Total
0-1	0.00%	0.00%	0.00%	0.00%	0.00%
0-4	0.00%	0.00%	0.00%	0.00%	0.00%
5-9	0.00%	0.00%	0.00%	0.00%	0.00%
10-14	0.10%	0.55%	1.92%	1.57%	4.14%
15-19	0.57%	3.02%	2.86%	3.92%	10.37%
20-24	0.76%	3.84%	3.85%	5.15%	13.60%
25-29	0.47%	1.97%	3.70%	3.73%	9.86%
30-34	0.23%	0.60%	3.54%	2.66%	7.04%
35-39	0.11%	0.18%	3.39%	2.24%	5.92%
40-44	0.06%	0.06%	3.30%	2.08%	5.50%
45-49	0.04%	0.02%	3.21%	1.99%	5.25%
50-54	0.02%	0.01%	3.12%	1.91%	5.06%
55-59	0.01%	0.00%	2.54%	1.55%	4.10%
60-64	0.01%	0.00%	1.96%	1.19%	3.16%
65-69	0.00%	0.00%	1.25%	0.76%	2.02%
70-74	0.00%	0.00%	0.55%	0.33%	0.88%
75-79	0.00%	0.00%	0.45%	0.27%	0.72%
80-84	0.00%	0.00%	0.35%	0.21%	0.56%
85-89	0.00%	0.00%	0.17%	0.11%	0.28%
90-94	0.00%	0.00%	0.00%	0.00%	0.00%
95-99	0.00%	0.00%	0.00%	0.00%	0.00%
100+	0.00%	0.00%	0.00%	0.00%	0.00%
Total	0.16%	0.70%	2.32%	1.94%	5.11%

Chart 2.14: Estimated age-gender prevalence of total eating disorders in Australia



Total eating disorders – prevalent cases

Multiplying the age-gender prevalence rates from Table 2.9 with ABS 2012 population figures for Australia⁸ indicates that there are over half a million (580,621)

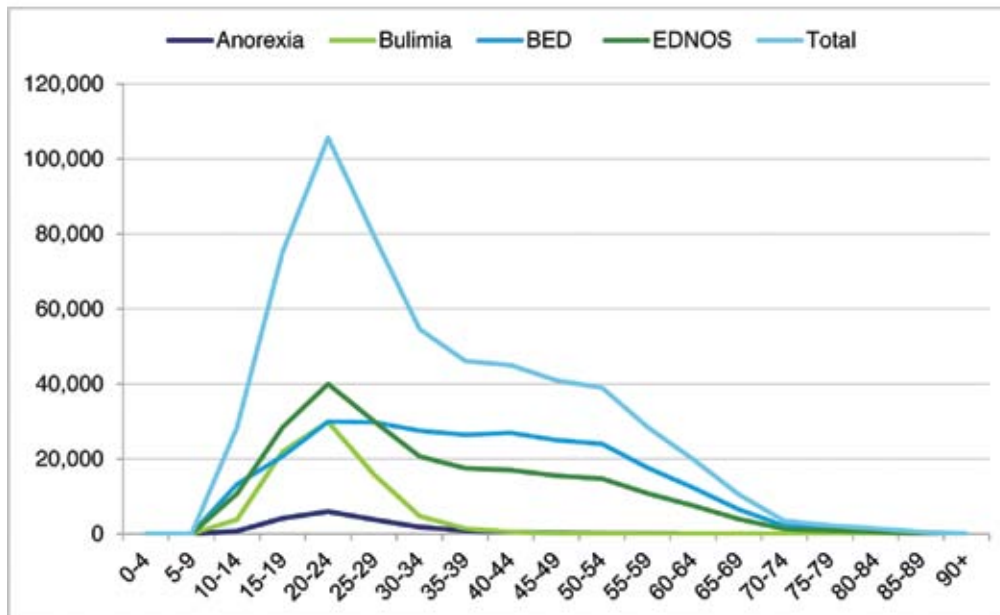
women with eating disorders, as well as over a third of a million men (333,365). Peak prevalence is in the 20 to 24 year age group in both genders.

Table 2.11: Estimated prevalent ED cases in Australian females, 2012

Age	Anorexia	Bulimia	BED	EDNOS	Total
0-4	0	0	0	0	-
5-9	0	0	0	0	-
10-14	689	3,778	13,183	10,742	28,392
15-19	4,115	21,892	20,712	28,432	75,150
20-24	5,938	29,837	29,887	39,960	105,622
25-29	3,788	15,842	29,792	30,077	79,500
30-34	1,760	4,691	27,486	20,653	54,591
35-39	885	1,378	26,426	17,459	46,148
40-44	511	490	26,945	17,007	44,953
45-49	278	164	24,987	15,475	40,903
50-54	157	56	24,004	14,738	38,956
55-59	83	18	17,618	10,783	28,503
60-64	43	6	12,295	7,512	19,856
65-69	20	2	6,493	3,965	10,481
70-74	9	0	2,133	1,304	3,446
75-79	4	0	1,375	839	2,219
80-84	2	0	875	534	1,411
85-89	1	0	304	186	490
90+	0	0	0	0	0
Total	18,284	78,154	264,516	219,667	580,621

⁸ ABS Population Projections, Australia, 2006 to 2101, Cat. No. 3222.0

Chart 2.15: Estimated prevalent ED cases in Australian females, 2012



34

Table 2.12: Estimated prevalent ED cases in Australian males, 2012

Age	Anorexia	Bulimia	BED	EDNOS	Total
0-4	-	-	-	-	-
5-9	-	-	-	-	-
10-14	467	1,448	1,357	2,140	5,411
15-19	1,330	8,411	8,120	11,682	29,543
20-24	1,820	11,474	11,727	16,365	41,386
25-29	1,665	5,932	14,958	14,752	37,307
30-34	1,028	1,732	17,134	13,011	32,905
35-39	520	499	19,787	13,608	34,413
40-44	302	176	21,158	14,151	35,786
45-49	162	59	20,689	13,676	34,586
50-54	89	20	20,764	13,652	34,525
55-59	45	7	12,524	8,225	20,800
60-64	23	2	5,688	3,737	9,450
65-69	11	1	4,286	2,811	7,108
70-74	4	0	2,803	1,836	4,644
75-79	2	0	1,828	1,197	3,027
80-84	1	0	1,168	764	1,933
85-89	0	0	325	212	537
90+	0	0	-	0	0
Total	7,469	29,761	164,317	131,818	333,365

Chart 2.16: Estimated prevalent ED cases in Australian males, 2012

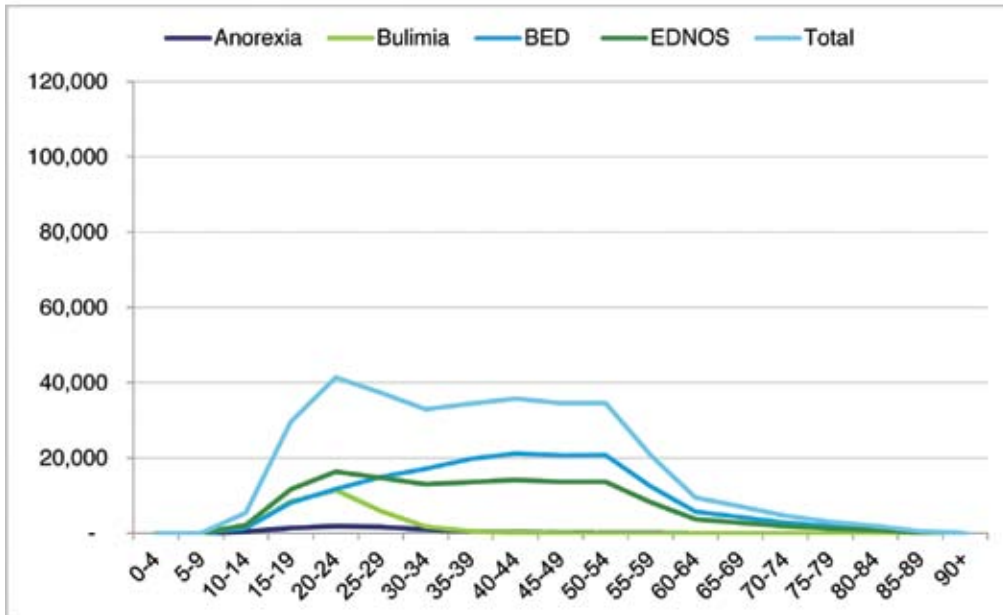


Chart 2.17: Estimated prevalence of eating disorders in females, by type

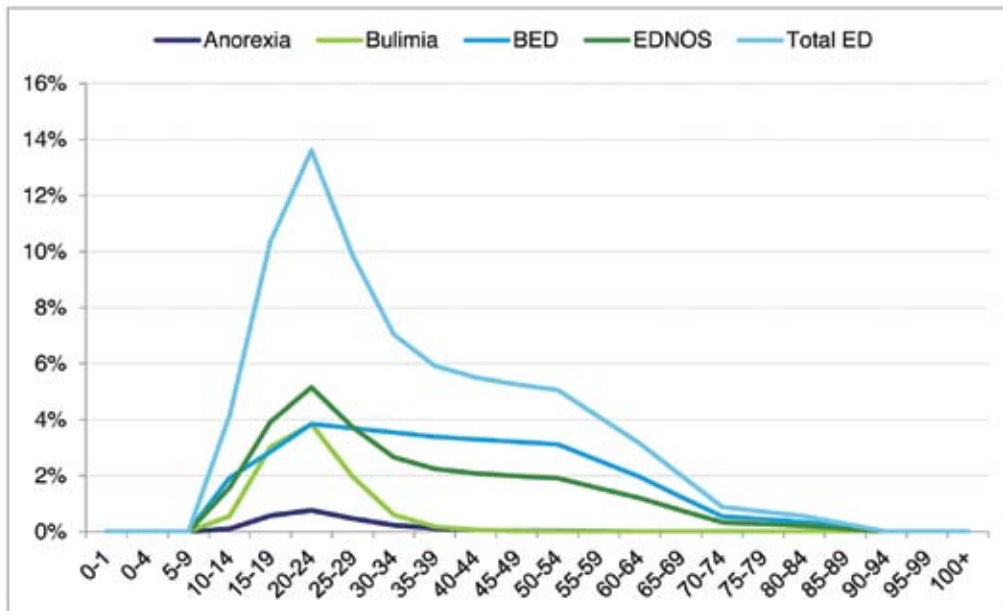
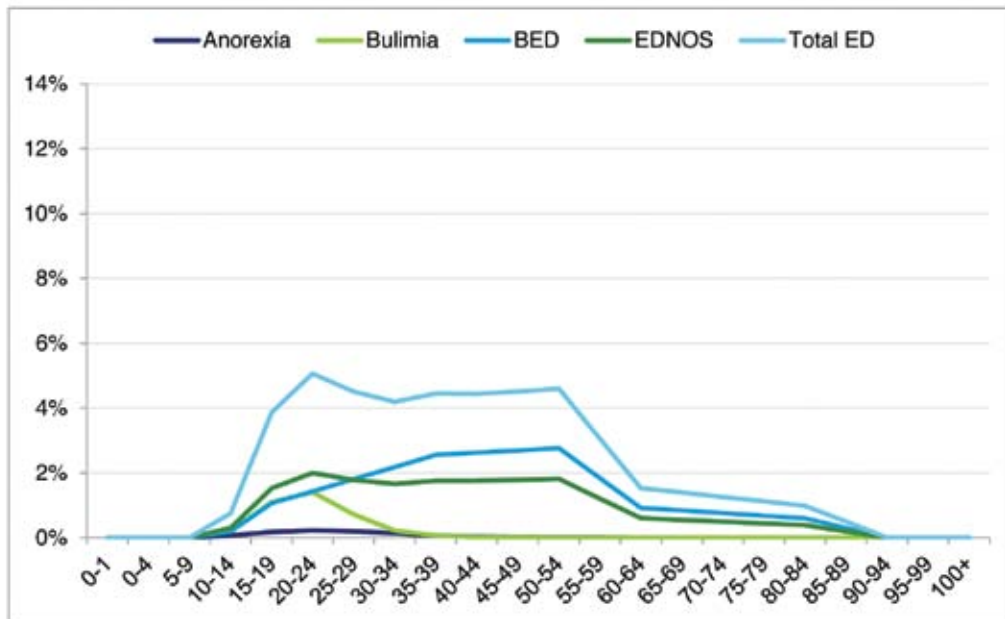


Chart 2.18: Estimated prevalence of eating disorders in males, by type



36

Prevalence projections to 2032

On current projections, there will be over a million people with eating disorders in less than ten years from now (1,017,600 by mid 2022).

- Growth rates may actually be considerably higher. Hay et al (2008) reported a doubling of disordered eating behaviour in South Australia over the ten

years to 2005. AIHW hospital data show a trebling in admissions for EDs other than AN or BN. While total ED admissions fell over the period, BED and EDNOS account for 85% of ED prevalence, increasing admissions for these disorders may indicate increasing total prevalence.

Chart 2.19: ED prevalent cases in males, by disorder, 2012 to 2032

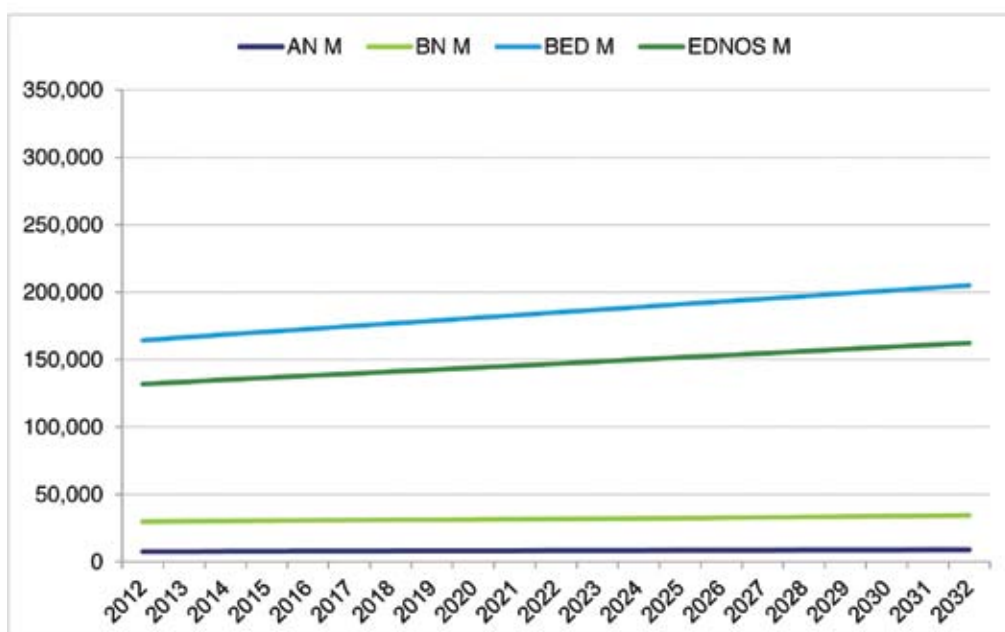
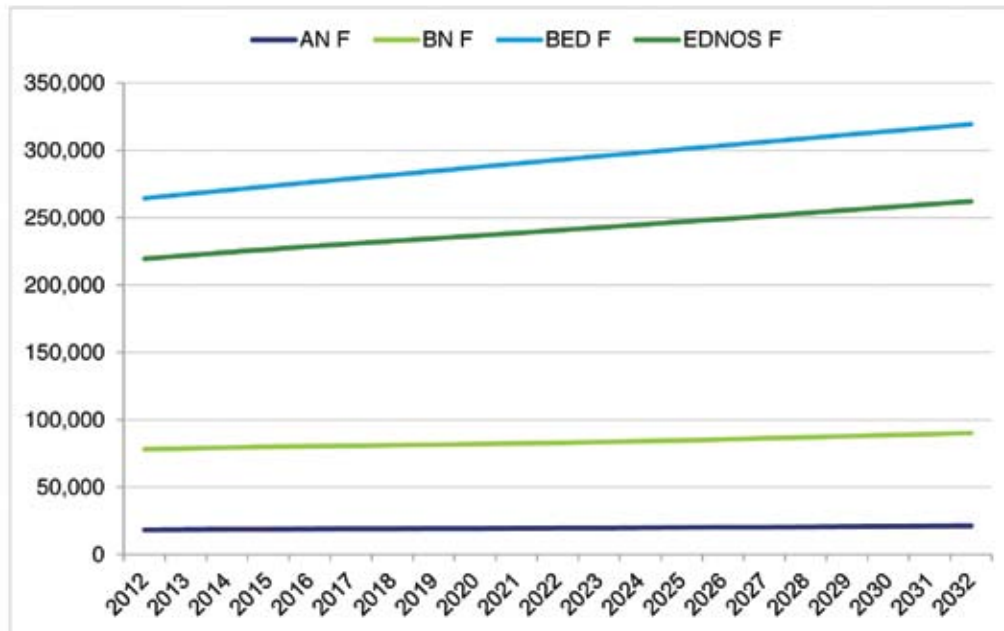


Chart 2.20: ED prevalent cases in females, by disorder, 2012 to 2032



2.3 Mortality

There are three ways to estimate current ED mortality.

- Latest official ABS reported deaths attributed to ED.
- Divide AIHW estimated ED prevalence for 2003 (latest year) by AIHW reported deaths in 2003, to obtain a standardised mortality ratio, and then apply this to current prevalence estimates.
- Take standardised mortality rates from a recent meta-study (the gold standard in health research) and apply these to current prevalence estimates.

The most recent ABS data (2012) attributed just 14 deaths to eating disorders in 2010.

The AIHW (Begg et al, 2007) estimated 11.3 deaths in 2003, from an estimated prevalence of 23,464 eating disorders, giving a mortality rate of 0.05%. Using the AIHW's age-gender mortality rates for the whole population, an age-matched group of 23,464 people without EDs would result in an estimated 10.2 deaths. This implies an ED standardised mortality ratio of 1.11 to 1. Applying this ratio to an estimated 2012 prevalence of 913,986, would imply 203 deaths due to EDs.

However, there are problems with using the AIHW approach. Most of the AIHW's reported deaths came

from "Other eating disorders". However, the AIHW did not estimate prevalence for "other eating disorders", only for AN and BN. (And then not for BN in males either, but this matters less as the AIHW did not estimate any deaths from BN.)

Arcelus et al (2011) performed a meta-analysis of 36 quantitative studies of mortality in eating disorders. Each of the included studies followed 15 or more participants for a minimum of one year. Overall, there were over 17,000 subjects with EDs, and over 750 deaths covered. The authors calculated standardised mortality ratios as follows; 5.86 for AN, 1.93 for BN and 1.92 for EDNOS. These are not used in the model as there is no age gender breakdown⁹. However, the authors did note that the death rate rises with age until 30 years. Specifically, a standardised mortality ratio of around 3 is seen in the youngest patient population, then 10 in the 15-19 years cohort, rising to almost 18 in those aged 20 to 29 years, and then dropping to approximately 6 in those who present for treatment at age 30 years or older.

- While a meta-study is the gold standard in health research, and Arcelus et al is a recent study in a prestigious journal, there may be some cautionary notes. A number of the studies included are

Table 2.13: ED prevalent cases in total population, by disorder and gender, 2012 to 2032

Year	AN	BN	BED	EDNOS	Total
Males					
2012	7,469	29,761	164,317	131,818	333,365
2013	7,550	30,032	166,397	133,408	337,387
2014	7,629	30,282	168,483	134,988	341,383
2015	7,705	30,487	170,568	136,535	345,295
2016	7,777	30,672	172,601	138,033	349,082
2017	7,844	30,836	174,597	139,490	352,768
2018	7,909	30,990	176,599	140,943	356,442
2019	7,972	31,142	178,616	142,402	360,131
2020	8,032	31,281	180,700	143,896	363,909
2021	8,094	31,468	182,786	145,422	367,770
2022	8,156	31,666	184,842	146,937	371,600
2023	8,220	31,897	186,898	148,475	375,490
2024	8,283	32,128	188,927	149,995	379,334
2025	8,344	32,360	190,991	151,536	383,230
2026	8,407	32,623	192,995	153,060	387,085
2027	8,473	32,915	194,988	154,597	390,973
2028	8,541	33,229	197,021	156,177	394,968
2029	8,609	33,541	199,031	157,740	398,922
2030	8,676	33,844	201,045	159,299	402,864
2031	8,743	34,135	202,998	160,810	406,686
2032	8,814	34,437	204,925	162,315	410,491
Females					
2012	18,284	78,154	264,516	219,667	580,621
2013	18,450	78,801	267,528	221,995	586,774
2014	18,607	79,401	270,495	224,261	592,764
2015	18,750	79,906	273,409	226,428	598,493
2016	18,878	80,355	276,314	228,547	604,094
2017	18,999	80,781	279,059	230,551	609,391
2018	19,112	81,172	281,828	232,542	614,654
2019	19,225	81,566	284,608	234,543	619,941
2020	19,329	81,913	287,360	236,492	625,093
2021	19,458	82,417	290,114	238,554	630,543
2022	19,590	82,942	292,836	240,610	635,979
2023	19,736	83,554	295,537	242,715	641,543
2024	19,881	84,162	298,215	244,803	647,061
2025	20,020	84,750	300,877	246,865	652,512
2026	20,180	85,448	303,514	248,992	658,135
2027	20,350	86,209	306,151	251,164	663,873
2028	20,533	87,036	308,826	253,406	669,800
2029	20,714	87,855	311,487	255,634	675,690
2030	20,890	88,656	314,154	257,851	681,551
2031	21,059	89,403	316,762	259,996	687,219
2032	21,235	90,188	319,365	262,166	692,955

⁹ Applying the same standardized mortality ratio to older cohorts, which already have high mortality, would yield excessively high ED mortality rates.

¹⁰ This step is necessary to separate out those with ED who die from other causes, and those with ED who die from ED.

¹¹ This does not affect the overall average.

relatively old, there is only one Australian study included, and there are more studies with short follow ups (which are associated with higher mortality rates) than long follow ups.

- On the other hand, Harbottle et al (2008) in their systematic review conclude that a woman who contracts AN at age 15 will have her life expectancy reduced by 25 years, which would support Arcelus' estimates.

The mortality rates (5.1 deaths per thousand person years for AN, 1.7 for BN and 3.3 for EDNOS) calculated by Arcelus et al (2011) were used to estimate the number of deaths in Australia in 2012 from eating disorders. If a weighted average across disorders is considered, Arcelus' ratios translate to around 1.95:1. That is, the population with EDs can expect to have almost twice the mortality rate of the rest of the population. In an age-gender matched population of 913,986 persons (the estimated ED population), it would be expected that 1,863 people could be expected to die from other causes¹⁰. Applying Arcelus' mortality rates yields an

expected total of 1,829 deaths due to EDs in Australia in 2012, a ratio of 1.98:1.

- An estimated age-gender breakdown of total ED mortality can be found in Chart 2.14. As noted, in the absence of age-gender rates, average mortality rates were applied to all cohorts. To the extent that ED mortality ratios appear to be higher in the peak prevalence 15 to 30 years age group than in the immediately preceding and following age cohorts, this breakdown may under-estimate mortality for the main group of ED sufferers, and over-estimate it for older and younger groups.¹¹

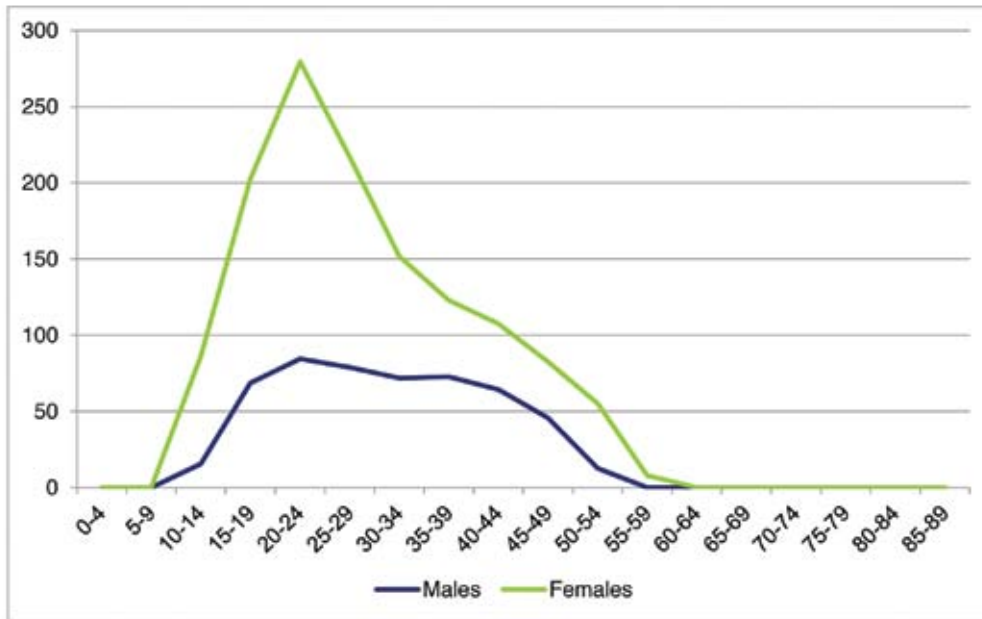
If scientific observation predicts far more deaths than are officially recorded, the implication must be that many deaths which are statistically due to EDs are classified under other causes; for example, suicide, renal failure, cardiac failure due to malnutrition for AN, or consequences of obesity for BED. The AIHW (2012) notes that the average person has three causes of death, and a death is equally likely (20%) to have five causes as to have one.

Table 2.14: Estimated deaths to eating disorders, Australia, 2012

Age	Males	Females
0-4	0	0
5-9	0	0
10-14	16	86
15-19	69	203
20-24	85	279
25-29	79	217
30-34	72	152
35-39	73	123
40-44	64	108
45-49	46	83
50-54	13	55
55-59	0	8
60-64	0	0
65-69	0	0
70-74	0	0
75-79	0	0
80-84	0	0
85-89	0	0
90+	0	0
Total	515	1,313

Note: Due to lack of age-gender specific rates in Arcelus et al, common mortality rates have been applied, however Arcelus et al note that ED mortality ratios are higher in the 15 to 30 age group than in the immediately younger and older cohorts. Source: ABS (2010), Arcelus et al (2011)

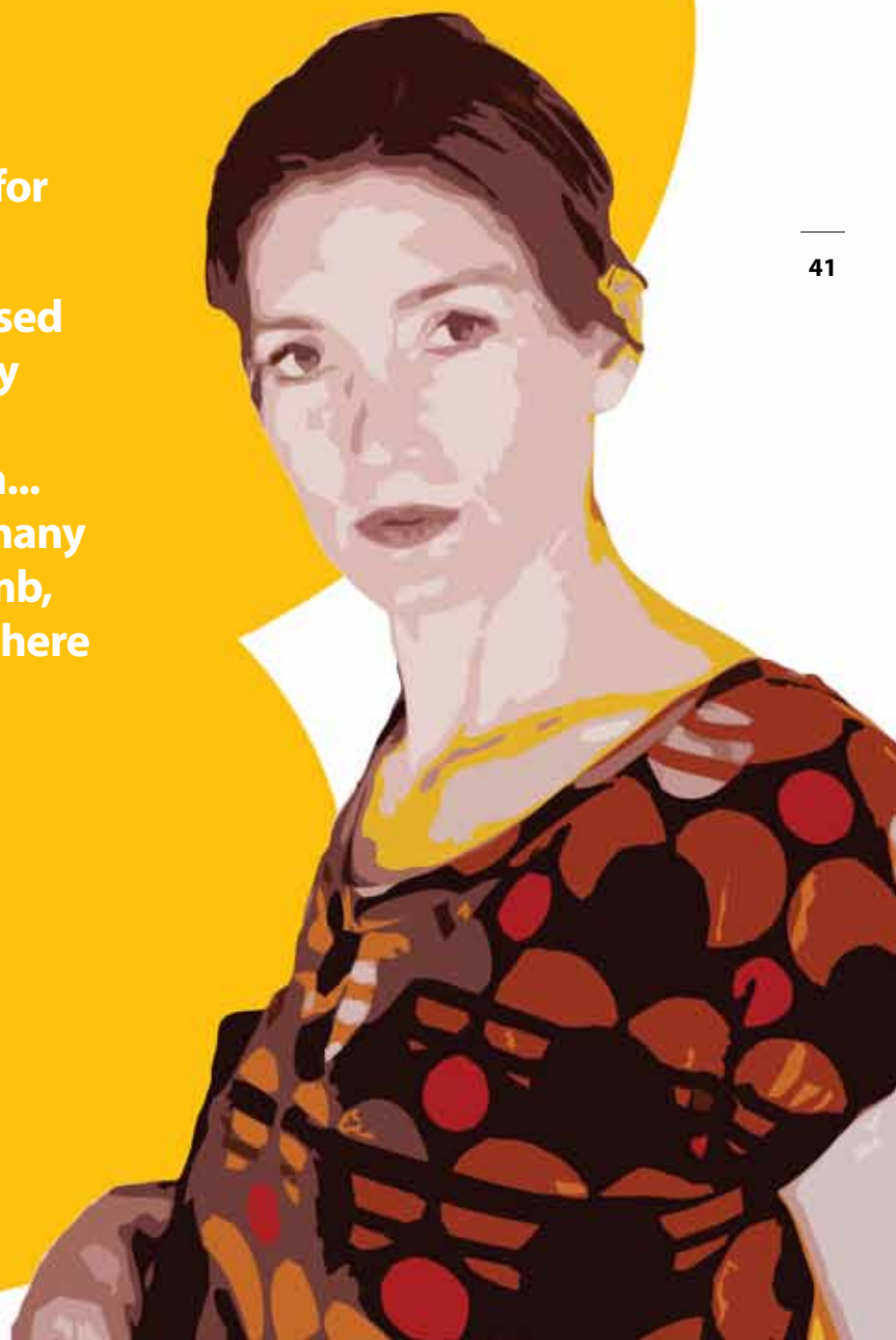
Chart 2.21: Estimated deaths to eating disorders, Australia, 2012



Source: ABS (2010), Arcelus et al (2011).

I had not had any help for the first 20 years.

In my 30's I was diagnosed and began recovery - by then I also had chronic anxiety and depression... decades of struggle... many relapses. Slip, slide, climb, slip, slide... Finally got there at age 55.



Chapter 3 :: Case studies





**We live in a parallel universe,
help comes from the very
few who understand the
illness and we often slip
through the cracks.**

Initially I thought if I could just make her eat she would get better.

But eating disorders are much more complicated than that.

They devastate not just the individual but the whole family.



JULIE'S STORY

I have a daughter who has suffered with anorexia nervosa for over a decade. Initially I thought if I could just make her eat she would get better. But eating disorders are much more complicated than that. They are a group of insidious mental illnesses that devastate not just the individual but the whole family.

It didn't take very long for me to realise that what I was trying to deal with was something I had no control over. No amount of motherly love was going to fix this illness. However, you have to give your unconditional love, attention and support. It is so important to keep telling your child how much you love them and how important they are in your life. Though, this does not stop the feeling of hopelessness that consumes you.

Unfortunately, as this illness often presents itself in the teen years, the behaviour can be mistaken with "puberty blues" where your child no longer includes you in the day to day happenings in his/ her life. And then one day you realise that it is not puberty - there is something very wrong.

By then your child is very ill.

Treatment is expensive and lengthy. I am going back to the year 2000 now when each visit to a practitioner was costing between \$300 and \$500. My daughter was requiring at least three visits per week to psychiatrists and psychologists. Then there was the weekly visit to the dietician which was about \$150 per visit.

So you can see there is a substantial financial commitment to receiving adequate treatment. Medicare helps but if you do not have private health cover the financial costs are extremely high.

As a carer your ability to work effectively is also compromised. You may have to down tools, at the drop of a hat, to attend to the sufferer. I have had many instances where I was phoned to urgently attend my daughter when she was in hospital and/or at home.

When your child is very ill your mind is not 100% on the job. You are constantly distracted by thoughts of how your child is managing

There is also the huge emotional cost to both the sufferer and the family.

As I said, there were at least three or four visits to practitioners each week. They are not necessarily close

to where you live so you have to take into account travel time as well. The round trip to one specialist was at least three hours and often they were running late. We made this trip twice a week for many months.

This meant that while you were doing that, you either had your other children with you or you left them at home, if they were old enough.

At one time early on in her illness, my daughter was hospitalised, for more months than not, over a period of about two years.

The visiting hours are reasonably restricted in the few facilities that offer treatment and are usually after school hours. So again the rest of the family have to deal with you being absent for long periods every day. This was heartbreaking to me, when all I wanted was to be able to make her better.

The financial and emotional cost to the family is often irreparable and can lead to exhaustion for the carers, and even marriage breakdown.

Also, depending on their age, the sufferer can lose the best years of their life, unable to really enjoy being with friends, socialising, and eating pizza. Things that many of us take for granted.

After years of regular treatments and several episodes of hospitalisation, some headway has been made and at least now my daughter wants to get well, although there will still be a few years of treatment until my daughters is well again.

Hopefully she can maintain a forward motion with her "recovery".

**I'm not just asking for help,
I'm "screaming and jumping up
and down for it".**

**I was just so tired of fighting two
battles solo...within myself and
against the health care system.**

IRENE'S STORY

I've been suffering from an eating disorder for the past five years.

At the age of 17 I was referred to see a psychologist in my local home town, six hours away from Sydney. The psychologist, like many, had little to no experience dealing with eating disorders. Unfortunately the experience led to me avoiding any kind of treatment for the next few years.

At the age of 19 I once again sought help, but this time I was living in Sydney and was in my second year of university studies. My bulimia had gotten completely out of control. My blood results always came back normal and as my weight remained stable and in the normal range, there was nothing to physically indicate the struggle I was dealing with in private. I was seeing a psychiatrist (with little experience dealing with eating disorders) and my GP regularly, and soon was referred to a hospital outpatient service for eating disorders. Unfortunately, by the time I actually received an interview, seven weeks had already passed...enough time for me to talk myself out of going because the extensive wait time that meant I wasn't 'sick' enough to be treated.

One year later, I went back to see a GP. At this time my bulimia was the worst it had been. I was spending hundreds of dollars per week on food alone, studying full time, and working nights in hospitality to pay for my disorder. My weight dropped as at this time I kept down little to no food. The night before I was due to start first semester I was hospitalised for dangerously low potassium levels. They keep you in overnight... just long enough to 'top you up' and push you out. University became too much for me and I deferred my studies. I was bingeing and purging from the moment I woke up to the moment I slept, and soon after I had to quit my job. After being referred to the same hospital again I followed through with my outpatient appointment before waiting five weeks for the next one.


By this time I had been linked up with a psychiatrist following an admission at another hospital, in my local area, and she arranged a six week admission in the Psychiatric Emergency Care centre unit. Despite not specialising in eating disorders, the nurses there put in the best efforts to come up with an appropriate treatment plan to mimic an ED treatment centre.

Upon discharge I was medically stable and it was hoped that I'd be now well enough to go to Derwent House.

My mother signed me up for private health insurance, which we can't actually afford. My family have gone to extreme lengths to help me, from putting locks on the pantry and fridge, to buying me a cat to combat the isolation an eating disorder can bring. As I require more specialist support than my local town can offer, I fly to Sydney every two weeks to attend appointments with my psychiatrist and psychologist.

One of my nurses said earlier this year that I'm not just asking for help, I'm "screaming and jumping up and down for it". There were numerous times when ending it all crossed my mind because I was just so tired of fighting two battles solo...within myself and against the health care system.

I'm currently telling my story from my hospital bed where I'm once again receiving an intravenous drip for my potassium and magnesium levels, making this my ninth eating-disorder related hospitalisation in this year alone. I'm telling my story of fighting to get treatment because I hope that it will contribute to bringing treatment changes for people with any kind of eating disorder.



Allison's next admission was at a private hospital, where she slipped out undetected and took her life.

ALLISON'S MOTHERS STORY

Allison's GP was an ED specialist, who thankfully bulk-billed her. We were lucky to meet this ED-specialist GP through business connections. Finding the right professionals is difficult. Then getting the appointments is a waiting game. Getting a bed at a clinic is very much a waiting game, you have to ring every day.

Thank God we had private health insurance with AHM, who were brilliant. This paid for the clinic admissions after the first \$500, and included psychiatric cover.

On the other hand, Allison saw a psychologist for a whole year before being referred to the ED specialist. This was despite my raising concerns about her weight and eating behaviour with that psychologist.

The psychologist told me she was gaining Allison's trust and dealing with family issues. But it was still a whole year wasted. In the end, Allison's medical bills came to over \$75,000 in under two years.

In addition to the medical costs, Allison had been working three days a week at her permanent part-time marketing job, but resigned prior to her first admission at a clinic. (Although apparently her employers had not realised she was sick.) She applied for other jobs after that, but was unsuccessful due to being repeatedly readmitted (116 days over the next nine months). I also had to cut back my work by ten hours a week to care for her.

During this time, as well as her inability to work, Allison faced the costs of social isolation, the lack of

understanding of her friends and relatives, and was unable to exercise. This led to depression, apathy and boredom. We spent over \$1,000 on DVD rentals, movies and outings to try to fill the empty days.

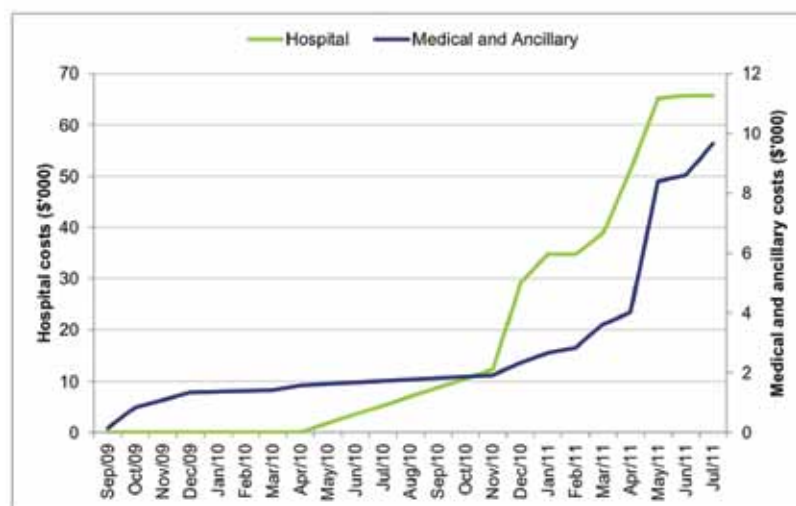
Allison made slow progress at the clinic. On the physical side of things, she gained weight on the first and third admissions although it was very difficult to maintain her weight in a home environment. But, on the mental side of things, I don't believe any significant progress was made.

Allison's next admission was at a private hospital, where she slipped out undetected and took her life. This causes serious concerns, as Allison had had a history of suicide attempts, including a previous emergency admission for attempted suicide (although this was not attributed to her eating disorder in her admissions data).

There is an epidemic of EDs in Australia, but this mental illness is just not well understood. It is socially isolating for both sufferer and carer, and takes a huge toll on family life. Allison's suicide is a burden that her friends and family continue to bear.

Two years on, I still have weekly counselling. Living with an ED is hard. Living with a suicide is worse.

Chart 3.1: Allison's cumulative health expenditure



Source: personal communication

Chapter 4 :: Financial costs





I have limited earning capacity as a result of having been so set back in my life choices due to being so ill for so long and at such a young age.

Chapter 4 :: Financial costs

60% of health system costs are borne by individuals and their families. The productivity impacts of EDs are estimated at \$15.1 bn in 2012, similar to the productivity impacts of anxiety and depression.

This chapter estimates financial costs of eating disorders, while the next chapter estimates the burden of disease (the loss of healthy life from eating disorders). Knowing the costs to the health system can be useful for planning resource allocation. Often, however, the largest costs from a disorder are not health expenditure, but lost productivity. Healthy people work and contribute taxes government revenue. People with EDs – and their carers – often work less, and so pay less taxes. Some people with EDs, and their carers, are out of the workforce altogether and have to draw welfare payments.

If interventions are implemented to help combat EDs more effectively, in addition to saving on health expenditure, they also have potential to save on welfare payments and raise more taxes. These savings can then be used to pay for the extra interventions.

- As noted in Chapter 2, this report uses a prevalence rather than an incidence approach. Thus, it measures the total costs caused by EDs in any given year. The alternative, using incidence, would measure the discounted net present value of costs that people who contract EDs in 2012 would be expected to incur over their lifetime from their EDs

4.1 Methodological overview

There were four types of financial costs calculated in this report¹²:

1. Health system expenditure (Section 4.2) comprises the costs of running hospitals, GP and specialist services reimbursed through Medicare and private funds, the cost of prescription pharmaceuticals funded through the Pharmaceutical Benefits Scheme and privately, as well as research and health administration attributed to eating disorders.
2. Productivity costs (Section 4.3) include the losses in productivity for people with an eating disorder (due to reduced workforce participation, absenteeism, presenteeism, and premature

mortality) and the value of informal care provided by family members and others.

3. Other financial costs (Section 4.5) can include all other government and non-government programs and out-of-pocket expenses (such as formal care, aids, transport and accommodation costs associated with receiving treatment) and the bring-forward of funeral costs.
4. Transfer costs (Section 4.6) comprise the deadweight losses (DWLs) associated with government transfers, such as taxation revenue forgone, welfare and disability payments. Welfare payments include the Carer's Allowance and Disability Support Pension which are sometimes provided to individuals whose eating disorder or caring role impairs their ability to engage in paid employment. These payments are transfers so affect the distribution of who bears the costs, but are also associated with deadweight losses to society since taxation is required in order to pay them, assuming fiscal neutrality overall.

The costs of ED are borne by different individuals or sectors of society. Clearly the persons with an ED bears costs, but so do employers, government, friends and family, co-workers, charities, community groups and other members of society.

It is important to understand how costs are shared in order to make informed decisions regarding interventions. From the employer's perspective, depending on the impact of ED, work loss or absenteeism will lead to costs such as higher wages (i.e. accessing skilled replacement short-term labour) or alternatively lost production, idle assets and other non-wage costs. Employers might also face costs such as rehiring, retraining and workers' compensation.

While it may be convenient to think of these costs as being purely borne by the employer, in reality they may eventually be passed on to end consumers in the

form of higher prices for goods and services. Similarly, for the costs associated with the health system and community services provided to the person, although the government meets this cost, taxpayers (society) are the ultimate source of funds. However, for the purpose of this analysis, a 'who writes the cheque' approach is adopted, falling short of delving into second round or longer term dynamic impacts.

Typically six groups who bear costs and pay or receive transfer payments are identified:

1. people with EDs;
2. friends and family (including informal carers);
3. employers;
4. Australian government;
5. state and local government; and
6. the rest of society (private health insurers, not-for-profit organisations, and others).

Everyone should have access to support .

It is NOT FAIR that many, many people cannot access this type of care due to cost.



¹²"Burden of Disease" costs, which are market-based valuations of the cost of healthy life lost from EDs, are not considered financial costs, but are covered in a separate chapter (5).

Chapter 4 :: Financial costs

Outlining the four cost categories and six groups enables a framework for analysis, as shown in Table 4.1.

There are essentially two ways of estimating each element of cost for each group:

- **top-down:** these data may provide the total costs of a program element (e.g. health system); or
- **bottom-up:** these data may provide estimates of the number of cases in the category and the average cost for that category; the product is

the total cost (e.g. the wage rate for lost earnings multiplied by the reduction in employment, and the number of people to whom this applies).

It is generally more desirable to use top-down national datasets in order to derive national cost estimates to ensure that the whole is not greater or less than the sum of the parts. On the other hand, it is often difficult to obtain top-down estimates. In this report the top-down approach is applicable to health system and burden of disease costs and the bottom-up approach applies in

Table 4.1: Costs associated with ED

Conceptual group	Subgroups	Bearers of Cost	Comments
Health system costs	Costs by type of service eg, hospital inpatients, pharmaceuticals, GPs, allied health etc.	Person*, governments and society (private health insurers, workers' compensation)	
Productivity costs	Lower workforce participation rates	Person and government [#]	Includes premature retirement
	Lost productivity from temporary absenteeism (time off work)	Person, employer and government [#]	
	Lost productivity from greater 'presenteeism' (lower productivity at work)	Employer	
	Premature death	Person and government [#]	Loss of productive capacity
	Additional search and hiring replacement	Employer	Incurred when prematurely leave job
	Lost unpaid work of person	Person, friends and family	Includes housework, yardwork, childcare and volunteer work
	Lost informal carer productivity	Friends and family, and employer [#]	Includes both paid and unpaid work
Other financial costs	Cost of care, aids, equipment, modifications, and various assistance programs etc	Person, government and society	Includes aids, equipment and home modifications, alternative and herbal medications, transport costs, private domestic assistance, and miscellaneous out-of-pocket costs not included in other cost categories.
	Funeral costs brought forward	Friends and family	
Transfer costs	DWL	Society	Relate to transfers from taxation, welfare and other government payments

* Friends/family may also bear loss of wellbeing, health costs and lower living standards as a result of the individual's ED; however, care is needed to assess the extent to which these are measurable, additional (to avoid double counting) and not follow-on impacts. For example, a spouse may pay a medical bill and children may share in lower household income if the person's work hours are reduced – but as this is simply redistribution within family income it is not measured here.

Where earnings are lost, so is taxation revenue and frequently also there are other transfers, such as welfare payments for disability/sickness/caring etc, so governments share the burden.

other cases such as productivity impacts.

- Data on health system costs and burden of disease are derived from the AIHW, which in turn are based on other data sources, such as the Australian Hospital Statistics and Bettering the Evaluation and Care of Health (BEACH) data for GP costs.
- Data on other financial costs are drawn from a variety of sources, for example Centrelink, survey responses, and literature searches.

4.2 Health costs

For this report, a top-down approach to costing was the preferred choice for estimating health costs, as the AIHW advised that they were able to supply health expenditure data by:

- Type – admitted hospital patients, out of hospital medical expenditure and pharmaceuticals;
- Age and gender (ten year groups); and
- Disorder – AN, bulimia and “other eating disorders”.

However, there were gaps in the data that the AIHW was able to supply.

- Total expenditure could only be broken down by disorder and expense type, not by age or gender.
- Neither expenditure type, nor disorder costs could be broken down by age or gender.

- The only component that could be broken down by age and gender was total hospital costs.
- Out of hospital medical expenditure did not include any allied health expenditure
- No data were available for pharmaceutical expenditure for bulimia.

A small consultation survey was also conducted, but this was not intended to measure total health system expenditure, but rather to measure the economic and social impacts on people with EDs and carers (including out of pocket treatment costs).

- As ethics clearance was not in scope for this project, questionnaires were only sent to people who had indicated they were willing to participate, and 84 complete responses were received.
- Approximately 51% of respondents had AN and 39% had bulimia, which means that the results are not representative of EDs as a whole.

The survey was useful for triangulating AIHW data, but due to its limitations in terms of representativeness was not able to reliably fill data gaps. For example, it sought total out of pocket treatment costs, but not separately for allied health.

The survey and its findings are presented in Appendix A and Appendix B respectively. A summary of the out-of-pocket costs estimated from the survey is provided in Table 4.2.

Table 4.2: Median out-of-pocket costs

Category	Cost
Treatment by health professionals	\$1,750
Medication	\$750
Hospital	\$125
Travel	\$750
Food	\$750
Any other directly related costs	\$750
Cost of treating other health consequences	\$375
Total	\$4,375

Note: Total is the median of individual total expenditure, not the sum of the above categories, as some only pertain to a minority of respondents.

Source: 2012 survey results.

Chapter 4 :: Financial costs

4.2.1 AIHW health cost estimates

Estimates for direct health system costs are derived in Australia by the AIHW from an extensive process developed in collaboration with the National Centre for Health Program Evaluation for the Disease Costs and Impact Study (DCIS). The approach measures health services utilisation and expenditure (private and public) for specific diseases and disease groups in Australia. The DCIS methodology covers a range of direct health costs from hospital morbidity data, case mix data, the National Health Survey and other sources. AIHW (2012b) provides a summary of the main results of estimates of health expenditures by disease and injury for the year 2008-09. The advantage of a top-down methodology is that cost estimates across diseases will be consistent, enhancing comparisons and ensuring that the sum of the parts does not exceed the whole (total health expenditure in Australia).

The AIHW data used here, by special request, include hospital expenditures, out-of-hospital expenditure (including GP services, imaging, pathology, psychologists and medical specialists), and prescription pharmaceutical costs in 2008-09. The proportions of health costs borne by each party are based on 2008-09 AIHW data on payers for health system costs. These data were inflated to current 2012 prices by using health inflation indices (AIHW, 2012b).

The AIHW supplied costs by category (hospital admissions, outpatient medical services and prescription pharmaceuticals), disorder (AN, BN and other eating disorders) and ten year age-gender groups for the year 2008-09. Total expenditure came to \$80.4 million, with the majority (\$57.8 million) being accounted for by admitted services for AN.¹³ The AIHW made no estimate for pharmaceutical costs in other eating disorders. As admitted patient services account for over 90% of the total, Deloitte Access Economics has assumed the share of "other disorders" in total pharmaceutical expenditure is the same as its share of admitted patient expenditure, i.e. \$200,000, increasing the total to \$80.6 million.

To derive per person expenditure figures, total expenditure by disorder in 2008-09 is divided by total estimated prevalence in 2009. This yields a per person total in 2008-09 dollars (Table 4.3).

- The cost per capita for AN appears similar to that for other disorders. For example, Access Economics (2009) estimated that the average health system cost for young people (aged 15 to 25 years) with a mental illness was \$1,417.
- The costs for BN may be lower because treatment is more outpatient based – or because consumers often avoid seeking treatment.
- Figures for other eating disorders appear very low.

Table 4.3: Total health system expenditure, by category and disorder, 2008-09 (\$m)

Total	Hospital admitted patient services	Out-of-hospital medical expenses	Prescription pharmaceuticals	Total	Prevalence 2009	Cost per capita
Anorexia nervosa	57.8	1.5	0.5	59.8	24,506	\$2,440
Bulimia nervosa	5.8	1.0	0.8	7.6	103,099	\$74
Other eating disorders	12.6	0.4	0.2	13.0	740,557	\$18
All EDs	76.1	3.0	1.3	80.6	868,162	\$93

Notes. Hospital admitted patient services does not include non-admitted patient services. Out of hospital medical services includes GPs, specialists, imaging and pathology. It does not include allied health.
Source: AIHW (special data request).

¹³ Anorexia accounted for 53% of ED admissions in 2007-08.

¹⁴ Cost per capita is in current dollars, adjusted for health inflation since 2009.

This may be due to under-reporting – for example, the AIHW does not report any expenditure on pharmaceuticals in this category, which is implausible. However, as noted in the survey, the vast majority of people with EDs had comorbidities, most commonly anxiety and depression (Chart B.8). It is possible that pharmaceutical expenditure for people with other eating disorders is attributed to their other conditions.

Dividing AIHW 2008-09 health costs by our estimated prevalence for 2009 yields an average person cost of \$93¹⁴. This is far smaller than the median out of pocket cost for treatment, medication and hospital items (i.e. excluding travel) recorded by survey recipients, of \$2,625 (from Table 4.2). However, given that 55% of survey respondents had AN, the estimated national cost per person with AN (\$2,440) tallies closely.

- However, even then, once allowance is made for the fact that survey results are out of pocket costs, reported survey results are still far higher than AIHW results (Table 4.3).

The following sections provide further information on particular AIHW health cost elements.

4.2.2 Inpatient costs

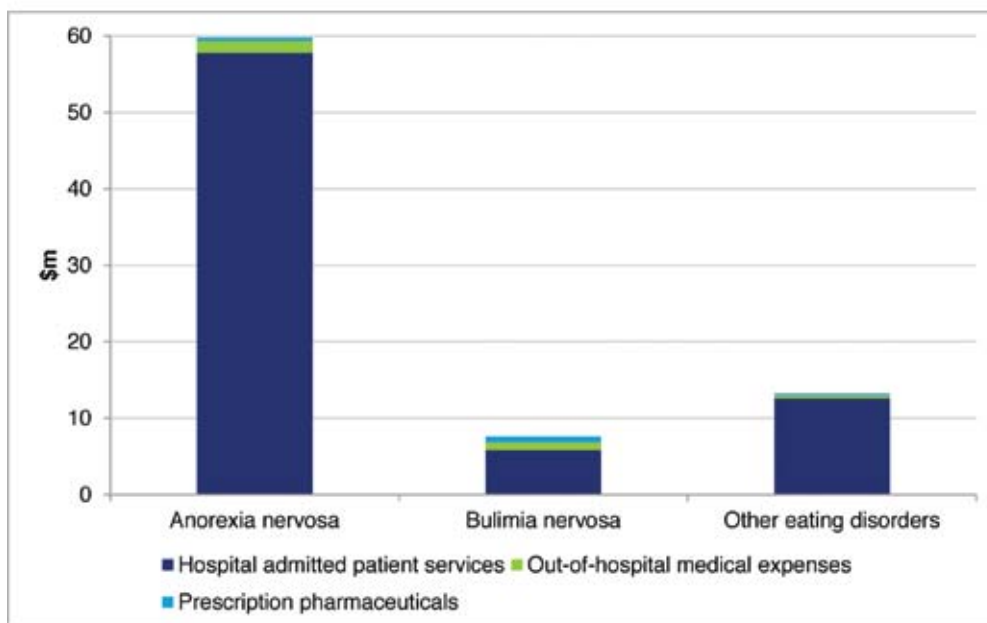
A minority of individuals with an eating disorder are hospitalised. Such patients are acutely unwell and require 24 hour medical stabilisation which may involve re-feeding and weight restoration. Hospitalisation can occur at a public hospital or private clinic. Admitted patients represent the great majority of costs for each disorder.

It is likely these costs underestimate inpatient expenditure as only cases for which the primary diagnosis was an ICD code listed in Table 4.4 are considered. Some patients may be admitted under other codes such as dehydration and kidney failure.

The estimated per person hospital inpatient cost for eating disorders overall is \$13, 123. Hospital inpatient costs for AN are more than twice as high as for either bulimia or other eating disorders.

The estimated cost for AN separations (\$18,785 in 2007-08) compares well with case-mix data. The average public patient admitted for the “eating disorders / obsessive compulsive disorders”¹⁶ cost \$21,565 in 2009-10. While these are costs for a combined group,

Chart 4.1: Total health system expenditure, by category and disorder, 2008-09



Chapter 4 :: Financial costs

eating disorders accounted for 88% of the combined admissions in 2009-10.¹⁷

- 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.
- Only around 10% of recorded admissions in this category are in private hospitals, but the average length of stay there is longer, 23.25 days, and costs were lower, at \$17,333¹⁸.

4.2.3 Out of hospital medical services

Treatment for eating disorders is most frequently conducted in an outpatient setting by one or more specialists including a psychologist, psychiatrist, dietitian or social worker.

AIHW costs in this category only include GPs, specialists, imaging and pathology. They do not include allied health, such as dietitians or physiotherapists.

Unlike hospital costs, where the denominator is

Table 4.4: Estimated inpatient expenditure overall, 2008-09 (\$m)

Age group	Females	Males	Total spend
0-4	-	-	-
5-14	12.3	1.9	14.2
15-24	43.1	2.1	45.2
25-34	7.7	0.4	8.1
35-44	4.5	0.3	4.8
45-54	2.7	-	2.7
55-64	0.5	0.1	0.6
65-74	0.1	0.1	0.2
75-84	0.2	-	0.2
85+	0.1	-	0.1
All	71.3	4.8	76.1

Source: AIHW.

Table 4.5: Estimated costs per separation, by disorder, 2007-08

Per Person	Hospital admitted patient services (\$m)	Separations	Average cost
Anorexia nervosa	\$57.8	3,077	\$18,785
Bulimia nervosa	\$5.8	944	\$6,144
Other eating disorders	\$12.6	1,778	\$7,087
All eating disorders	\$76.1	5,799	\$13,123

Note: This table compares 2007-08 prevalence to 2008-09 costs. This is because admissions under the ICD-10 code F50.9, which contains nearly all the "other eating disorders" are not reported in 2008-09¹³. As a result, there are only 93 "other eating disorder" admissions, which would increase average admission costs for this category nearly twenty fold.

Source: Total costs, AIHW special data request, separations AIHW National Hospital Morbidity Database.

¹⁵ At time of drafting (November 2012), the AIHW has confirmed (pers comm) that the new series of online hospital data cubes are not currently displaying all ICD-10 codes correctly for 2008-09 and 2009-10.

¹⁷ AIWH National Hospital Morbidity Database 2009-10.

¹⁶ Australian Refined Diagnosis Related Group classification U66Z.

¹⁸ Private hospital data is 2008-09, latest available at time of writing. Estimated costs per person here are illustrative, as the percentage of people with eating disorders who are hospitalised is not known.

¹⁹ Bettering the Evaluation and Care of Health, <http://sydney.edu.au/medicine/fmrc/beach>. Minimum cost of accessing this data is \$24,000. If this data were publicly available, it would be possible to estimate number of people with ED visiting GPs and specialists, and thus average costs per patient.

²⁰ <http://sydney.edu.au/medicine/fmrc/icpc-2-plus/index.php> (ICPC-2 PLUS is also known as the BEACH coding system).

admitted patients, it is not straightforward to derive average unit costs for medical services. The number of AIHW medical services is based on patients treated for EDs in the general practitioners survey, BEACH¹⁹. Expenditures for Imaging and Pathology are also allocated to EDs on the basis of GP encounters, while expenditure for specialist services is allocated to disease on the basis of the referral pattern in BEACH.

The AIHW collects data pertaining to prescription

drugs, both subsidised and private. The expenditure on pharmaceuticals among individuals with an eating disorder is low compared to other cost categories with just \$0.6 million and \$0.9 million for AN and BN respectively spent in 2012.

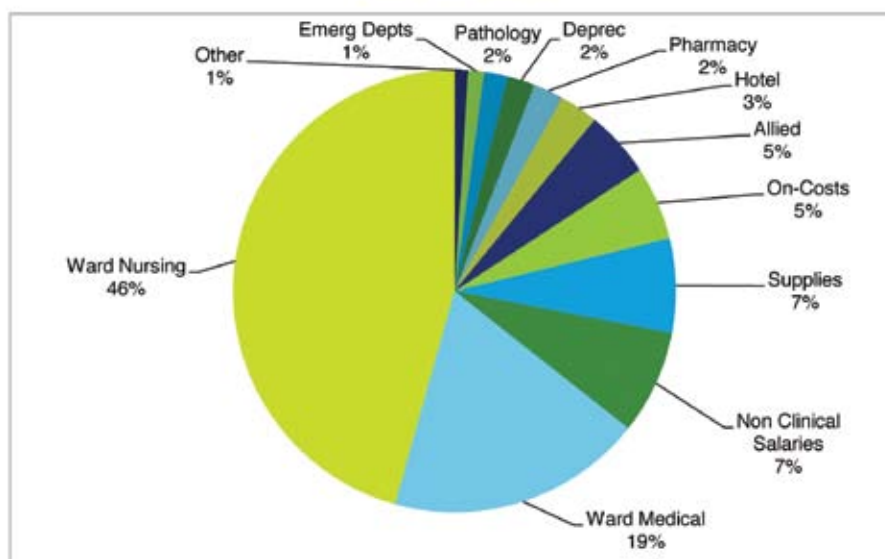
- AIHW data are based on the International Classification of Primary Care (ICPC) 2 PLUS²⁰. This system has a collective category for AN and bulimia (P86), but not specifically for BED or EDNOS.

Table 4.6: Average public hospital costs for "Eating and Obsessive-Compulsive Disorders", 2009-10 (\$)

	Direct	Overhead	Total
Ward Nursing	8,500	1,347	9,847
Ward Medical	3,208	823	4,031
Non Clinical Salaries	1,637		1,637
Supplies	498	989	1,487
On-Costs		1,161	1,161
Allied	879	170	1,049
Hotel	610		610
Pharmacy	410	67	477
Depreciation		427	427
Pathology	303	73	376
Emergency Departments	204	48	252
Imaging	75	12	87
Critical Care	61	15	76
Operating Rooms	32	7	39
Special Procedure Suites	5	1	6
Prostheses	3		3
Total	16,481	5,084	21,565

Source: Department of Health and Ageing.

Chart 4.2: Percentage breakdown of average public hospital costs for "Eating and Obsessive-Compulsive Disorders", 2009-10



Source: Department of Health and Ageing.

Chapter 4 :: Financial costs

- However, given “other disorders” are to a large extent sub-clinical manifestations of AN and BN, which require pharmaceuticals, it is apparent that there must be some expenditure on pharmaceuticals for “other disorders”. Accordingly, it is assumed that “other disorders” has the same share of total pharmaceutical expenditure as it has of out of hospital medical services (14%). This results in an estimated pharmaceutical expenditure for “other disorders” of \$208,000 in 2008-09, and increases total estimated expenditure by 0.25%, from \$80.4 million to \$80.6 million.

4.2.4 Estimated total health system expenditure on EDs in 2012

The per-capita health expenditure figures in Table 4.3 were updated using AIHW health cost inflation data (AIHW 2012b) into 2012 dollars, and then multiplied by the number of people in each age and gender cohort to ascertain total expenditure on EDs. However, the AIHW include only 87.5% of total recurrent health expenditure in their estimates of expenditure by disease and injury, referred to as ‘allocated’ health expenditure. The ‘unallocated’ remainder (12.5%) includes capital expenditures, expenditure on community health (excluding mental health), public health programs

Table 4.7: ICPC2 PLUS Codes for eating disorders

Category	Code
Anorexia Nervosa	P86002
Bulimia Nervosa	P86003
Disorder; eating; behavioural	P86004
Problem; eating; behavioural	P86005

Table 4.8: Estimated total health expenditure on EDs, 2012 (\$m)

Age	Males	Females	Total
0-4	0.0	0.0	0.0
5-9	0.0	0.0	0.0
10-14	2.5	16.0	18.5
15-19	1.1	23.3	24.4
20-24	1.6	32.7	34.3
25-29	0.3	6.3	6.6
30-34	0.3	4.3	4.6
35-39	0.2	3.0	3.2
40-44	0.2	2.9	3.1
45-49	0.0	1.8	1.8
50-54	0.0	1.7	1.7
55-59	0.1	0.4	0.5
60-64	0.0	0.3	0.3
65-69	0.1	0.1	0.2
70-74	0.1	0.0	0.1
75-79	0.0	0.2	0.2
80-84	0.0	0.1	0.1
85-89	0.0	0.1	0.2
90+	0.0	0.0	0.0
Total	6.5	93.4	99.9

(except cancer screening), health administration and health aids and appliances. Thus as a final step, allocated health expenditure is factored up by $(1/0.875)-1$ or 14.3% to obtain total mental health system expenditure per person. This results in a total expenditure of \$99.9 million, as broken down in Table 4.8

The AIHW (2012b) reports that total health expenditure paid by the Australian government is 42.7% of the total. State, territory and local governments contribute 26.4%, and individuals, family and friends 18.3%. "Other" sources (mainly private health insurance, compulsory third party motor vehicle insurance and workers compensation) fund the remaining 12.6%.

Health system costs of EDs in Australia are thus borne mainly by the Australian government (\$42.6 million) and state, territory and local governments (\$26.4 million). Individuals contribute \$10.4 million, while other and family/friends make up the remaining \$20.5 million (Table 4.9).

- The AIHW estimates that, of health costs not covered by governments, around 60% is borne by individuals and their families, and around 40% by other (including private health insurance). This fits reasonably well with evidence from the survey, which found that private health insurance covered less than half all non-hospital costs (see Appendix B, Chart B.6).

The AIHW's estimated health costs for EDs are small compared to other common diseases. For example, Access Economics (2010) estimated that the health system costs for obesity, anxiety and depression, smoking and alcohol abuse were each well over a billion dollars in 2010.

4.3 Productivity costs

Productivity losses are the cost of production that is lost when people with eating disorders are unable to work

because of their condition. They may work less than they otherwise would (either being employed less, being absent more often or being less productive while at work) or they may die prematurely.

Absenteeism costs are shared by the worker and the employer based on access to sick leave. Short term absenteeism was determined based on survey respondents who were employed in the paid workforce during the course of their disorder in the past year and who reported how many work days they were unable to work due to their condition (n= 60). Presenteeism costs are borne by the employer. Other productivity costs of ED are incurred by the worker (lost income) and the government (taxation revenue forgone). Key parameters around changes in employment participation and presenteeism were also determined through the survey, with 61 respondents providing estimates that could be used to calculate productivity impacts and 16 respondents on change in employment participation.

4.3.1 Employment participation

Eating disorders can affect a person's ability to work. A person's ability to find a job and do their job well can be inextricably linked to their self-esteem and can exacerbate comorbidities, such as depression or anxiety.

If employment rates are lower for people with eating disorders, this loss in productivity represents a real cost to the economy. The employment rate is calculated by dividing the total number of employed people by the number of people in each age-gender group. This calculation can be made for people with eating disorders and then compared with the employment rate for people without eating disorders in corresponding age-gender groups. The difference (or excess) between the two groups can then be attributed to eating disorders.

Table 4.9: ED expenditure by bearer, 2012 (\$m)

	Federal Government	State/Territory Governments	Individuals	Family	Other	Total
Expenditure \$m	\$42.6	\$26.4	\$10.4	\$7.9	\$12.6	\$99.9
Expenditure (%)	42.7%	26.4%	10.4%	7.9%	12.6%	100.0%

Source: AIHW special data request, DAE calculations.

Chapter 4 :: Financial costs

Data from the survey indicated that those who had an eating disorder had an 18.7% reduction in average employment earnings compared to what they were earning before the disorder. Data on average weekly earnings (AWE) and employment rates for each respective age gender group were combined to calculate the lost earnings due to reduced employment (Table 4.10).

- As EDs are fundamentally a mental disorder mostly affecting young people, by way of comparison, Access Economics (2009) calculated that youth mental illness reduced participation rates by 14.6%

This method yields a total loss of income of \$5.98 billion in 2012, equating to an estimated \$126 per week per person with ED, on average. This estimate also assumes that people with EDNOS and BED have similar

productivity impacts to those with AN and BN (the bulk of survey respondents). In this respect the NEDC (2010) note:

4.3.2 Absenteeism from paid and unpaid work

For people with eating disorders who are employed, the condition can adversely affect work performance through absence from work. Such absenteeism is measured by looking at the number of work days missed by people with eating disorders over a 12 month period.

According to the survey, those who have an eating disorder and are employed took 10 more days away from work per year due to their condition. The same number of days is estimated to be lost, for those who do not work, from their household productivity, which is valued at 30% of the average wage rate.

The diagnostic category of EDNOS is sometimes mistakenly assumed to describe individuals with milder or less serious forms of eating disorders. This is an incorrect assumption; individuals with EDNOS experience psychological and physiological morbidity and secondary impairment that is comparable to AN and BN.

Table 4.10: Average lost weekly earnings for persons with ED, 2012

Age	Males	Females
15-19	\$32.86	\$27.76
20-24	\$125.24	\$92.39
25-29	\$184.42	\$125.27
30-34	\$230.90	\$125.26
35-39	\$246.73	\$124.13
40-44	\$252.49	\$128.27
45-49	\$261.28	\$134.07
50-54	\$236.89	\$122.32
55-59	\$201.20	\$89.88
60-64	\$123.34	\$41.57
65-69	\$39.65	\$10.67
70-74	\$11.21	\$1.65

Source: ABS Employee Earnings and Benefits, Cat No 6310, DAE calculations.

The annual cost of lost earnings due to reduced employment participation from ED was estimated as \$5.98 billion in 2012.

Based on these parameters and the AWE for each age-gender group, in 2012, the total cost of absenteeism and lost home production due to eating disorders was estimated as \$1.8 billion.

This includes around \$1.45 billion due to absenteeism for people in paid work and around \$0.35 billion in lost household productivity for those in unpaid work.

- Mond and Hay (2007) reported that over a third (37.5%) of women with disordered eating behaviour had had it cause them to lose at least one day “out of role” (work or study) in the last four weeks.

Based on these parameters and the AWE for each age-gender group, in 2012, the total cost of absenteeism and lost home production due to eating disorders was estimated as \$1.8 billion. This includes around \$1.45 billion due to absenteeism for people in paid work and around \$0.35 billion in lost household productivity for those in unpaid work.

4.3.3 Presenteeism

Eating disorders can also affect a person’s ability to function effectively while at work, for the same reasons as it contributes to absenteeism and lower employment participation. Presenteeism can be estimated by multiplying the number of days worked with eating disorders by the percentage reduction in effectiveness on days worked with eating disorders.

Survey respondents were asked whether their eating disorder caused them to be less productive. The reported decrease in productivity was 20.4%. Using this reduction in productivity while at work and the AWE for each age-gender group, the lost work effectiveness was calculated.

In 2012, the total cost of ‘presenteeism’ (lower productivity while at work) due to ED is \$5.3 billion

4.3.4 Premature death

From the calculations in Section Table 2.13, there are an estimated 1,828 deaths due to ED in 2012 (515 males and 1,313 females). Based on the age-gender distribution of these deaths, and incorporating employment rates and estimates of average lifetime earnings for different age-gender groups, the present value of lost earnings due to mortality among those who would otherwise have been employed was estimated.

The estimated annual cost due to lost productivity from premature death due to ED is \$2.0 billion in 2012.

The predominant prevalence of ED for those in young age groups, where potential lifetime earning is significant, explains the cost contribution of this element. The peak rate of death is between 20 and 24 years of age, when expected lifetime earnings are over \$1 million for women and even higher for men, although they account for a smaller proportion of deaths.

Premature death also leads to additional search and hiring costs for replacement workers. These are

Table 4.11: Summary of productivity losses for people with eating disorders, 2012

	\$ million
Reduced workforce participation	5,977
Absenteeism	1,806
Presenteeism	5,309
Premature death	1,970
Search and hiring costs	1.4
Total	15,063

Chapter 4 :: Financial costs

estimated as the number of people with EDs (by age and gender) who die prematurely, multiplied by the chance of being employed (if they did not die), multiplied by the search and hiring cost brought forward three years. The search and hiring cost is estimated as 26 weeks at AWE and the three year bring forward reflects average staff turnover rates in Australia.

In 2012, additional search and hiring costs are estimated at \$1.37 million.

4.4 Carer costs

Carers are people who provide informal care to others in need of assistance or support. Most informal carers are family or friends of the person receiving care. Carers may take time off work to accompany people with ED to medical appointments, stay with them in hospital, or care for them at home. Carers may also take time off work to undertake many of the unpaid tasks that the person with eating disorder would do if they did not have an eating disorder and were able to do these tasks.

Informal care is distinguished from services provided by people employed in the health and community sectors (formal care) because the care is generally provided free of charge to the recipient and is not regulated by the government.

4.4.1 Carer productivity losses

While informal care is provided free of charge, it is not free in an economic sense, as time spent caring is time that cannot be directed to other activities such as paid work, unpaid work (such as housework or yard work) or leisure. As such, informal care is a use of economic resources. Carers may also experience health and quality of life impacts from caring, although in this study the measurement of carer costs is limited to their productivity losses.

There are three potential methodologies that can be used to place a dollar value on the informal care provided.

- Opportunity cost is the value of lost wages forgone by the carer.
- Replacement valuation is the cost of buying a similar amount of services from the formal care sector.
- Self-valuation is what carers themselves feel they should be paid.

Deloitte Access Economics has adopted the opportunity cost method in this report as it provides the most accurate estimate of carer costs and sufficient demographic data on providers of care for people with ED are available.

Informal care costs are the value of the care provided by informal friends or family carers. This report analyses data reported in the survey to gain estimates of the total number of hours of care provided to people with eating disorders, and the average unit cost of that care.

The survey indicated that carers spend 12.4 hours per week looking after people with an eating disorder.

In 2012, according to Centrelink data, there were 525 people who received Commonwealth payments to care for someone with AN or BN.

No data were available for carers of people with other eating disorders. Hence this estimate may be conservative. Based on 525 carers, who could otherwise work in paid employment at rates for 12.4 hours per week, the opportunity cost of lost wages in 2012 is estimated as \$8.54 million.

Table 4.12: ED Carer Allowance and Carer Payment outlays, 2012 (\$m)

	Carer Payment	Carer Allowance	Total
Anorexia	5.89	0.87	6.76
Bulimia	0.41	0.06	0.47
Total	6.30	0.93	7.23

Source: Department of Human Services – based on number of people receiving the payment on 9 March 2012.

4.4.2 Carer welfare costs

Centrelink provides support for people who care for someone with an eating disorder. There are two forms of this support, Carer Payment, and Carer Allowance.

- *Carer Payment* provides support for people who are unable to work in substantial paid employment due to providing full-time daily care to someone with a severe disability or medical condition, or to someone who is frail aged.²¹ Carers may be eligible for Carer Payment (caring for a person 16 years or over) if they provide constant daily care in the home of the person you care for and he or she:
 - Is aged 16 or more with a severe disability or medical condition or is frail aged, and receives an income-support payment from Centrelink or from the Department of Veterans' Affairs; or
 - Is a single child aged under 16 years with a severe disability or severe medical condition
- *Carer Allowance* is a supplementary payment for parents or carers who provide daily care to an adult or dependent child who has a disability or medical condition or is frail aged.²² Carers may receive Carer Allowance if they:
 - Are looking after a person aged 16 or more who has a disability or medical condition or is frail aged and needs additional care and attention on a daily basis and
 - Provide the care for that person in either their home or the caree's home

In 2012, Carer Payment was paid at a rate of \$712 per fortnight for singles, with \$114 per fortnight for Carer Allowance.²³

The Department of Human Services provided data on the combined outlays for those caring for people with

EDs totalling \$7.23 million in 2012, of which almost 90% was for AN.

4.5 Other financial costs

4.5.1 Out of pocket costs

Aids and modifications consist of out-of-pocket costs borne by the individual, and are taken to include aids, equipment and home modifications, alternative and herbal medications, transport and accommodation costs, and miscellaneous out-of-pocket costs not included in other cost categories.

The median travel and accommodation cost reported in the survey was \$750 per year. The median binge eating respondent estimated that this increased the household grocery bill by \$750 a year. Assuming this is applicable to people with BN and BED, this leads to an estimated "bingeing bill" of \$585.2 million dollars a year. This is included in the model.

The requirement of out of pocket costs associated with ED was estimated at \$585 million in 2012.

4.5.2 Funeral costs

The 'additional' cost of funerals borne by family and friends of people with eating disorders is based on the additional likelihood of premature death associated with eating disorders in the year 2012. However, some people (particularly older people) would have died in 2012 anyway; eventually everyone must die and thus incur funeral expenses. The Bureau of Transport and Road Economics (2000) calculated a weighted average cost of a funeral across all states and territories, to estimate an Australian total average cost of \$3,200 per person for 1996, or \$4,819 per person who died in 2012.

The bring forward of funeral costs associated with premature death for people with ED was estimated at around \$9 million in 2012.

²¹ <http://www.humanservices.gov.au/customer/enablers/centrelink/carer-payment>

²² <http://www.humanservices.gov.au/customer/services/centrelink/carer-allowance>

²³ <http://www.humanservices.gov.au/customer/enablers/centrelink/carer-payment/payment-rates> and <http://www.humanservices.gov.au/customer/enablers/centrelink/carer-allowance/payment-rates>

Chapter 4 :: Financial costs

4.6 Deadweight losses

Public funding of health care costs and reductions in income tax revenues related to eating disorders means that the government must increase tax revenue to achieve a budget neutral position²⁴. Consequently, taxation rates including income and indirect taxation rates must be higher than they would have otherwise been.

Tax and subsidy revenue is not an economic cost but a transfer of payments from one individual to another. It has therefore not been included in this study. However, increasing tax revenue is not frictionless as tax reduces the efficiency with which the economy's resources are used. For example, an increase in income tax rates will increase the relative price of work compared to leisure and therefore create a disincentive to work. Alternatively an increase in sales tax increases the price of goods and services and results in a loss in sales. Consequently, there is an associated reduction in consumer and producer surplus, which is known as the deadweight loss (DWL), or excess burden, of tax.

The costs associated with deadweight loss will depend on the method used to raise additional taxation revenue. Studies that have evaluated the marginal welfare cost of raising additional tax revenue – the marginal cost of public funds (MCPF). There are limited studies available that estimate the marginal welfare cost of raising additional tax revenue in Australia. Following the Productivity Commission (2003), it was assumed the marginal cost of raising additional tax revenue is 28.75 cents per dollar. This cost includes 27.5 cents per dollar of taxation raised in lost efficiency plus 1.25 cents per dollar of tax revenue raised for Australian Taxation Office administration.

In order to calculate the deadweight loss associated with eating disorders, the MCPF is applied to:

- The government financed component of the health system costs of ED;
- Welfare costs of ED; and
- The lost income tax revenue from productivity losses (4.3).

4.6.1 Health system expenditure DWL

As noted in Section 4.2.4, health system expenditure borne by governments totalled an estimated \$69.0 million in 2012. At an MCPF of 28.75 cents, this would result in DWL of \$19.8 million.

4.6.2 Welfare payment DWL

Transfer payments represent a shift of resources from one economic entity to another. The act of taxation and redistribution creates distortions and inefficiencies in the economy, so transfers also involve real net costs to the economy.

For many diseases and disorders, the Department of Human Services can provide the numbers of people receiving unemployment benefits, sickness benefits and disability support pensions, as well as the number of people who are paid to care for someone with an eating disorder.

However, the only data that the Department could supply in relation to welfare payments for EDs were for carer support (Carer Payment and Carer Allowance). No data were available for people with EDs in relation to unemployment benefit, sickness benefit or disability support pension.

Carer support totalling \$7.23 million ((Section 4.4) would incur DWL of \$2.08 million.

4.6.3 Lost taxation revenue

Reduced earnings due to reduced workforce participation, absenteeism and premature death also have an effect on taxation revenue collected by the Government. As well as forgone income (personal) taxation, there will also be a fall in indirect (consumption) tax, as those with lower incomes spend less on the consumption of goods and services.

Personal income tax forgone is a product of the average personal income tax rate (21.8%) and the forgone income. With an eating disorder and lower income, there will be less consumption of goods and services, with the indirect taxation rate estimated as 11.1%. These average taxation rates are derived for 2012 from the Deloitte Access Economics macroeconomic model.

²⁴ This implicitly assumes funds have not been directed from some other area of the health care system.

In 2012, lost taxation revenue due to ED impacts on productivity are estimated at \$4.84 billion. The DWL incurred in raising this revenue from other sources would be \$1.39 billion (Table 4.13).

4.6.4 Total DWLs

In total, estimated DWLs from eating disorders were \$1.41 billion in 2012.

Table 4.13: Lost earnings and taxation due to ED, 2012

	\$ million
Potential earnings lost	14,721
<i>Average personal income tax rate*</i>	<i>21.80%</i>
Potential personal income tax lost	3,209
<i>Average indirect tax rate*</i>	<i>11.11%</i>
Average indirect tax lost	1,636
Total potential tax revenue lost	4,845
Deadweight loss from additional taxation	1,393

* Deloitte Access Economics macroeconomic model (2012).

Table 4.14: Dead Weight Losses from ED, 2012 (\$ billion)

Category	Total impact	DWL
Health system costs borne by Government	0.07	0.02
Welfare Payments	0.01	0.00
Lost Taxes	4.84	1.39
Total	4.92	1.41

4.7 Summary of financial costs

In total, the non-health related financial costs of eating disorders were estimated to be \$17.1 billion in 2012. Together with the health system expenditures, total financial costs were estimated as \$17.2 billion.

Productivity losses dominate the financial costs. By way of comparison, Access Economics (2010) estimated that the productivity costs of anxiety and depression were \$17.9 billion in 2010, and the productivity losses from smoking were \$12.4 billion.

Table 4.15: Summary of other financial costs of eating disorders, 2012

	\$ million
Productivity costs	15,063
<i>Reduced workforce participation</i>	<i>5,977</i>
<i>Absenteeism</i>	<i>1,806</i>
<i>Presenteeism</i>	<i>5,309</i>
Premature death	1,970
Search and hiring costs	1.4
Carer costs	8.54
Other indirect	585
Funeral costs	9
DWL	1,415
Total other financial costs	17,080

Chapter 5 :: Burden of disease costs

It has destroyed my sense of self, and robbed me of a past and my hopes for the future.





Chapter 5 :: Burden of disease costs

The Burden of Disease (BoD) is estimated as \$52.5bn in 2012, higher than the BoD cost for anxiety and depression.

The burden of disease methodology was developed as a comprehensive measure of mortality and disability from diseases, injuries and risk factors for populations around the world in 1990, projected to 2020 (Murray and Lopez, 1996). It uses a non-financial approach, where pain, suffering and premature mortality are measured in terms of Disability Adjusted Life Years (DALYs).

DALYs are a measurement unit that quantify the morbidity aspect as well as the premature death associated with various diseases and injuries (Murray and Acharya, 1997). Under the DALY framework the total burden of disease for an individual with a condition is the sum of the mortality and morbidity components associated with that condition and consists of two components; years lost due to disability (YLD) and years of life lost due to premature mortality (YLL). YLLs are estimated based on the age of death, the attributable fraction of mortality to the disease, and the corresponding YLLs in the Standard Life Expectancy Table (West Level 26) with no discount rate and no age weighting. Using this framework it is possible to compare the overall mortality and disability burden of different diseases in a given population.

$$DALY = YLL + YLD$$

For each case of a disease, the YLD is obtained by multiplying the average duration of the condition (to remission or death) by a measure of severity of the disease. Disability weights are used to estimate the severity and are designed to quantify the equivalent loss of healthy years of life due to living with the health condition or its sequelae (Mathers et al, 2000). The disability weights are based on the person trade-off method for measuring health state preferences (Murray and Acharya, 1997).

Disability weights are measured on a scale of zero to one, where a zero represents a year of perfect health and a one represents death. Health states that result from

specific diseases or injuries are given a weight between zero and one to reflect the quality of life that lost due to that particular condition. A disability weight of, for example, 0.395 for people who survive a heart attack, is interpreted as a 39.5% loss in the quality of life relative to perfect health in the period following the heart attack.

The disability weight for AN and BN is 0.28 (Begg et al 2003).

The years of healthy life lost due to disability (YLD) for eating disorders was estimated together with the years of life lost due to premature death (YLL). These values were summed to estimate the DALYs.

The burden of disease as measured in DALYs can be converted into a dollar figure using an estimate of the value of a statistical life year (VSLY). As the name suggests, the VSLY is an estimate of the value society places on an anonymous life year. The VSLY is derived by measuring consumers' willingness to pay to avoid risk, largely derived through wage-risk trade-off studies (e.g. higher compensation for working in more dangerous occupations such as underground coal mining) as well as willingness to pay for safety²⁵.

The Department of Finance and Deregulation (2008) requires Commonwealth agencies to use a VSLY of \$151,000 (2007 dollars). This inflates to \$172,955 in 2012 dollars, and is used for calculations in modelling in this report.

Eating disorders are estimated to have caused 303,865 DALYs in 2012. At a value of \$172,955 per DALY, this equates to a cost of \$52.5 billion in 2012.

Access Economics (2010) estimated that the burden of disease for anxiety and depression was \$41.2 billion, for obesity \$52.9 billion, and for smoking \$183.6 billion.

²⁵ For example, paying more to fly Qantas, which has had no fatalities, rather than Aeroflot, which has had 8,321 fatalities. <http://news.travel.aol.com/2010/05/20/worlds-most-deadly-airline/>

Table 5.1: DALYs caused by eating disorders, 2012

	Males	Females	Total
YLD	93,342	162,574	255,916
YLL	13,130	34,819	47,949
DALYS	106,472	197,393	303,865

I lost a number of years of my life to anorexia... I have also lost my best friend as a result of her eating disorder and her death.



Chapter 6 :: The personal experience



People just don't 'get it'!

**We wouldn't be treated the way we have
been if our daughter had cancer.**



Chapter 6 :: The personal experience

The economic and social costs on sufferers and their families are devastating.

Participants reported long struggles with EDs, often lengthened by initial misdiagnosis – a common lament was the lack of ED knowledge throughout the health profession. In many cases, treatment was able to manage physical (weight) issues, but not the underlying mental causes. Another common complaint was the difficulty accessing treatment once they had found an effective provider (see recommendation 6.2.2.1) – a number moved interstate or even overseas to do so, at enormous expense.

Paying for treatment was also difficult. Many participants complained about recent changes to Medicare which have almost halved its psychiatric support (see recommendation 6.2.2.3). Similarly, while participants were grateful for private health funds coverage of private hospital costs, they also complained that the funds did not cover much of their outpatient costs (see recommendation 6.2.2.2.)

The economic and social costs on sufferers and their families are devastating. Even in this fairly small sample groups, there were deaths (including suicide), marriage breakups and heart attacks from stress. Actual and potential careers were destroyed (productivity impacts are discussed in section 4.3). People also reported it was difficult to get help from Centrelink, either for sickness benefits or carer payments.

The comments strongly align with issues that were identified by the NEDC (2010) particularly the difficulty people experienced finding clinicians with the knowledge and skill to treat their ED.

- Failure to diagnose early in illness and to appropriately support people post treatment due to a lack of knowledge in primary care clinicians
- Lack of training and knowledge of secondary care staff
- Long duration of illness (more than 5 years) with a pattern of recurrence, sometimes after a number of years or recovery
- Patterns of physical and behavioural recovery that are not matched by psychological recovery (absence of ED thoughts) leaving the person vulnerable to relapse
- The 'wrong' treatment – a) unskilled b) non personalised and/or c) medical or psychological treatment provided as a standalone rather than an integrated treatment approach – can make the condition worse and extend the course of illness
- The financial and health costs of ED are lifelong even when the person recovers from the ED (e.g. bone scans, dental treatment)
- The impact on relationships – breakdown of marriages, sibling health and social isolation – were clear themes and not an easy impacts to quantify
- The value of long term post recovery support to prevent relapse; one comment directly addressed this issue "I still see a psychiatrist every 2-3 months even though I am recovered from anorexia".

The sections below provide examples of free field text comments from survey respondents.

Are there any comments you would like to make about your condition / diagnosis?

Respondents reported long struggles, with multiple recovery and relapse periods. Often EDs were not recognised alongside, or mistaken for, mental health comorbidities. Also, a number of respondents had multiple EDs over time.

Long duration

Diagnosed with anorexia in 2007 and hospitalised for three months. Relapsed in 2009 and 2011 but no further hospitalisation. Continue to struggle with ED-related symptoms, such as restrictive eating, purging and episodes of binge eating.

My daughter was diagnosed approx 12 years ago and took 7 years to recover. She relapsed 3 years later and currently has a serious anorexic condition requiring full time care for the past year and is now overseas in a Specialised Clinic in the United States and is recovering from this illness.

My daughter was diagnosed with anorexia 12 years ago. It took her 7 years to get to recovery. She was good for 3.5 years but relapsed a year ago.

Mental comorbidities

Diagnosed with complex PTSD at the same time.

Resulted from undiagnosed and untreated attention deficit disorder

Suffered with depression prior to developing anorexia, still going through both.

Other comorbidities

Participants reported the need frequent dental and bone treatment, and other expenses

- Dental treatment, iron infusions for anaemia.
- I considered myself recovered in 2008 but have spent about \$150 each time on bone scans at the

end of 2008, 2010 & will have to again (hopefully for the last time) at the end of this year.

- Tests such as bone density scans, heart monitoring etc.
- Clothes to fit my ever changing frame, make up to hide how sick I look, vitamins, gym, dentist bills.
- Injuries e.g. broken bones, unable to drive, taxis, falls, rehabilitation of broken bones etc.

Multiple eating disorders

Have had EDNOS which progressed to bulimia

I developed anorexia at age 11 and this evolved into bulimia during adolescence. I was not diagnosed until early 30s.

I have been both bulimic and anorexic in the past. I'm surprised there is scope to tick only one box here as I understand that it's quite common to change from anorexia to bulimia or back.

I was diagnosed with both anorexia and bulimia

I've been diagnosed with both anorexia and bulimia at different stages, but anorexia was most prominent - I fell into bulimia when I "recovered" from anorexia.

I was diagnosed with anorexia in 2003. However, I have also cared (not the primary carer) for a sister this year who was diagnosed with anorexia.

Misdiagnosis

In the early part of her disease GPs and specialists (including dieticians and psychologists) failed to recognise her eating disorder even though she was significantly underweight and with amenorrhoea

I was diagnosed with depression when I was 14 & hospitalised for a week during which time I lost 1kg (I had been losing weight prior to admission also). I was discharged & my parents were told to 'keep an eye on me'. I was again hospitalised a few months later after losing another 5kg. I regained enough weight to just keep me

Chapter 6 :: The personal experience

out of hospital until I finished school, moved away & lost the lot plus more & ended up back in hospital. I managed to talk myself out of there in a week. It was not until I moved back home my parents found/ hand picked their own support network that 'real' recovery started.

I was misdiagnosed for six years - told I had hypoglycaemia, and other illnesses. Had to wait 7 months for first appointment with the psychiatrist who would save my life.

In the early stages it was difficult to obtain treatment. Firstly, because the illness was not diagnosed by GPs and other health professionals and secondly and eating disorder psychiatrist books were full. Also no public services in Sutherland Shire that we could access.

Recovery status

Respondents reported that recovery is seldom complete.

- currently still restrict my intake but my BMI is not in the anorexic diagnostic criteria anymore.
- In recovery - I very rarely behave in a disordered way, however I do still experience thoughts.
- In recovery. Have had no behaviours for 6 months, but do not consider myself fully recovered yet due to still having eating disorder thoughts.
- Recovered according to physical stats, still undergoing maintenance treatment.
- Working on maintaining the ground I have gained and continue the process.
- As much as can be recovered. Still very dependent.
- Mostly recovered, still underweight but normalised eating
- They now live independently although regular contact is maintained. Returned home 12mths ago (for 6mths) to stabilise health.

In several instances, parents stopped being carers, not because the person with an ED recovered, but because they became too ill to stay at home.

- They are now in supported accommodation with a full treatment team as illness was too severe to continue caring at home.

- Patient has had to seek treatment overseas.
- She is currently overseas receiving treatment so am not currently caring for her, but would be if she were at home.
- She is now overseas in California.

Are there any comments you would care to make on how treatment has helped you – positives and/or negatives?

Many participants reported that treatment had addressed the physical consequences of their EDs, but not the underlying mental causes. The need for ED training in hospital staff was a common observation. Several participants had to move interstate for treatment. Several also sought treatment overseas, which they said was more effective than Australian treatment, but very expensive.

Effective treatment

Being referred to a psychologist has helped a lot in dealing with depression, and consequently my eating has becoming better. Have not purged in 6 months.

Group therapy - made very strong friendships

I was very fortunate because I was able to access great psychiatric care and able to afford hospital admission. The cost was more in lost wages and effective society contribution.

What I found helpful the most was community based services such as ISIS. I also got a lot of help recently from a dietician that had long experience with people with eating issues.

Mixed treatment results

Current treatment in specialist hospital is now slowly helping. Force feeding and behaviour modification through punishment in 1998 was extremely counterproductive and made condition worse. Tens of thousands of dollars has been spent seeing outpatient psychologists etc is ineffective as the food was not getting inside me by sitting in an office.

Holistic Health helped. Medical - not so much

My recovery took place over 25 years. Many difficult years.

Prescription drugs saved my life but confused my mind and my sense of identity. Lack of knowledge by doctors hampered recovery.

*Negatives - one size fits all treatment programmes.
Positives - being listened to and receiving a personalised treatment programme*

Not all of the treatment I had was completely effective at the time but the end result has been that because of the high standard and intensity of treatment I have had it was completely effective in that I am no longer suffering from anorexia or depression. Initially I was seeing a different psychiatrist to the one I ended up getting well under and was admitted to a private general psych ward which was completely ineffective and my eating disorder worse (lost weight, just as rigid with food, had unlimited leave to exercise excessively). Once I was able to access a specialist clinic with an eating disorder unit and began seeing the psychiatrist there I got much more specific and appropriate care for the needs that I had.

Saw a number of different therapists that were completely ineffective, if not making the problem worse. Wasn't until I was admitted to Butterfly Day Program in Melbourne that I began to recover.

While physical conditions have stabilised the underlying cause in my head which manifested as anorexia nervosa in this iteration is still being addressed

My sister was rehabilitated through [a regional hospital] using the Maudsley (family-oriented re-feeding) approach, which was highly successful at helping her return to a healthy weight. However, her psychological treatment appears to have been somewhat inadequate as she continues to struggle psychologically despite the regain in weight and we now feel she needs additional psychological support.

Out of 5 hospital admissions (commencing in 2000 - 2004) treatment was only successful in the last program which was significantly different from any other experience

When I finally got the right treatment it was highly effective; however the 5 years prior to this, treatment was either ineffective or made the condition worse.

Without privately accessed and purchased services I have no doubt she would not have survived.

Ineffective treatment

I never taught me how to eat normally, in ways it kept me existing rather than living, I got sicker in treatment than I ever was.

My psychiatric treatment was horrendous; punitive, traumatising and disempowering. Since then (as an adult) I have found my own forms of treatment, which have been very helpful. Primarily they have been Gestalt Therapy, Group Self-Help Therapy, Yoga, Complementary Therapies that promote Relaxation and Self-Care Strategies, Anti-Depressants and Social Work Academic Studies (gave me a framework and a sense of purpose)

Being in treatment meant she is surviving. But treatment appears to be experimental and she regularly needs to go back into inpatient hospital care or day program to gain some weight. Her treatment is very intensive but she has not been able to work full time since 2005, so it does not appear that current treatment is effecting a cure.

In SA there is very limited help. We took our daughter to Westmead Children's Hospital in Sydney to undergo treatment through their eating disorder program

Medical treatment in Australia is 3rd world as public hospitals in NSW don't have protocols for the treatment of eating disorder patients.

Not able to afford ongoing treatment

Need for ED training in health professionals

People just don't 'get it'! This includes so many in the medical profession. We wouldn't be treated the way we have been if our daughter had cancer! So many doctors want to blame us for her condition and suggested that we should not be a part of her recovery. They also want to focus on what caused the illness and get her to talk about it. Living with the illness day in day out we know that our daughter cannot reason when it comes to her eating disorder. There is no point in discussing it with her. The eating disorder (ED) will trick, deceive, lie and cheat to get what it wants. What she requires is food - her medicine. I don't see why doctors can not understand this. Weighing and revealing her weight to her is a disaster. Putting her with other ED patients in the same hospital bay/room was a disaster. The dietician letting her choose her own meals was a disaster. Probably the biggest thing though

Chapter 6 :: The personal experience

was discharging her because her BMI was fine! One hospital discharged her because she was medically stable - even though she had not eaten or drunk anything for 24 hours!!! When medical staff didn't judge our daughter and had some understanding of what was happening within her head - in other words had read and learnt about eating disorders - they were much better able to help her. Another huge gripe is that our daughter spent time in Hospital. Her psychologist is located right next door at the Uni. Due to bureaucracy the psychologist is not allowed to enter the hospital to work with patients. She is a world renowned specialist/researcher in this area and the doctors at the Hospital do not want to know about her or engage her services - and she is right next door!

Depends on how trained in eating disorders the hospital staff are

78

Whilst admitted to an adolescent psychiatric unit due to her eating disorder we were often told staff were not trained in this area, even though at the time of our daughter's admission 5 of the 8 patients in the unit had an eating disorder.

More education is needed for health professionals to understand how to deal with clients with eating disorders.

It took a long time to access appropriate treatment and I don't really think the health professionals had expertise in adult eating disorders... however I am recovered. I just think it took longer

The GP that I initially presented to at my university health service had no idea about eating disorders and referred me to a generalist psychiatrist who also wasn't appropriately supported or connected (with an ED unit) to treat EDs. I was lucky in that my psychologist and dietician and later my second psychiatrist and specialist unit were fantastic and had an advanced and in depth knowledge of treatment of EDs.

General Practitioners that don't know how to work positively with eating disorders are a dime a dozen, and many cause more problems than they resolve!

Hard to find psychologists that have some understanding of eating disorders, that also provided reimbursement under Medicare

No one knew what was going on

GPs are generally not effectively trained in how to treat this disorder.

In Adelaide there are NO FACILITIES for people under the age of 16. The only assistance is via a paediatric ward that doesn't understand eating disorders

Most medical people have little idea or understanding of eating disorders. We have had to search the country looking for support. We had to fly weekly to the Oak House in Melbourne until it closed down due to lack of funding. We have had to relocate to Sydney so that she could be an inpatient at Wesley Hospital. We have searched for our 'own team' to support us. We finally found a GP who knew nothing about eating disorders but was prepared to listen. Previous GPs had their own (out-dated) concept about them. We also finally found a psychologist who has had training from Tracey Wade! We also managed to secure the services of Tracey ourselves - it has been so tough and has taken 5 years to get to this point.

Cost is prohibitive and few professionals have the knowledge

Finding qualified psychiatrists for the treatment of patients suffering from eating disorders is a nightmare. There are very few skilled in this area of mental health and who have a solid understanding of this illness

Medical practitioners are not familiar with treatments and causes of eating disorders and treat only the physical symptoms, not the emotional or associated symptoms

Overseas treatment

\$300,000 dollars including local and overseas treatment

Over \$250,000 as she is overseas trying to recover from her illness. In addition I have needed to supplement all her other medical costs for doctors, psychologists etc amounting in excess of \$30,000

We paid approximately \$9,000 out of pocket for psychology/ \$1,500 for GP/pathology costs. She is currently being treated overseas. Costs are \$1,450 per day. We expect treatment and related costs (airfares, etc) will amount to at least \$200,000.

Have had to seek overseas treatment \$100,000

\$12,000 for travel to the USA

Treatment overseas \$300,000.

Positive results in the last 18 months have been achieved from overseas treatment.

Treatment overseas has helped. No success in Australia

Treatment in Australia has not been very effective. The treatment that our daughter is now getting in the US is far more effective and superior to anything available in Australia.

Are there any comments you would care to make about the difficulty (or ease) of accessing appropriate treatment?

Only one respondent mentioned a program that they thought was easy to access. "Canberra 2005/2006 had a government program that was fantastic". Everyone else reported getting access to appropriate treatment was difficult, and even then only available in large cities.

Being an adult male it was very difficult to be taken seriously. I had 3 GPs and a nutritionist all fail to diagnose the condition

Expensive and stop-and-start nature of treatment limits the amount of change possible (particularly cognitively - the things that drive the ED).

Getting access to the right treatment/practitioner/ assistance has been really hard

I live on the South Coast of NSW - not a great deal of support for eating disorder sufferers down here. I needed intensive treatment and had to travel to Sydney to get that treatment.

It was not easy to find good practitioners specialised in eating disorders.

Most treatment is hard to afford, especially counselling

Only one day program available for Melbourne, long waiting list

Parents had no idea what was available and thought what we were given was all there was. Later in my illness they realised there was other treatment available and that they would need to search around and find what suited me specifically.

Specialist care was refused until recently as I was told I would never get better. Seeing private practitioners did not help the condition. Even when finally accepted into hospital, the waiting list to get in is extensive.

The wait is too long to get into a psychiatrist ... and GP wasn't sure who to refer to... was a matter of who was available. Took GP a while to diagnose

There weren't any specialists or points of call on the Gold Coast that a single parent could afford to access for help. We went through CYMHS each time who were useless.

Due to rural location meant effective hospital treatment was 700kms away.

Finding the right thing at the right time was very difficult, once found, appointments were fine. One of the highest difficulty was having mother and the whole family labelled as "sick" and dysfunctional because we insisted on working for a good outcome instead of accepting the merry-go-round that was offered.

Given my sister primarily accessed her care through the public health system, I was surprised by how quickly her case was referred and she received an appointment to begin treatment. When she was referred to see a paediatrician, again access was relatively easy to obtain.

GP needed to refer quicker. Waiting time to first available appointment at eating Disorder clinic was 5 weeks. My daughter needed urgent admission via A&E prior to her first appointment date.

Living in a rural area there are no choices in treatment at all. Only other treatment clinics were in Melbourne and this meant splitting the family for an extended length of time and I still had other children to consider.

The only treatment was through a physician who does NOT specialise in eating disorders, BUT who was incredibly helpful and supportive.

There are not enough facilities for treatment as inpatients or outpatients for the number of people with eating disorders out there.

There is a great shortage of good professionals for treating EDs making access very difficult.

Waiting lists are very long!

Chapter 6 :: The personal experience

Other treatment pathways

Many people reported no treatment in the early years or a 'roller coaster' treatment patterns.

26 year long history. No treatment for the first ten years. Spent most of 1996-1998 in hospital. Refused treatment 1999-2006. Unable to access treatment until 2012 due to co morbidities e.g. self-harm, extreme anxiety, and very poor physical health. The medical wards said I was too mentally ill to treat and the psych wards said I was too physically ill to treat. A supportive work environment has assisted in getting me well enough to access care in 2012. Still undergoing hospital treatment.

I had no help for the first 20 years. In my 30s, was diagnosed and began recovery - by then also had chronic anxiety and depression - placed on many drugs. Decades of struggle. Many relapses. Slip, slide, climb, slip, slide. No quick fix. Finally got there at age 55.

High frequency majority of the time with intense treatment during relapses and severe illness but gradually becoming less frequent during the 12 months before recovery.

Intense in severe or relapse...slightly less intense but still weekly outside of crisis

They gave up after I had my first relapse

Up / down / up again in frequency of appointments with psychologist and/or psychiatrist since 2006

Was higher frequency in first year issues of alcohol abuse required treatment in last year ..so that was higher again but constant contact .. I still see psychiatrist every 2-3 months even though I am recovered from anorexia

This is an absolute roller coaster - up and down - you think you are getting there and then you have another drop.

Totally constant with intense treatment and hospitalisation with relapses

Is there anything else you would like to comment about regarding economic, emotional, social or other costs/impacts you have experienced from your eating condition?

The economic and social costs on sufferers and their

families are devastating. Just in this fairly small sample groups, there were deaths (including suicide), marriage breakups and heart attacks from stress. Actual and potential careers were destroyed. People also reported it was difficult to get help from Centrelink, either for sickness benefits or carer payments.

People with eating disorders

Study / career and financial impacts

I am now 5 years behind my peers in the area of study I've always wished to pursue as the eating disorder meant I could not commit to a full year of study

I lost a number of years of my life to anorexia- I am 4 years behind my university year level I started with and have lost a number of friends and social connections as a result. I have found it difficult to have intimate relationships with others and my family relationships suffered immensely. I also lost my best friend as a result of her eating disorder and her death and the grief I still experience haunts me on a daily basis. I am financially a long way behind my peers my age and as such will not have the money to move out of home/ buy a house/ have children etc till later in life than I would have ideally planned. Anorexia affected every aspect of my life and the costs are in no way limited to monetary however this was a substantial part of it, and I'm one of the lucky ones. I feel immensely fortunate to have been able to afford (parents paid) the out of pocket costs for my treatment in addition to having had life-long private health cover and the ability to access high quality private inpatient care. Without the inpatient intervention (on no less than 10 occasions) I wouldn't be alive today.

I was in a senior professional role working full time... I have only worked part time ever since.

Isolation. At my worst unable to study, work, have any form of life. Could barely walk a few metres, passing out all the time - absolutely no life - and unable to access care other than very expensive psychologists that didn't treat the immediate conditions.

It led to me missing around 1/3-1/2 of every high school year (7-12) due to hospitalisation and illness, it forced me to take a year off uni in the middle AND I spend most of my holiday periods in hospital. It has led to more times of unemployment than I would have had otherwise. My family had to sacrifice many luxuries in order to pay for

my treatment. I spend over half my weekly pay quite often for treatment. I also have a significant physical disability (in a wheelchair) and with the two put together I am under considerable financial strain and rely on my family for help even though I am an adult.

Loss of wages as unable to work. Less effective study and thus career choices effected. Loss of effective contribution to society.

Mother's weekly wages [were lost].

My limited earning capacity - as a result of having been so set back in my life choices due to being so ill for so long and at such a young age. I am intelligent but not very well qualified as my condition impacted my ability to make well thought out study/work/relationship choices and the effects of those years are still present in my life even though I am now fully recovered.

Social / self esteem impacts

My eating disorder has resulted in me struggling for 3 decades to build myself into a productive, capable, confident and regular member of society. I believe that is because I have had to put all the pieces of the puzzle together myself, as well as try to override stigma and misunderstanding about the condition (even in myself). Whilst I am grateful for the Public treatment I did receive and the psychological support I have received thru ATAPS etc, I do wish it could all have been easier, sooner, more gentle and more comprehensive.

It has destroyed my sense of self, and robbed me of a past and my hopes for the future.

Severe impacts on personal relationships, especially with my partner. Affects my world view and my self-esteem. I feel like the ED has closed off a lot of possibilities for me, even though I recognise that partly it's my choice not to pay for more ongoing treatment. I am not contributing to society as much as I could if I didn't have an ED. I may never reach my 'full potential' because of this thing in my life.

Severely affected work, education and social life.

Estrangement from family of origin, including loss of inheritance, and loss of marriage due to misunderstanding of eating disorder impact. Personal

cost cannot be calculated.

Socially I missed out on my high school years & the few after that. I shut myself off from everyone & everything. There was also a huge impact on my family & my younger sister & brother put up with much more than they should ever have had to.

Stigma - I still do not tell people about my eating disorder

Social, emotional, developmental and costs in every other possible area incurred.

Can't put a value on the loss of my marriage.

Carers

Social / family impact

My daughter died by suicide in 2011, aged 23.

Due to the family stress involved in dealing with this issue caused myself to have a serious heart attack in August of this year. My lifestyle going forward now has changed

I think the siblings' emotional health is probably more affected than the sick daughter in some ways (now she is well). The damage from the fear, uncertainty, suicidal behaviour, loss of parent time and energy and the impact of having the family unit analysed and being forced to join in therapy sessions has been huge for all family members, particularly for the youngest. This sibling now has a fear of seeking help, so she is really struggling and still has quite serious anxiety issues. This daughter left school before the end of year 11 due to severe anxiety which I attribute to the ED too. The eldest moved out of home at 18 which was certainly sooner than she would have and I feel she was unprepared for this move. She subsequently dropped out of uni and spent 5-6 years drifting between casual and often menial work, before finding her way again. I still suffer post traumatic stress from some of the horror of the experiences of the ED. I have spent a lot of money on my own therapy as well as feeling the need to speak out and put back into changing things (as part of my recovery) which has affected my ongoing work productivity. (The ill daughter is now completely well and is living a full and satisfying life, completing a masters this year in a career she is passionate about).

It is extremely disruptive to the whole family. It puts your

Chapter 6 :: The personal experience

life on hold. It stops the support group from achieving including study and business

Massive disruption to family unit. Son has developed drug problem and depression. Significant impact on the family due to the need for constant supervision by one or both parents

My wife has had to quit her job in order for her to relocate to Sydney (from Adelaide) to support our daughter while she is inpatient at Wesley Hospital, Ashfield. Most doctors we have come across, who want to blame parents, would say that they (we) are dysfunctional. What I would argue is that by the time doctors see these families, the eating disorder probably has made them dysfunctional. We are a normal, calm and quiet, well functioning family normally. This disorder though changes all of that really quickly. People with less patience than us would not survive and would give up. Families who are not able to stand up to doctors or afford the associated costs would really struggle and their children, quite simply, would die because of this illness. It is so tough, day in day out, every hour and sometimes every minute! Our normally calm, polite, compassionate, caring, delightful daughter becomes an absolute monster when ED takes over and is raging. Our family and friends cannot believe that our daughter could be like that. This presents a real problem: families, friends, colleagues just don't understand or get it. If medical people don't then why would they? What it does though is that it leads to extreme loneliness for the carers. The eating disorder takes away your life. Everything is based around meals in life and society. The eating disorder rules our lives - we cannot eat with others because we have to help our daughter eat - she cannot manage others. Our social and family life is basically non-existent. Our life stops until we get her better. It has sent us broke and we have had to borrow money to survive. Trying to get a carer's allowance was like trying to extract teeth from a chicken! We have been thrown so many hurdles: economic, emotional, social!

[They] struggle to access the help they need at a time when an intervention would probably be most effective. Instead, they are told they are not sick enough to be referred to appropriate care. I think that the emotional costs/impacts of this experience cannot be overstated.

This illness affects the whole family. When the sufferer was

in hospital I would visit as often as allowed and my time was always given to her first and foremost with taking her to her treatment sessions. This means that other children in the family take a back stage position. It is really difficult trying to give each child quality time. This puts enormous stress on the family as a unit and has caused our family unit to split apart.

Work / financial impact

Financial outlays over the past ten years have led to a reduced ability to save more to fund future retirement needs. My partner continued to work to 67 to help meet ongoing costs (especially of psychologist). Anorexia has also resulted in a measure of social isolation for our family - we are reluctant to entertain at home because food can become a serious emotional issue when our daughter is at home, which is most of the time.

I had to give up full-time work to care for my daughter. Obviously this has impact on our family economically. I was in a management role and these positions do not come up too often. Anorexia is a very isolating disorder for both the sufferer and the family. Our friends have remained very supportive via phone, email etc but we have not been able to see them too often.

I have had to put large parts of my life on hold to care for my daughter. I have not been able to take part in previous pastimes like art/painting for 12 years, and have not been able to work for 9 of these years. The emotional toll on our whole family has been huge. Our other 2 children (now adults - 31 and 35) have also suffered greatly having to live with the daily stresses of life with an ED sufferer. The illness consumes the whole family and has resulted in all of us needing counselling to cope with the stresses. My husband suffered a heart attack during one of her hospital admissions.

Our daughter is no longer the person we once knew, she enjoys very little quality of life and her studies, social and emotional life are greatly restricted by her illness. We have also suffered severe emotional and financial impacts with having to relinquish work to care for her and pay for medical and accommodation costs.

Socially isolating, financially draining, emotionally taxing and challenging. It also provides individuals with an opportunity to grow through resilience.

That there be some understanding as to the huge cost to the community because of lack of productivity of the patients themselves, emotional strain and heartache for all members of the nuclear and extended families.

There has been a particular social impact on my family - even after all these years. Our friends stopped visiting and still do not visit due to the length of time it has taken to partially recuperate and the stigma attached to the disorder, and other people do not understand.

Centrelink issues

There is very limited financial support available for those who suffer from eating disorders. Centrelink does not provide disability or illness support unless you either have a full time job to return to, or have had the illness for at least two years. This leaves a lot of people falling through the cracks.

Whilst caring for someone with an ED it is not possible to work or socialise as normal. Also very emotional and carers need to seek treatment and support for themselves which adds more cost. Centrelink are very black and white with payments, mental health is not black and white. The Government needs to make it easier for people caring for someone with a mental illness to access financial support and support services.

If there was one thing you would most want to see done to help reduce costs for people with eating disorders, what would it be?

Respondents particularly sought greater financial support (either from Medicare or private health funds) to be able to pay for outpatient treatment. They also sought more inpatient facilities, better training in ED for all health professionals, and noted the need for prevention (including through community education) and early intervention.

Medicare coverage

Cover 100% of treatment outside of hospital. Most healing is done at this stage, not within the hospital. I have met many people who due to financial circumstances were not able to either get or continue with quality care. Unfortunately, the public health system just doesn't have the resources.

Increase the amount of coverage given under Medicare

for those on a Mental Health Care Plan

Even for other mental disorders - Having a greater number of sessions with a psychologist per year rather than just 10.

Greater number of psychology visits that receive government funding. I think we have had 16 visits this year that attract some government support, my understanding is that next year this number will decrease to 10 visits. This year alone we have spent close to \$10,000 in psychology fees.

INCREASE the number of Medicare psychology sessions covered per year. This is a desperate need.

More psychology sessions covered, not reduced to 10 per year!!!!

Funded treatment programs with qualified teams

I think a specialty Eating Disorder Medicare item needs to be developed to enable patients to access outpatient psychologists/ dieticians etc at a significantly reduced cost (not limited to a ridiculously low number of sessions per year such as 10). People with serious EDs need weekly monitoring by often in excess of 2 health care professionals each week and little of this is currently claimed under Medicare unless the GP is the primary person and a psychiatrist the other. We also need much better public hospital care that can deliver programs of equal standard to the private system (proper group therapy sessions and structured treatment models) so that this type of care is not only available to those with enough money to have private health insurance (or for those who have recently taken it out and have to wait a waiting period for psychiatric/ pre-existing conditions)

There needs to be more ED treatment programs and this needs to include public and private. There is no excuse for the lack of accessibility to good quality treatment facilities for those without private health insurance. It is disgraceful in its current state.

More access to subsidised medical treatment [programs] - including psychiatric and psychological appointments

More funding for community based counselling services, especially for women's services. More training for GPs around eating issues. Cheaper and free counselling.

Chapter 6 :: The personal experience

Cheaper or free access to a dietitian without having to get a mental health care plan from a GP

More government funded therapy sessions (dietician was crucial in my recovery but I know it is different for everyone). Sessions need to be frequent to be effective. If they were more affordable I'm sure the future medical costs would be reduced.

Reduced costs of access to GPs (who have improved knowledge)

Everyone should have access to publicly funded support. We are lucky enough to be able to beg and borrow enough to support the care we received. It is NOT FAIR that many many people cannot access this type of care due to cost. There needs to be support for a full range of care because different things work for different people at different times. The support needs to be seamless so there is easy in, easy up, easy back etc.

Public specialised services in every state, that cater to the full experience of an ED...psychiatric, medical, psychological, emotional, nutritional, support for carers, education...like a Headspace for people with eating difficulties and body image concerns. The one stop shop, easily accessible and affordable for all. Would change everything in my opinion.

Day programs in all states of Australia. More beds for in-patient treatment. More accessible hospital treatment.

Private health funds

Health funds have a 12mth waiting period on mental illness. Unfortunately this cost my family a lot of money. If someone gets sick quickly then 12mths is too long to wait for access to treatment.

Understanding!! For everyone to consider it as a real illness. We even had medical professionals judge us. For health funds to cover treatment in clinics so it could be considered as an option. For treatment to be available to rural people not just in Melbourne.

More facilities / staff

Have appropriate and enough specialist facilities in each state. South Australia is abysmal with its facilities.

Education of the medical, educational and wider community of this most serious illness, that would lead to

Establishment of specialised eating disorder facilities for people of all ages in Adelaide. This facility could model the one at Westmead in Sydney

Access to more professional help (including psychological sessions, dental, dietician)

Adequately distributed treatment resources around Sydney - all are on the North Shore. Better education of general health practitioners and ancillary workers

Better access to psychology treatments and intensive outpatient programs.

Specialised help being more available

More hospital beds in public hospitals. Longer time period for mental health care plan to reduce specialists accounts. Less stigma and more understanding by medical profession.

Improve accessibility to ED professionals, either through lower treatment costs or encourage wider understanding of EDs for health professionals. It's very easy to be put off treatment when you see a health professional who is (through no fault of their own) inexperienced or unaware of EDs.

More beds available. Not everyone needs to be hospitalised, but there are people who do need to be hospitalised, and receiving that intensive treatment, who aren't. The issue is that eating disorders are already competitive as it is - why add fuel to the fire?

Provide a helpline which would enable people with eating disorders to obtain low cost immediate counselling and contact rather than endure long waiting periods for costly appointments and by which time their condition has exacerbated.

Prevention / early intervention

Earlier and more effective treatment.

Effective treatment at the initial diagnosis stage. Access to information.

I think it is essential for the government to start to support organisations that are trying to educate the public on eating disorders in the hope of preventing some of the devastation this illness causes. In the long run this will help to reduce the costs that individuals have to pay.

Eating disorders are such debilitating diseases and their ripple effect is felt so widely. I'm not sure what one thing I would like to see done to help reduce costs for people with eating disorders, but I think that more funds need to be spent around prevention and education, particularly in schools.

Early intervention. Not refusing care when one seeks it, reduced waiting lists, more community support to keep people well in the community, supportive living accommodation, independent skills living programs, community help with shopping, cooking, planning meals e.g. Day to day living programs, PHaMs programs specialising in eating disorders, more community group programs to reduce the isolation and take the burden off the carers.

Education. Preventative education. Education for health professionals. Education in Schools and for fitness professionals.

More early intervention with family-based treatment, more support in the home, more training for carers. The entire family is affected by an eating disorder and everyone in the family needs to be involved in recovery - the learning of coping skills is imperative.

Other

Financial support to ease the burden on the sufferer and their family. It would allow them to fully focus on recovery, without having to worry about the return to work until they were fully ready. I believe this would reduce the chances of further relapse.

I would like the federal government to properly fund mental health including those suffering from eating disorders and to provide proper medical care for its patients and assistance for their families.

Recognition by health authorities and governments that eating disorders are a serious condition requiring a holistic treatment framework such as exist for cancer, diabetes, heart disease etc

Treat the whole person, not just with drugs for physical symptoms, but the emotional impact and psychological effects of the symptoms as well.

It is important to note that unless more effective treatment becomes more accessible and affordable,

these people will lean on the health system, often for a lifetime. Whilst our daughter is only 23, she maintains her anorexia, manages it, survives, but the side effects may only increase and become apparent as she gets older."

Is there anything you would like to say about how helpful (or otherwise) having private health insurance was?

Participants were divided on private health insurance. Many said they could not have survived without it. Conversely, many said it was not helpful at all. A few noted that it was helpful for private hospitals, but not much else.

Useful

Crucial as it would be very expensive to see a psychiatrist otherwise and to cover hospital admissions.

My family and I would be bankrupt without it

Without Private health insurance there is no way I would have (my parents would have) been able to afford private treatment for me as my total private hospital inpatient and day program attendance totalled in excess of \$300,000 in the 3.5 years I was in and out of hospitals

She was with AHM, I organised this to include psychiatric care and it covered her 3 admissions at clinic (except for the first \$500 I recall); and her 1 admission to a private hospital. Private Health Cover (using the advice of iSelect was the best decision I ever made. It would have crippled us as her first admission lasted approximately 10 weeks.

BUPA (MBF) has been our family medical fund for more than 30 years now. My daughter also joined in her own right; has looked after her very well in subsidising her medical costs. All the shortfalls for the medical bills paid to doctors, medications, psychologists and nutritionists were paid my myself.

BUPA has paid all hospital costs in the past year excluding \$250 excess each year. My daughter spent 52 days in a private hospital in 2011 at an approx. cost of \$70,000. In 2012 she has had 101 days in a private hospital costing BUPA approximately \$150,000. In addition she has spent 33 days in a public hospital as a private patient costing BUPA \$14,058 for the gap. We are most grateful to BUPA!

Chapter 6 :: The personal experience

We would not have been able to afford necessary hospital treatment without private health insurance. Without admission to a private hospital treating eating disorders, our daughter would have died

We wouldn't survive without it. Essential for someone with an eating disorder - especially if they have times of hospitalisation.

Mixed

Really only helpful for private hospital admission. This probably saved her life as public hospital system was exhausted first

Only really applicable for hospitalisation. Other rebates were via Medicare NOT Private Health

The health fund really didn't cover many expenses outside of in-hospital treatment. When I was in hospital, all treatment was 100% covered, but when not in hospital, it was mainly Medicare that covered part of my expenses and the health fund covered very little.

Very grateful that psychologist cost mostly covered by Medicare as a concession card holder. Otherwise I would not be have been able to afford the treatment I'd been having. Private health insurance hasn't provided anything in this area. Only used for physio sessions.

I didn't have private health when I was unwell, I went through the public system and was incredibly traumatised by my experience of a public adolescent psychiatric ward in the 1980s. I now have private health 'just in case' and I feel reassured by that!

GP, counsellor, psychiatrist, dietician, hospitalisation and other specialist treatment were generally covered by Medicare or as part of the public health system

Not helpful

It is not nearly enough coverage for effective treatment. Health funds do not cover any expenses for overseas treatment.

To date we have seen the psychologist 44 times this year alone and our health fund covers us for 3 visits at \$75 per visit. Our psychologist charges \$220 per visit.

Health fund was useless.

My private health insurance (at the time) did not cover any of the key costs incurred to recover from my eating disorder ie psychologist costs. I had top level HBA cover at the time.

Not especially useful

Not very helpful when advised by private hospitals that are covered by the fund that I was "far too ill to come to hospital". Took me three years to be well enough to access hospital care, as the local public hospitals won't treat eating disorders and the private hospitals wouldn't take me.

Private health insurance wasn't helpful, Medicare covers most things related to what I use (psychology/GP/psychiatrists)

Private health wasn't relevant for the majority of assistance I have received from medical professionals for my eating disorder.

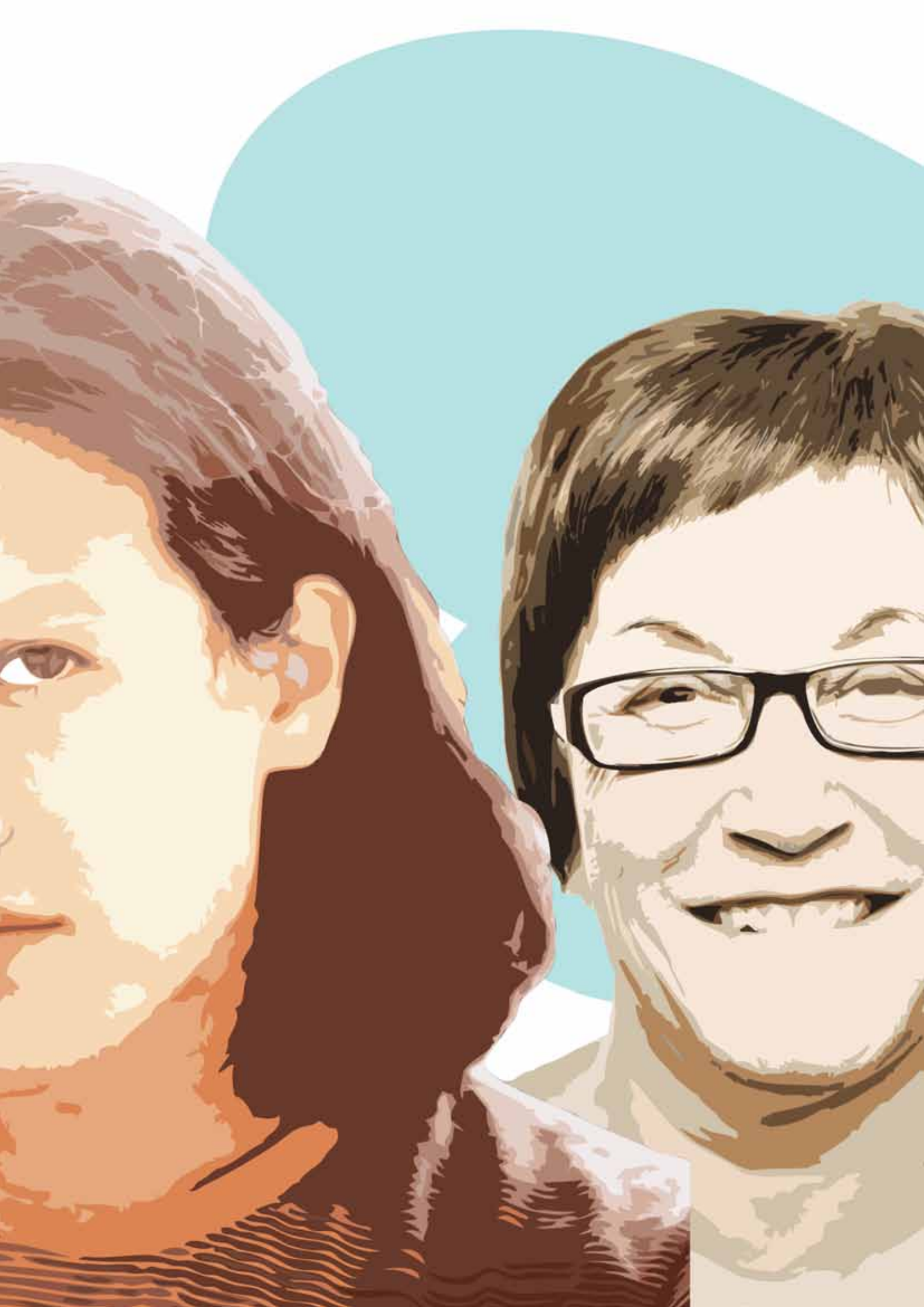
Emotional health of siblings has been more affected than the sick daughter in some ways...

I still suffer post traumatic stress from some of the horror of the experiences of the eating disorder and I have spent a lot of money on my own therapy.



Chapter 7 :: Conclusions





Chapter 7 :: Conclusions

The extent of impacts was found to be larger than expected, although our methods were conservative.

7.1 Findings

In 2012, there were an estimated 913,986 people with an eating disorder in Australia. This is lower than suggested by a single Australian epidemiological study, but substantially larger than a much older (mid-1990s) AIHW estimate based on foreign data and which only considered two eating disorders – AN and BN – and made no estimates of BN for males. Moreover, the Australian study (Hay et al, 2008) reported that the rate of disordered eating behaviour had doubled between 1995 and 2005 and, while total admissions for EDs have been falling, those for disorders other than AN and BN have been rising. Hence prevalence rates of EDs in Australia may be increasing, although we have conservatively assumed age-gender prevalence rates are constant in our projections.

Based on a recent meta-analysis (the gold standard of health research), mortality rates are almost twice as high for people with eating disorders than in the general population – and 5.86 times higher for people with AN (Arcelus et al, 2011). As such, in 2012 there were an estimated 1,863 deaths from eating disorders.

The total financial cost of EDs in Australia in 2012 was estimated as \$17.18 billion (Table 6.1). If the burden of disease is included – valued at \$52.6 billion – then the total socioeconomic impact of EDs is \$69.7 billion.

- The majority (\$9.97 billion, or 58%) of this cost is borne by individuals, mainly through lost earnings. If the value of healthy life lost (burden of disease) is included, then the total share of costs borne by individuals rises to 90%.
- The Australian Government is the second largest bearer of the financial costs of EDs, with \$4.89 billion (29%) of these costs. This is mostly from taxation revenue lost because of productivity impacts, rather than from funding health system expenditure and welfare payments.
- Lost productivity accounts for the 88% of financial costs (\$15.1 billion). If non-financial costs are included, the burden of disease accounts for 75% of total costs (\$57.5 billion).
- Deadweight losses (again mainly from lost taxation) are the second largest cost by type.

Official health system costs and welfare cost data are far from complete. Welfare cost estimates are missing the costs of providing unemployment benefits and disability support pensions, due to no data being available. AIHW health cost data do not include allied health costs and probably exclude some ED-related health costs (e.g. which might be classified as obesity-related instead). Thus, health system expenditure and carer costs are both conservative estimates.

While survey data was able to provide details of costs to individual carers, it was not able to indicate how many people care for someone with ED. Centrelink ED carer data appear to also be incomplete, only reporting carers for people with AN and BN, excluding those with BED or EDNOS. As family costs in the model are a function of the number of carers, this component too would also appear to be conservative.

Table 7.1: Total ED costs, by type and bearer, 2012 (\$m)

	Individuals	Family /Friends	Federal Government	State Government	Employers	Society /Other	Total
Health system costs	10.4	7.9	42.6	26.4	0.0	12.6	99.9
Productivity costs exc. carers	9,378.1	0.0	4,841.9	0.0	843.0	0.0	15,063.0
Carer costs	0.0	5.7	2.8	0.0	0.0	0.0	8.5
Other financial costs	585.2	8.8	0.0	0.0	0.0	0.0	594.0
DWL	0.0	0.0	0.0	0.0	0.0	1,414.8	1,414.8
Transfers	0.0	-7.2	7.2	0.0	0.0	0.0	0.0
Total financial	9,973.8	15.2	4,894.6	26.4	843.0	1,427.4	17,180.2
BoD	52,554.9	0.0	0.0	0.0	0.0	0.0	52,554.9
Total with BoD	62,528.7	15.2	4,894.6	26.4	843.0	1,427.4	69,735.2

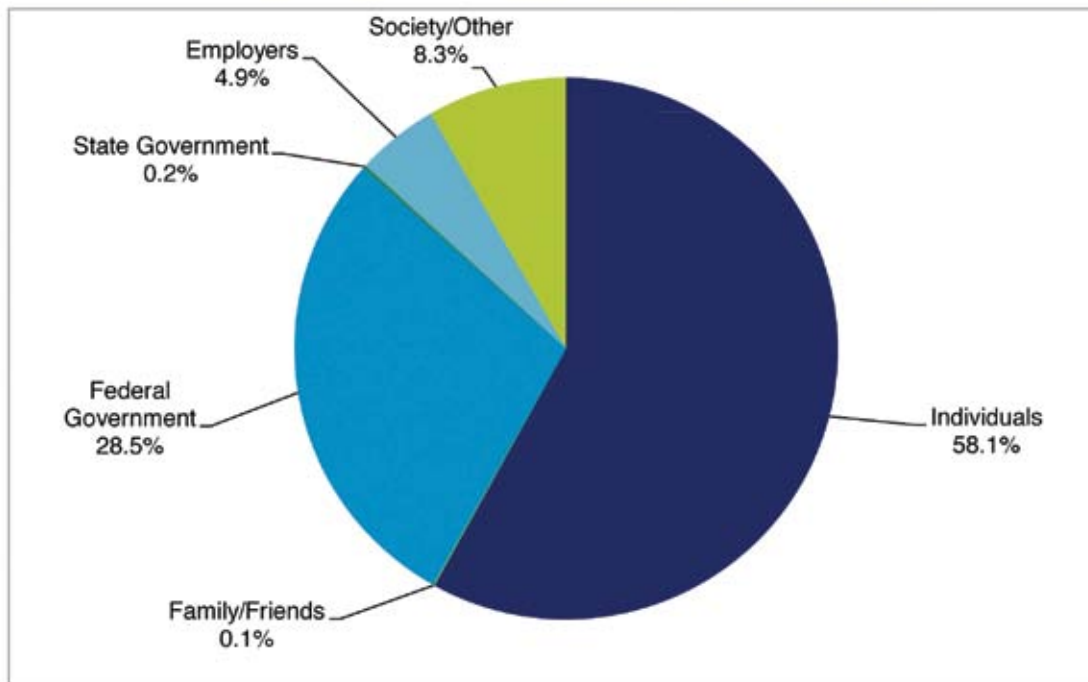
91

Table 7.2: ED costs per case, by type and bearer, 2012 (\$ per person)

	Individuals	Family /Friends	Federal Government	State Government	Employers	Society /Other	Total
Health system costs	11	9	47	29	0	14	109
Productivity costs exc. carers	10,261	0	5,298	0	922	0	16,481
Carer costs	0	6	3	0	0	0	9
Other financial costs	640	10	0	0	0	0	650
DWL	0	0	0	0	0	1,548	1,548
Transfers	0	-8	8	0	0	0	0
Total financial	10,912	17	5,355	29	922	1,562	18,797
BoD	57,501	0	0	0	0	0	57,501
Total with BoD	68,413	17	5,355	29	922	1,562	76,298

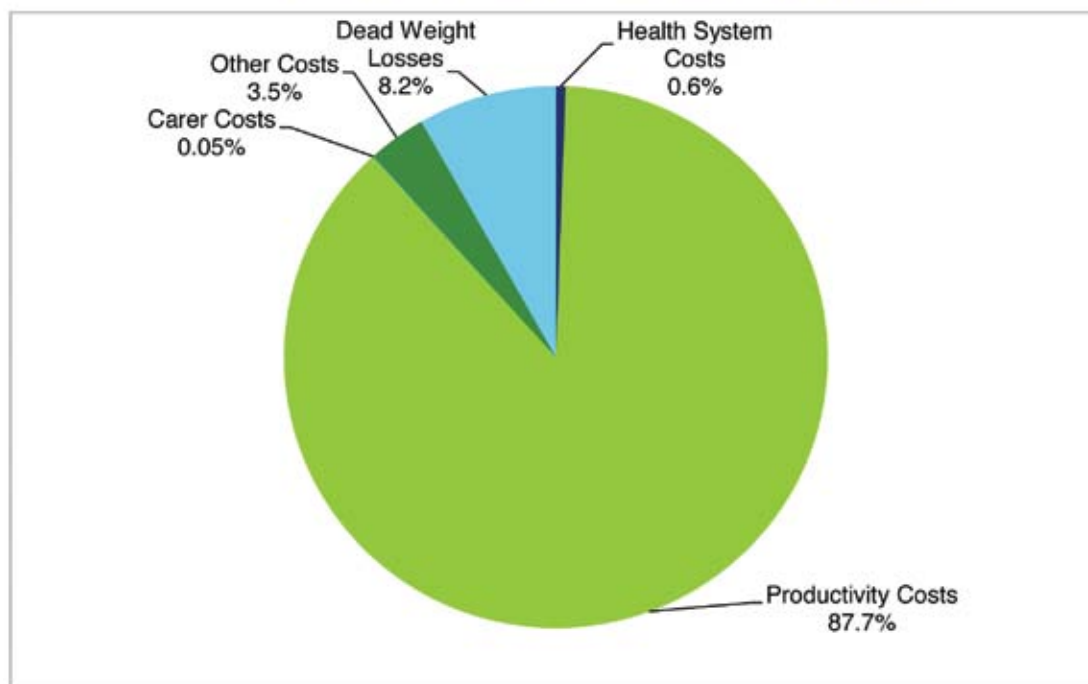
The financial cost per case of ED in 2012 was estimated as \$18,781; including the burden of disease increases this cost to \$76,282 per case.

Chart 7.1: Distribution of financial costs of ED, by bearer, 2012



92

Chart 7.2: Distribution of financial costs of ED, by type, 2012



²⁶ The 1997 Mental Health and Wellbeing survey asked a question about food as a specific focus for people with Obsessive-Compulsive Disorder. In personal communication with the ABS, the Bureau indicated that they were not aware of any other surveys that had included questions about eating disorders.

7.2 Recommendations

7.2.1 Data and monitoring

A pressing need in relation to eating disorders is collecting better information, particularly in relation to tracking prevalence, mortality and health system costs, and better defining less well known eating disorders. While AN and BN are well defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM IV), EDNOS is composed of disparate criteria. One of these – BED – is the most common single ED, and in early 2013 will be classified independently in the DSM 5. Almost half (44%) of people with BED are severely obese i.e. with BMI >35 (Spitzer et al, 1993), and it is probable that many of these people may currently have their treatment classified as “consequences of obesity” rather than BED.

7.2.1.1 Prevalence data

The ABS does not appear to have fielded any survey questions specifically about eating disorders.²⁶ Collecting prevalence data should be a relatively straightforward matter. Both the New Zealand Mental Health Survey, and the US National Comorbidity Survey use the World Health Organisation Composite International Diagnostic Interview to obtain population data about ED prevalence.

It is recommended that the ABS includes questions about eating disorders in its next national health or mental health survey. However, since self-reported data are not as reliable as epidemiological data, an Australian epidemiological study would be very valuable to better understand eating disorders and their impacts nationally. EDs should be recognised as a serious psychiatric disorder

7.2.1.2 Mortality data

The AIHW (Begg et al, 2007) estimated mortality rates that are substantially lower than the latest meta-analysis (Arcelus et al, 2011) would suggest. Applying AIHW mortality rates to current prevalence estimates implies fatalities some twenty times larger than official ABS estimates. However, using mortality rates from higher quality literature evidence (Arcelus et al, 2011) implies estimates ten times higher again. It thus appears that most deaths that result from eating disorders are

attributed to other conditions; most people have at least three causes of death (AIWH 2012). For example, Arcelus et al (2011) report that one in five AN deaths are suicides; but these may be just recorded as death suicide, without attribution to AN.

It is recommended that ED mortality data be re-assessed, which would also be assisted by funding a national epidemiological study.

7.2.1.3 Productivity and welfare expenditure data

EDs have a substantial impact on productivity: the lower workforce participation, absenteeism and presenteeism impacts are high while the person has the condition, and the condition lasts for a long time. For those who die prematurely, remaining lifetime earnings are lost. However, there are almost no data collected on employment impacts or welfare payments pertaining to EDs. The Department of Education, Employment and Workplace Relations does not collect data on how many people are on unemployment benefit or sickness benefit due to eating disorders, nor does Centrelink collect data on how many people are on disability support pension due to eating disorders.

It is recommended that such data be collected by Centrelink and the Department of Education, Employment and Workplace Relations.

7.2.1.4 Health system data

Dividing available costs for AN by either separations or prevalence, and BN by separations yields per capita health costs similar to other conditions. But this is not the case for people with BED or EDNOS, who appear to have either negligible health expenditure, or to be classified under other conditions (for example, consequences of malnutrition or obesity). This may be due in part to the fact that under the DSM IV, EDNOS includes half a dozen diverse conditions (see Table 1.1) that may not be documented by GPs when responding to BEACH surveys.

The ICPC 2 Plus is an Australian categorisation system used by the AIHW to measure non-hospital treatment by disease type. At present, it contains categories for AN and BN, but not for BED. Once the DSM 5 has been released, there may be merit in reviewing the inclusion of BED.

Chapter 7 :: Conclusions

It is recommended that once the DSM 5 is released in 2013, BED is included in the ICPC2 and the BEACH survey highlights the existence of BED as a separate disorder with the same 'status' as AN and BN.

7.2.2 Treatment recommendations

Relative to prevalence, there appears a lack of focus on treatment for eating disorders across acute and community care settings. The reports from survey participants on not being able to access appropriate treatment when needed are harrowing.

7.2.2.1 Accessing treatment / improving patient journeys

There appears to be a serious mismatch between the number of people who have eating disorders, and the number of providers who know how to treat it. Of survey respondents, 85% found it 'difficult to very difficult' to access treatment. Similarly, many respondents gave stories of finally getting some treatment, but then falling through the gaps in the health system and relapsing. These are distressing disorders for both the victims and their families requiring long-term support which is in critically short supply.

Deloitte Access Economics commends COAG's recent initiative to establish a network of Medicare Locals and give them responsibility for coordinating and improving patient journeys. Another chronic disease, diabetes, has been allocated as initial priority in this respect. Diabetes is often caused by obesity, which is often a consequence of Binge Eating Disorder, thus combating eating disorders would be a logical progression for Medicare Locals

It is recommended that improving patient journeys for people with ED should become a priority for Medicare Locals.

7.2.2.2 Private Health Insurance

The testimony of many survey respondents was that PHI is necessary but not sufficient. PHI covers the majority of hospital costs, but not the majority of any other costs.

It is recommended that health insurers examine options that may enable them to reimburse a greater proportion

of the out of pocket costs for people with eating disorders.

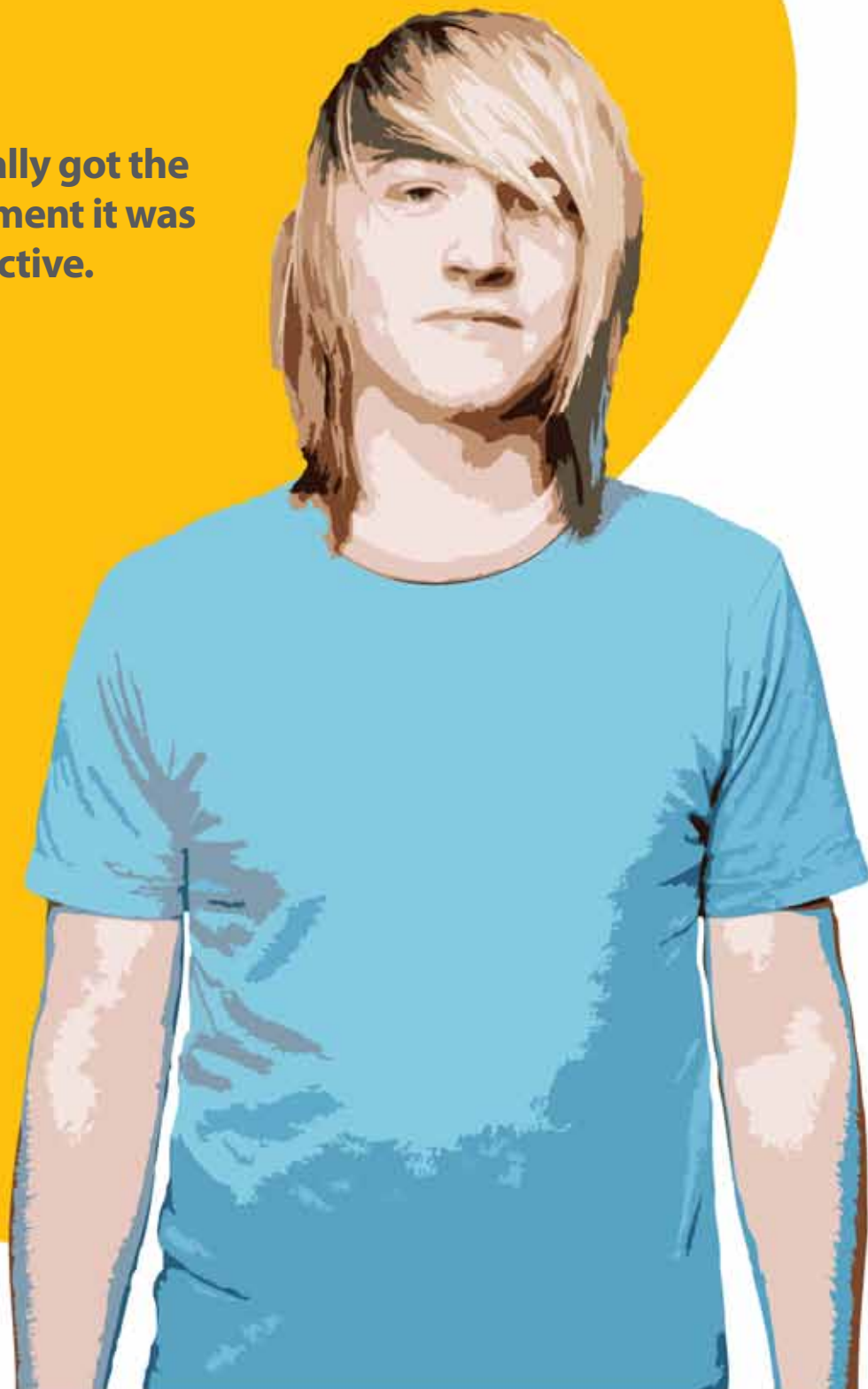
7.2.2.3 Medicare coverage

Counselling – often on a long term basis – is an integral component of ED treatment. However, a number of survey respondents complained about the Government capping psychology sessions at a maximum of ten per year. Prior to the 2011-12 Federal Budget, the Better Access to Mental Health Scheme allowed 18 treatments per annum, which was at least close to the minimum evidence-based quanta of 20 treatments (Australian and New Zealand Academy for Eating Disorders, 2011).

Given the high productivity costs of eating disorders – and thus lost taxation revenue – it is possible that increasing the visit cap may have little adverse impact on the net Commonwealth budget position, particularly since the cap may drive patients to seek additional treatment in the public hospital sector. Alternatively, if the cap is approached, referral into the PIR program may be appropriate for those where symptoms are severe and persistent.

It is recommended that the Government review Medicare psychology support for people with ED.

When I finally got the right treatment it was highly effective.



:: Charts

Chart 2.1 : Hospital admissions for eating disorders, Australia, 1998-99 to 2007-08	22
Chart 2.2 : Estimated Australian ED one-year prevalence, by disease and gender, 2012	23
Chart 2.3 : Male AN prevalence and separations (2003)	24
Chart 2.4 : Female AN prevalence and separations (2003)	24
Chart 2.5 : Estimated age-gender prevalence of AN in Australia	25
Chart 2.6 : Female BN prevalence and separations (2003)	26
Chart 2.7 : Distribution of male BN separations, female BN prevalence and male AN prevalence (2003)	26
Chart 2.8 : Estimated age-gender prevalence of BN in Australia	27
Chart 2.9 : Prevalence of binge eating behaviour, Australia, 2005	28
Chart 2.10 : Reported prevalence of BED in the United States in 2003	29
Chart 2.11 : Prevalence of disordered eating behaviour in Germany in 2009	29
Chart 2.12 : Estimated age-gender prevalence of BED in Australia	29
Chart 2.13 : Estimated age-gender prevalence of EDNOS in Australia	30
Chart 2.14 : Estimated age-gender prevalence of total eating disorders in Australia	33
Chart 2.15 : Estimated prevalent ED cases in Australian females, 2012	34
Chart 2.16 : Estimated prevalent ED cases in Australian males, 2012	35
Chart 2.17 : Estimated prevalence of eating disorders in females, by type	35
Chart 2.18 : Estimated prevalence of eating disorders in males, by type	36
Chart 2.19 : ED prevalent cases in males, by disorder, 2012 to 2032	36
Chart 2.20 : ED prevalent cases in females, by disorder, 2012 to 2032	37
Chart 2.21 : Estimated deaths to eating disorders, Australia, 2012	40
Chart 3.1 : Allison's cumulative health expenditure	49
Chart 4.1 : Total health system expenditure, by category and disorder, 2008-09	57
Chart 4.2 : Percentage breakdown of average public hospital costs for "Eating and Obsessive-Compulsive Disorders", 2009-10	59
Chart 7.1: Distribution of financial costs of ED, by bearer, 2012	92
Chart 7.2: Distribution of financial costs of ED, by type, 2012	92
Chart B.1 : Usual residence of respondent	122
Chart B.2 : Distribution of eating disorders among survey respondents	122
Chart B.3 : Average duration of eating disorders in respondents	123
Chart B.4 : Proportion of respondents attending consultations	123
Chart B.5 : Distribution of total median out-of-pocket costs	124
Chart B.6 : Average proportion of cost reimbursed by members' health fund	125
Chart B.7 : Distribution of comorbidities in respondents	126
Chart B.8 : Distribution of other conditions in participants with comorbidities	126
Chart B.9 : Reported difficulty in access treatment for ED	127
Chart B.10 : Distribution of treatment patterns among respondents	127
Chart B.11 : Efficacy of different treatment regimes	128

:: Tables

Note: Number in tables have be rounded

Table i : Estimated prevalence of eating disorders, 2012	9
Table ii : Total ED costs, by type and bearer, 2012 (\$m)	10
Table 1.1 : Eating disorders definitions (DSM IV)	14
Table 2.1 : NEDC estimates of the lifetime prevalence of eating disorders in Australia	21
Table 2.2 : Sources of ED point prevalence estimates	22
Table 2.3 : Average ED point prevalence estimates, by disease and gender	22
Table 2.4 : Disease prevalence rates from HOS, 2005	23
Table 2.5 : Estimated age-gender prevalence of AN in Australia	25
Table 2.6 : Estimated age-gender prevalence of BN in Australia	27
Table 2.7 : Estimated age-gender prevalence of BED in Australia	30
Table 2.8 : Estimated age-gender prevalence of EDNOS in Australia	31
Table 2.9 : Estimated ED prevalence by age and disease in males	32
Table 2.10 : Estimated ED prevalence by age and disease in females	32
Table 2.11 : Estimated prevalent ED cases in Australian females, 2012	33
Table 2.12 : Estimated prevalent ED cases in Australian males, 2012	34
Table 2.13 : ED prevalent cases in total population, by disorder and gender, 2012 to 2032	38
Table 2.14 : Estimated deaths to eating disorders, Australia, 2012	39
Table 4.1 : Costs associated with ED	54
Table 4.2 : Median out-of-pocket costs	55
Table 4.3 : Total health system expenditure, by category and disorder, 2008-09 (\$m)	56
Table 4.4 : Estimated inpatient expenditure overall, 2008-09 (\$m)	58
Table 4.5 : Estimated costs per separation, by disorder, 2007-08	58
Table 4.6 : Average public hospital costs for “Eating and Obsessive-Compulsive Disorders”, 2009-10 (\$)	59
Table 4.7 : ICPC2 PLUS Codes for eating disorders	60
Table 4.8 : Estimated total health expenditure on EDs, 2012 (\$m)	60
Table 4.9 : ED expenditure by bearer, 2012 (\$m)	61
Table 4.10 : Average lost weekly earnings for persons with ED, 2012	62
Table 4.11 : Summary of productivity losses for people with eating disorders, 2012	63
Table 4.12 : ED Carer Allowance and Carer Payment outlays, 2012 (\$m)	64
Table 4.13 : Lost earnings and taxation due to ED, 2012	67
Table 4.14 : Dead Weight Losses from ED, 2012 (\$ billion)	67
Table 4.15 : Summary of other financial costs of eating disorders, 2012	67
Table 5.1 : DALYs caused by eating disorders, 2012	71
Table 7.1: Total ED costs, by type and bearer, 2012 (\$m)	91
Table 7.2: ED costs per case, by type and bearer, 2012 (\$ per person)	91
Table B.1 : Summary of median out-of-pocket costs	125

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:: Notes

Appendix A :: Survey form

Cost of Eating Disorders in Australia

Introduction

WHAT IS THIS ABOUT: Deloitte Access Economics has been commissioned by the Butterfly Foundation to estimate the economic costs of Anorexia, Bulimia, Binge Eating Disorder and other eating disorders. As there is very little published data, we are asking people who have an eating disorder to tell us what financial impacts they have incurred. We are also seeking to find out about the costs imposed on parents, partners and others who care for someone with an eating disorder.

If you consider you have an eating disorder, and would like to tell us about your experiences, we would like to hear your story. All questions in the survey are entirely voluntary; you can answer as many or as few as you choose.

HOW YOU CAN HELP. We invite you to participate if you :

- Have an eating disorder;
- Have had an eating disorder in the last ten years;
- Care for someone with an eating disorder; or
- Have cared for someone with an eating disorder in the last five years.

We would appreciate your response to this survey by **14 Nov 2012**.

ABOUT THE SURVEY: This survey is organised in five sections after this page which we anticipate to take approximately 15 to 20 minutes to complete:

- Brief information about you;
- Brief information about your eating condition;
- Impact on your ability (&/or your carer's) to work / study;
- Treatment costs; and
- Any other matters you think are important.

YOUR PRIVACY: Deloitte Access Economics will treat all information gathered in the strictest confidence. We will only report aggregated summaries to the Butterfly Foundation, and not any data that could identify individuals. The overall results of the survey will be used as an input into a report for the Butterfly Foundation on the economic costs of eating disorders. If you chose participate, we will take it that you consent to your responses being included in this summary.

If you have any questions about this survey, or would like a copy of the results, please contact Deloitte Access Economics by email: scmitchell@deloitte.com.au

Cost of Eating Disorders in Australia

About you

This section asks some basic demographic questions, such as your age, gender and where you live.

1. How old are you?

(if you are under 18 please request that a parent or guardian fills out the survey for you)

Your age:

2. Gender

Male

Female

3. Where do you live?

What is the postcode of your usual residence?

4. Are you from a non-English speaking background?

Yes

No

Prefer not to answer

5. Are you an Aboriginal or Torres Strait Islander?

Yes

No

Prefer not to answer

6. What is your approximate annual income?

Annual income (please click on drop down arrow at right of answer box)

Cost of Eating Disorders in Australia

7. What is your occupation? (please tick all that apply)

- Student
- Full time paid worker
- Part time paid worker
- Stay at home parent
- Unpaid carer
- Pensioner / retiree
- Unemployed / on disability support pension

Other (please specify)

102

Cost of Eating Disorders in Australia

You and eating disorders

This section asks whether you have (or have had in the last five years) an eating disorder, or whether you care for someone who has (or did so during the last five years). If someone needs to care for you because of your condition, you can each fill out a survey if you want to.

8. Have you had an eating disorder in the last five years?

- Yes
- No

9. Have you cared for someone with an eating disorder in the last five years?

- Yes
- No

Cost of Eating Disorders in Australia

Consumer health condition

This section asks about what kind of eating disorder you currently suffer from, or used to suffer from.

10. Which eating disorder do (or did) you have?

- Diagnosed with Anorexia
- Diagnosed with Bulimia
- Diagnosed with Binge Eating Disorder
- Diagnosed with other eating disorder

I haven't had a formal diagnosis, but I have had symptoms of an eating disorder. For example:

Binge eating – months of frequently eating an unusually large amount of food in one go, and feeling like the eating could not be prevented or stopped.

Purging – months of frequent weight control through the use of laxatives, diuretics (water tablets), or self-induced vomiting.

Going on a very strict diet or eating hardly anything at all for a time for the purpose of weight or shape control.

Feeling very anxious about your weight or shape, while also weighing a lot less than you should. (That is, having a Body Mass Index (BMI) under 18)

Don't know / prefer not to state

Are there any comments you would like to make about your condition / diagnosis?

11. How old were you when you first noticed eating disorder symptoms?

Age in years

12. Are you currently still suffering from your eating disorder, or have you recovered?

- Still suffering
- Recovered

Other (please comment)

Cost of Eating Disorders in Australia

Carer health condition

This section asks about what kind of eating disorder the person you care for currently suffers from, or what they used to suffer from when you cared for them in the past.

13. Which eating disorder did the person you care (or cared) for have?

- Diagnosed with Anorexia
- Diagnosed with Bulimia
- Diagnosed with Binge Eating Disorder
- Diagnosed with other eating disorder
- The person I care (or cared) for has not had a formal diagnosis, but they have (had) symptoms of an eating disorder. For example:
Binge eating –months of frequently eating an unusually large amount of food in one go, and feeling like the eating could not be prevented or stopped.
Purging – months of frequent weight control through the use of laxatives, diuretics (water tablets), or self-induced vomiting.
Going on a very strict diet or eating hardly anything at all for a time for the purpose of weight or shape control.
Feeling very anxious about their weight or shape, while also weighing a lot less than they should. (That is, having a Body Mass Index (BMI) under 18)
- Don't know / prefer not to state

Are there any comments you would like to make about their condition / diagnosis?

14. How old was your caree when you (or they) first noticed symptoms of their eating disorder?

Age in years

15. How old are they now?

Age in years

16. Are you currently caring for them, or have they now recovered from their eating disorder?

- Currently caring
- Not currently caring due to recovery

Other reason for not currently caring (please comment)

Cost of Eating Disorders in Australia

17. What is your relationship to the person you care (or cared) for?

Parent / guardian

Partner / spouse

Other (please specify)

Cost of Eating Disorders in Australia

Consumer role impact

This section asks about how your condition has affected your ability to work (or study) and what impact that has had on your income.

18. Over the last year (or last year with the condition), did your eating disorder cause you to work (or study) less hours than you would have wanted to? If so, by how many hours per week on average?

None (i.e no less work/study participation than if you had no eating condition)

Up to 10 hours per week on average less participation.

11 to 20 hours less participation.

21 to 30 hours less participation.

31 to 40 hours less participation

Prevented engaging in paid work / attending regular study.

19. Approximately how many days were you unable to work or study in the last year (last year before recovery) due to your eating condition? e.g. 'sick' days off work

Days

20. When you were at work / studying, did your eating condition cause you to be less productive?

no reduction in productivity

up to 5% less productive

6 to 10% less productive

11 to 25% less productive

more than 25% less productive

21. What was your approximate annual income before your eating disorder?

Annual income

Cost of Eating Disorders in Australia

Your treatment costs

This section asks about how much money you have had to spend on treatment, and on which types of treatment and how frequently.

22. Did you receive professional treatment for your eating condition in the last 12 months? ([or last 12 months before recovery])? If so, from who? (please tick all that apply)

- GP
- Counsellor / social worker
- Psychologist
- Psychiatrist
- Dietician/Nutritionist
- Eating disorder specialist
- Other health professional (please specify)
- Non-health professional (please specify)

Please specify

23. In the last year (or last year before recovery), how many times did you see a health professional about your condition?

- 1 or 2 times
- 3 to 5 times
- 6 to 10 times
- 11 to 20 times
- 21 to 35 times
- 36 to 50 times
- More than 50 times

24. Are you a member of a private health insurance fund?

- Yes
- No

Cost of Eating Disorders in Australia

Your treatment costs (continued)

25. What percentage of the following costs did the fund pay for?

	<20%	21-40%	41-60%	61-80%	81-100%	Not applicable
GP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Counsellor / social worker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychiatrist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dietician/Nutritionist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eating disorder specialist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hospitalisation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other health professional	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Non-health professional	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Is there anything you would like to say about how helpful (or otherwise) having private health insurance was?

26. How much money have you had to spend on treatment by health professionals out of your own pocket? (ie. which was not reimbursed by the government or a health fund)

- Up to \$250
- \$251 to \$500
- \$501 to \$1,000
- \$1,001 to \$1,500
- \$1,501 to \$2,000

Over \$2,000 (please indicate to nearest \$1000)

27. How much have you had to spend on medications out of your own pocket? (ie. which was not reimbursed by the government or a health fund)

- Up to \$250
- \$251 to \$500
- \$501 to \$1,000
- \$1,001 to \$1,500
- \$1,501 to \$2,000

Over \$2,000 (please indicate to nearest \$1000)

Cost of Eating Disorders in Australia

28. Were you hospitalised in the last 12 months / last 12 months before recovery, because of your eating condition?

Yes

No

Cost of Eating Disorders in Australia

Your treatment costs (continued)

29. How many times were you hospitalised in the last 12 months (last 12 months before recovery)?

Number:

30. How long for (total days for all admissions)?

Days:

31. Was your admission classified as being due to your eating condition?

- Yes
- No (if you know, please specify below what the records show they were admitted for)
- Don't know

Please specify

32. Did you have to pay any hospital cost out of your own pocket (ie. which was not reimbursed by the government or a health fund)?

- Up to \$250
- \$251 to \$500
- \$501 to \$1,000
- \$1,001 to \$1,500
- \$1,501 to \$2,000

Over \$2,000 (please indicate to nearest \$1000)

33. Have you incurred travel, accommodation or relocation expenses when accessing treatment?

- No
- Up to \$250
- \$251 to \$500
- \$501 to \$1,000
- \$1,001 to \$1,500
- \$1,501 to \$2,000

Over \$2,000 (please indicate to nearest \$1000)

Cost of Eating Disorders in Australia

34. If regularly binge eating, how much do you think your food bill may have increased over the past year?

- Not applicable
- Up to \$250
- \$251 to \$500
- \$501 to \$1,000
- \$1,001 to \$1,500
- \$1,501 to \$2,000

Over \$2,000 (please indicate to nearest \$1000)

35. Have you or your family had to access finance, mortgage property or sell assets etc. to pay for treatment?

- No
- Yes, to the value of less than \$1,000
- Yes, to the value of between \$1,001 and \$5,000
- Yes, to the value of between \$5,001 and \$10,000
- Yes, to the value of over \$10,000

36. Are you aware of any other costs you have incurred as a direct result of your eating condition over the last year?

- No
- Up to \$250
- \$251 to \$500
- \$501 to \$1,000
- \$1,001 to \$1,500
- \$1,501 to \$2,000
- Over \$2,000

Please specify the nature of these costs

Cost of Eating Disorders in Australia

37. How effective do you feel the treatment you have received over the duration of your condition has been?

Completely ineffective or made condition worse Slightly effective Reasonably effective Highly effective Completely effective / no longer have condition

Are there any comments you would care to make on how treatment has helped you – positives and/or negatives?

38. How difficult was it for you to access appropriate treatment - including both finding the right professional(s) for you and then obtaining appointments?

Very difficult Difficult About the same as treatment for other conditions Easier than for other conditions Not difficult at all

Are there any comments you would care to make about the difficulty (or ease) of accessing appropriate treatment?

39. Do you currently experience other health consequences as a result of the eating disorder? (Including from a past eating disorder that is now in recovery)

- Osteoporosis
- Infertility
- Digestive disorders - stomach, oesophagus and intestinal damage
- Kidney damage
- Dental erosion and dental caries
- Obesity and obesity related disorders including diabetes
- Heart disease and/or cardiac abnormalities
- Anxiety and/or depression

Other (please specify)

Cost of Eating Disorders in Australia

40. Would you be able to estimate the costs of treating these other health consequences in the most recent 12 months?

- Up to \$250
- \$251 to \$500
- \$501 to \$1,000
- \$1,001 to \$1,500
- \$1,501 to \$2,000

Over \$2,000 (please indicate to nearest \$1000)

41. Which, if any, of the following patterns would best describe your treatment pathway?

- High frequency at first then gradually tapering off
- Low frequency at first, followed by a peak and then a general tapering off
- Reasonably constant during whole course of disease
- Intense treatment when problem is severe / relapses, but little or nothing in between, when issue is manageable / in recovery
- Other. (If so, would you care to briefly describe your pattern?)

Other pathway (please specify)

112

Cost of Eating Disorders in Australia

Other consumer issues

Only some of the costs of eating disorders can be captured by numbers. This section asks about non-financial impacts you might like to tell us about.

42. Is there anything else you would like to comment about regarding economic, emotional, social or other costs/impacts you have experienced from your eating condition?

43. If there was one thing you would most want to see done to help reduce costs for people with eating disorders, what would it be?

Cost of Eating Disorders in Australia

Carer role impact

This section asks about how having to care for someone with an eating condition has affected your ability to work (or study) and what impacts that has had on your income.

44. Over the last year (or last year before recovery), did their eating condition cause you to work (or study) less hours than you would have wanted to? If so, by how many hours per week on average?

- None (i.e no less work/study participation than if you had no eating condition)
- Up to 10 hours per week on average less participation.
- 11 to 20 hours less participation.
- 21 to 30 hours less participation.
- 31 to 40 hours less participation
- Not currently wanting/able to engage in paid work / attend regular study.

45. Approximately how many days were you unable to work or study in the last year due to their eating condition? e.g. 'sick' days off work

Days

46. When you were at work / studying, did caring for their eating condition cause you to be less productive?

- No reduction in productivity
- up to 5% less productive
- 6 -to 10% less productive
- 11 to 25% less productive
- more than 25% less productive

47. What was your approximate annual income before you began caring for someone with an eating disorder?

Your income

Cost of Eating Disorders in Australia

Their treatment costs

This section asks about how much it has cost to treat the eating disorder of the person you have cared for (are caring for).

48. Did they receive professional treatment for their eating condition in the last 12 months (last 12 months before recovery)? If so, from who? (please tick all that apply)

- GP
- Counsellor / social worker
- Psychologist
- Psychiatrist
- Dietician/Nutritionist
- Eating disorder specialist
- Other health professional (please specify)
- Non-health professional (please specify)

Please specify

49. In the last year (last year with the condition), how many times did they see a health professional about their condition?

- 1 or 2 times
- 3 to 5 times
- 6 to 10 times
- 11 to 20 times
- 21 to 35 times
- 36 to 50 times
- More than 50 times

50. Is the person you care for a member of a private health insurance fund? (This includes if they are part of your family membership)

- Yes
- No

Cost of Eating Disorders in Australia

Their treatment costs (continued)

51. What percentage of the following costs did the fund pay for?

	0-20%	21-40%	41-60%	61-80%	81-100%	Not applicable
GP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Counsellor / social worker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychiatrist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dietician/Nutritionist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eating disorder specialist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hospitalisation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other health professional	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Non-health professional	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Is there anything you would like to say about how helpful (or otherwise) having private health insurance was?

52. How much money have you and your family had to spend on treatment by health professionals out of your own pocket? (ie. which was not reimbursed by the government or a health fund)

- Up to \$250
- \$251 to \$500
- \$501 to \$1,000
- \$1,001 to \$1,500
- \$1,501 to \$2,000

Over \$2,000 (please indicate to nearest \$1000)

53. How much have you had to spend on medications out of your own pocket? (ie. which was not reimbursed by the government or a health fund)

- Up to \$250
- \$251 to \$500
- \$501 to \$1,000
- \$1,001 to \$1,500
- \$1,501 to \$2,000

Over \$2,000 (please indicate to nearest \$1000)

Cost of Eating Disorders in Australia

54. Were they hospitalised in the last 12 months (last 12 months before recovery) because of their eating condition?

Yes

No

Cost of Eating Disorders in Australia

Their treatment costs (continued)

55. How many times were they hospitalised in the last 12 months (last 12 months before recovery)?

Admissions over the past year:

56. How long for (total days)?

Total days

57. Was their admission classified as being due to their eating condition?

- Yes
- No (if known, what do the records show you were admitted for?)
- Don't know

Please specify

58. Did you have to pay any hospital cost out of your own pocket (ie. which was not reimbursed by the government or a health fund)

- Up to \$250
- \$251 to \$500
- \$501 to \$1,000
- \$1,001 to \$1,500
- \$1,501 to \$2,000

Over \$2,000 (please indicate to nearest \$1000)

59. If they regularly binge eat, how much do you think your food bill may have increased over the past year?

- Up to \$250
- \$251 to \$500
- \$501 to \$1,000
- \$1,001 to \$1,500
- \$1,501 to \$2,000

Over \$2,000 (please indicate to nearest \$1000)

Cost of Eating Disorders in Australia

60. Have you incurred travel, accommodation or relocation expenses when accessing treatment?

- No
- Up to \$250
- \$251 to \$500
- \$501 to \$1,000
- \$1,001 to \$1,500
- \$1,501 to \$2,000

Over \$2,000 (please indicate to nearest \$1000)

61. Have you had to access finance, mortgage property or sell assets etc. to pay for treatment?

- No
- Yes, to the value of less than \$1,000
- Yes, to the value of between \$1,001 and \$5,000
- Yes, to the value of between \$5,001 and \$10,000
- Yes, to the value of over \$10,000

62. Are you aware of any other costs you have incurred as a direct result of their eating condition over the last year? (If yes, please specify)

- Up to \$250
- \$251 to \$500
- \$501 to \$1,000
- \$1,001 to \$1,500
- \$1,501 to \$2,000

Over \$2,000 (please indicate to nearest \$1000)

63. How effective do you feel the treatment they have received over the duration of their condition has been?


Completely ineffective or made condition worse	Slightly effective	Reasonably effective	Highly effective	Completely effective / no longer have condition
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Are there any comments you would care to make on how treatment has helped, positives and/or negatives?

Cost of Eating Disorders in Australia

64. How difficult was it to access appropriate treatment, including both finding the right professional(s) for them and then obtaining appointments?

Very difficult Difficult About the same as treatment for other conditions Easier than for other conditions Not difficult at all



Are there any comments you would care to make about the difficulty (or ease) of accessing appropriate treatment?

65. Do they currently experience other health consequences as a result of the eating disorder? (Including from a past eating disorder that is now in recovery)

- Osteoporosis
- Infertility
- Digestive disorders - stomach, oesophagus and intestinal damage
- Kidney damage
- Dental erosion and dental caries
- Obesity and obesity related disorders including diabetes
- Heart disease and/or cardiac abnormalities
- Anxiety and/or depression

Other (please specify)

66. Would you be able to estimate the costs of treating these other health consequences in the most recent 12 months?

- Up to \$250
- \$251 to \$500
- \$501 to \$1,000
- \$1,001 to \$1,500
- \$1,501 to \$2,000

Over \$2,000 (please indicate to nearest \$1000)

Cost of Eating Disorders in Australia

67. Which, if any, of the following patterns would best describe their treatment pathway?

- High frequency at first then gradually tapering off
- Low frequency at first, followed by a peak and then a general tapering off
- Reasonably constant during whole course of disease
- Intense treatment when problem is severe / relapses, but little or nothing in between, when issue is manageable / in recovery
- Other. (If so, would you care to briefly describe your pattern?)

Other pathway (please specify)

Cost of Eating Disorders in Australia

Other carer issues

Only some of the costs of eating disorders can be captured by numbers. This section asks about any non financial impacts you might like to tell us about.

68. Is there anything else you would like to comment about regarding economic, emotional, social or other costs/impacts you have experienced from their eating condition?

69. If there was one thing you would most want to see done to help reduce costs for people with eating disorders, what would it be?

Cost of Eating Disorders in Australia

Survey end

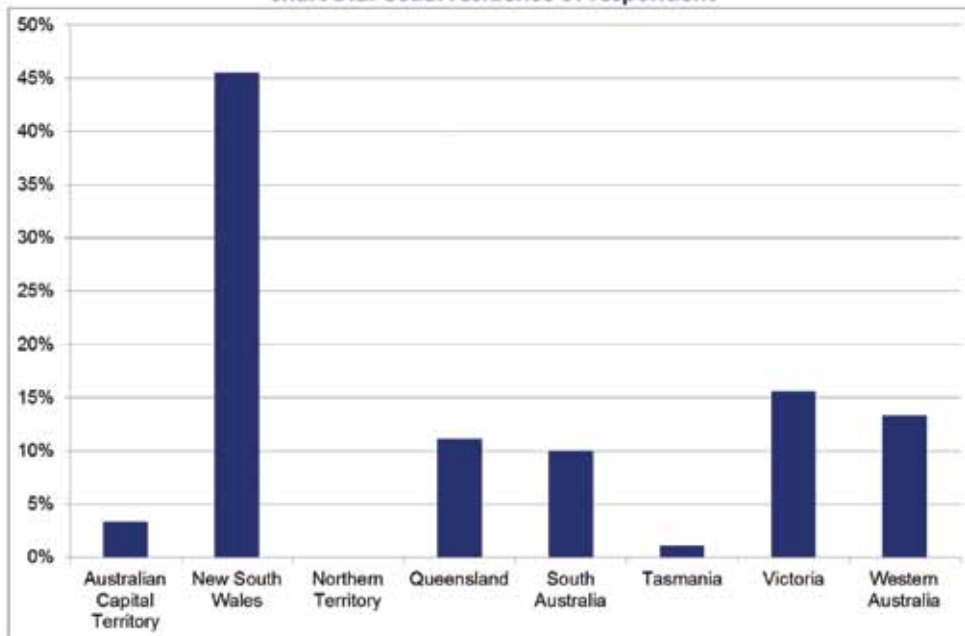
Thank you very much for participating in our survey. Hopefully your responses will help enable more effective help for people with eating disorders.

Appendix B :: Survey information

In October 2012, a link to an on-line consultation questionnaire was sent via email to approximately 300 people, with 95 responses. Almost half the respondents came from NSW (Chart B.1).

Of those who participated, around two-thirds had experienced an eating disorder over the past five years and around one third had cared for someone with an eating disorder over the past five years with about half of these currently caring.

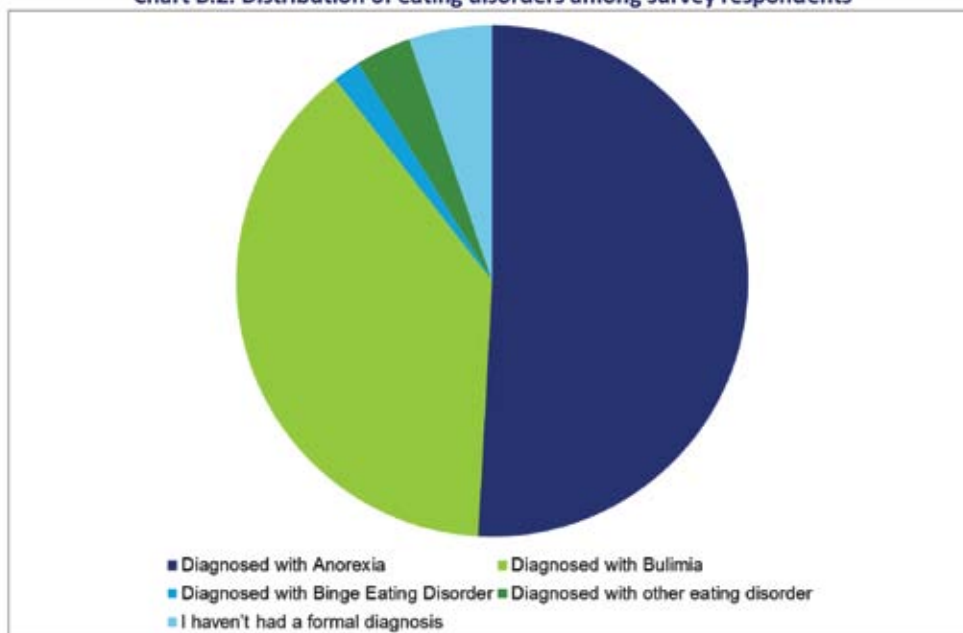
Chart B.1: Usual residence of respondent



Source: 2012 survey results.

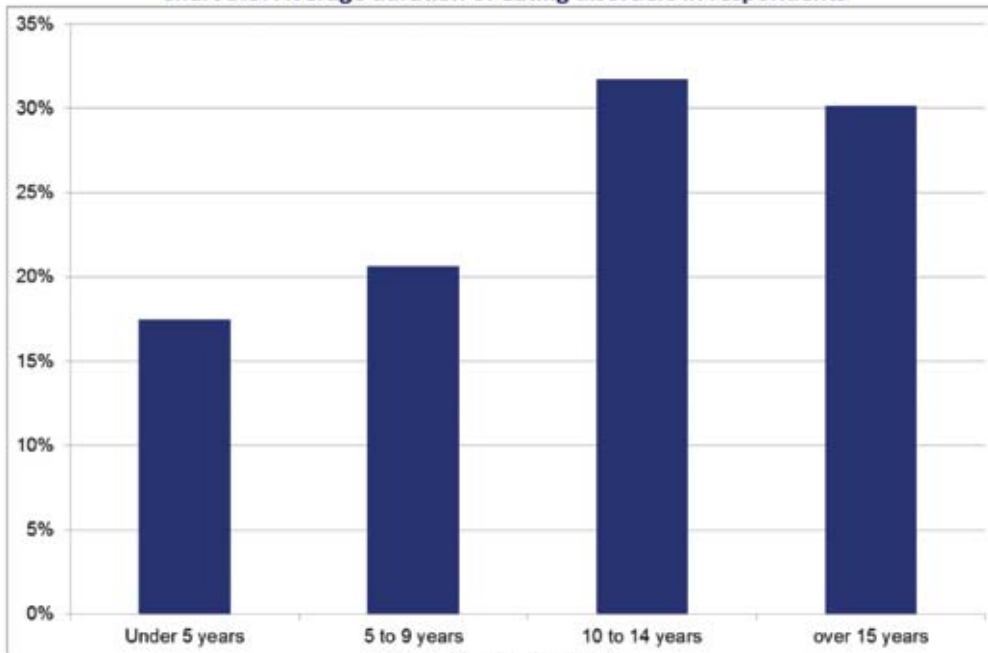
The average respondent had been living with their disorder for over a decade (13.2) years, with the highest being 46 years. For respondents now self-reporting as 'in recovery', the average time since onset was 14.6 years. The median age for onset of symptoms was 15 years.

Chart B.2: Distribution of eating disorders among survey respondents



Source: 2012 survey results.

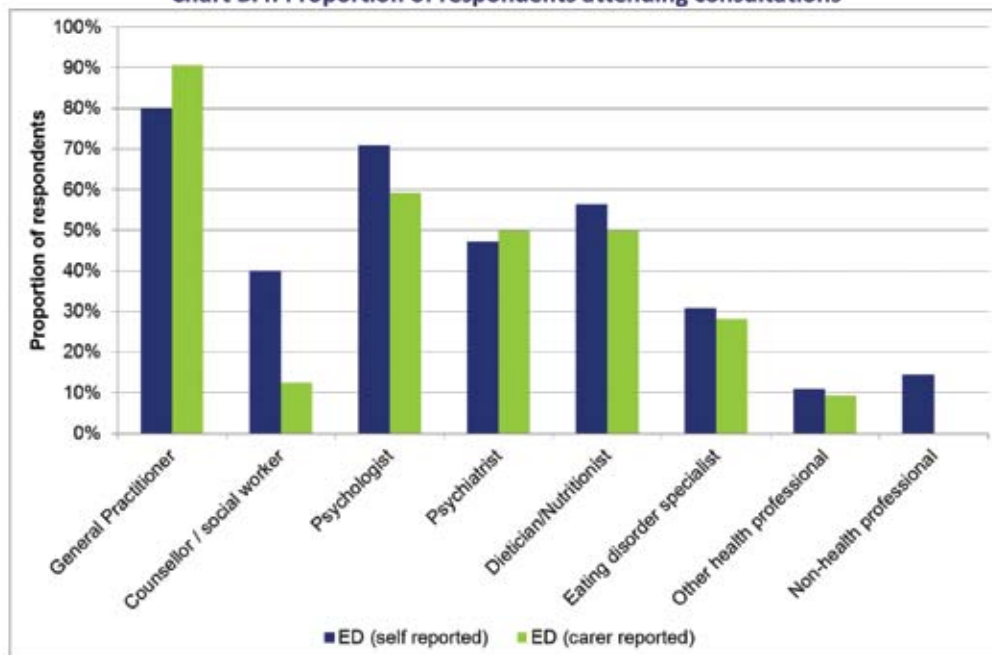
Chart B.3: Average duration of eating disorders in respondents



Source: 2012 survey results.

Most (71%) of respondents had private health insurance which was reported to largely cover inpatient stays but appeared to offer limited cover for outpatient consultations in most cases. GPs and psychologists were most frequently involved in patient care (Chart B.4) although the number of consultations undertaken with health care professionals in the last year, or last year before recovery, varied substantially across survey participants. 35% of respondents needed more than 50 consultations for them or their care. Private health insurance or government rebates most often covered less than 20% of the cost of these consultations

Chart B.4: Proportion of respondents attending consultations



Source: 2012 survey results.

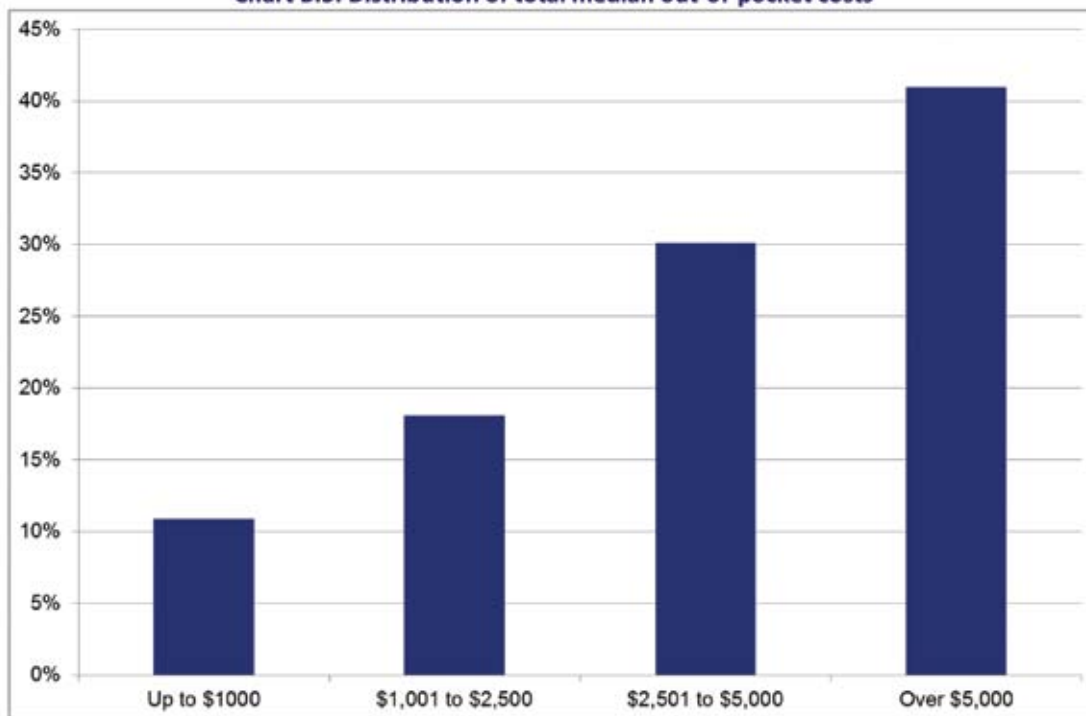
Appendix B :: Survey information

The survey included questions concerning out of pocket treatment costs including the cost of treatment by health care professionals and private clinic stays. Some 77% of respondents spent more than \$2,000 a year out of their own pockets on treatment. Some respondents reported spending well over \$100,000²⁸.

We paid approximately \$9,000 out of pocket for Psychology and \$1,500 for GP/Pathology costs. She is currently being treated overseas. Costs are \$1,450 per day. We expect treatment and related costs (airfares etc) will amount to at least \$200 000.

Because responses mostly appeared to come from the more severe end of the spectrum, which may not be representative of costs for total eating disorders, median costs were considered more appropriate than mean costs. The median annual out of pocket health expenditure was \$4,375.

Chart B.5: Distribution of total median out-of-pocket costs

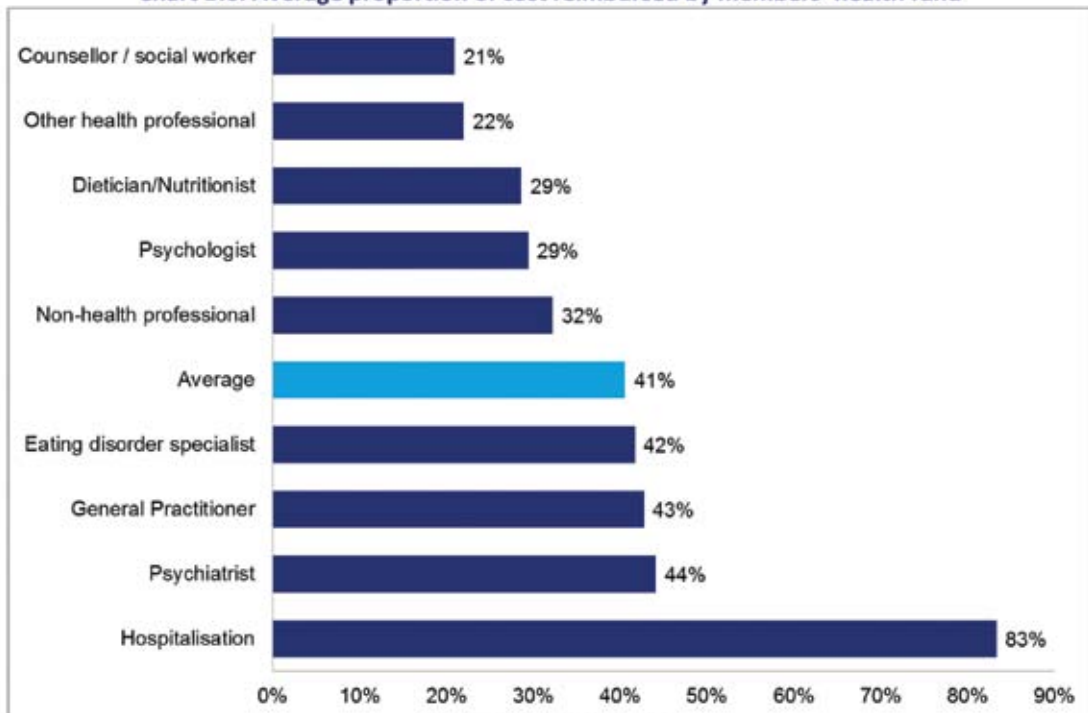


Source: 2012 survey results.

Of all respondents, 41% had been hospitalised during the last twelve months of their condition. The median number of inpatient days (for all admissions) was 58 and 120, as reported by consumers and carers respectively. When hospitalisation occurred, this was almost always (88%) due to an eating disorder. Other classifications given for admission were depression / anxiety, post-traumatic stress disorder, and complications from diabetes.

Stays were largely covered by the government or a health fund with 85% of survey participants paying \$50 or below for their stay. Median out of pocket costs were \$125. However, health funds only reimbursed 43% of GP fees and less for other service providers. In total, health funds reimbursed 83.3% of hospital services and 34.4% of non-hospital services.

Chart B.6: Average proportion of cost reimbursed by members' health fund



Source: 2012 survey results.

Median travel / accommodation costs were reported as \$750. However, high travel, accommodation or relocation expenses were reported by those who have sought treatment overseas.

While the great majority of respondents (84%) had not had to access finance to fund treatment, there were seven families who had needed to borrow over \$10,000.

Table B.1: Summary of median out-of-pocket costs

Category	Cost
Treatment	\$1,750
Medication	\$750
Hospital	\$125
Travel	\$750
Food	\$750
Any other directly related costs	\$750
Cost of treating other health consequences	\$375
Total	\$4,375

Note: Total is the median of individual total expenditure, not the sum of the above categories, some of which only pertain to a minority of respondents.

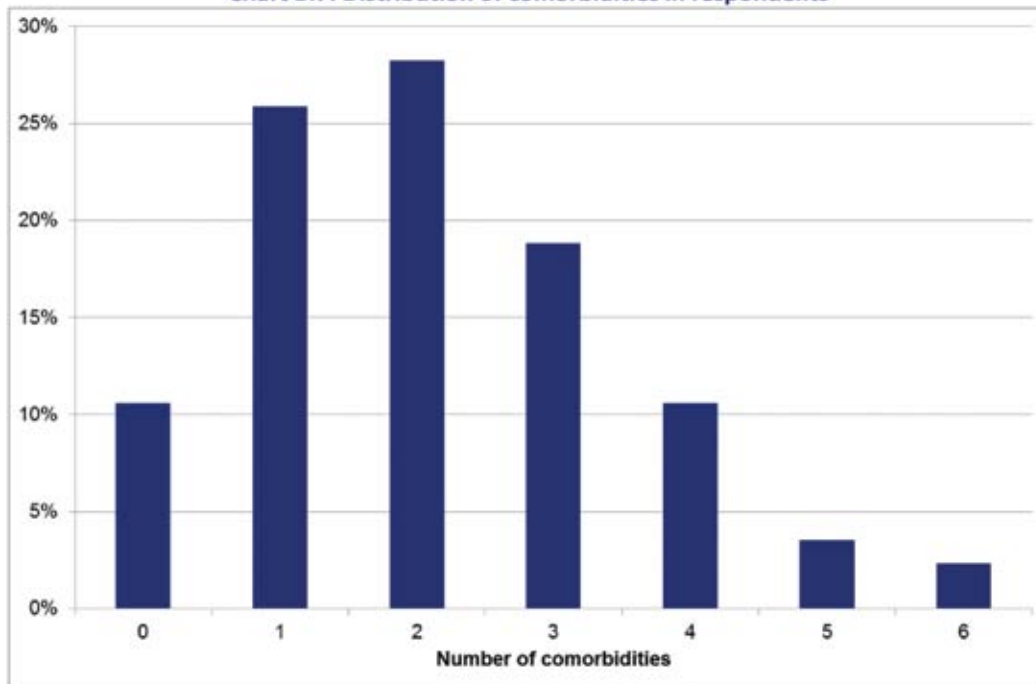
Source: 2012 survey results.

Of respondents, 90% reported comorbidities as a result of their eating disorder. The average respondent had 2.4 comorbidities, representing an average additional cost of \$750 a year²⁹.

²⁹ Respondents reporting no comorbidities assigned \$0 extra costs, respondents reporting comorbidities but not estimating a cost were not included in the average.

Appendix B :: Survey information

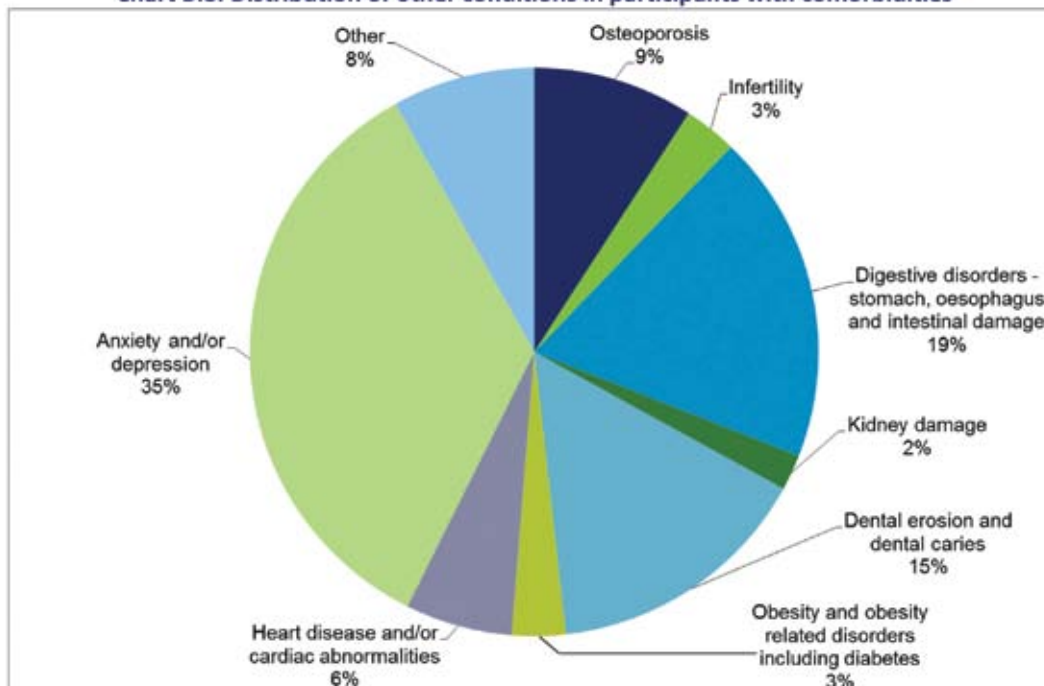
Chart B.7: Distribution of comorbidities in respondents



Source: 2012 survey results.

The most commonly reported comorbidities were anxiety and/or depression (35% of all comorbidities), and digestive disorders (19%).

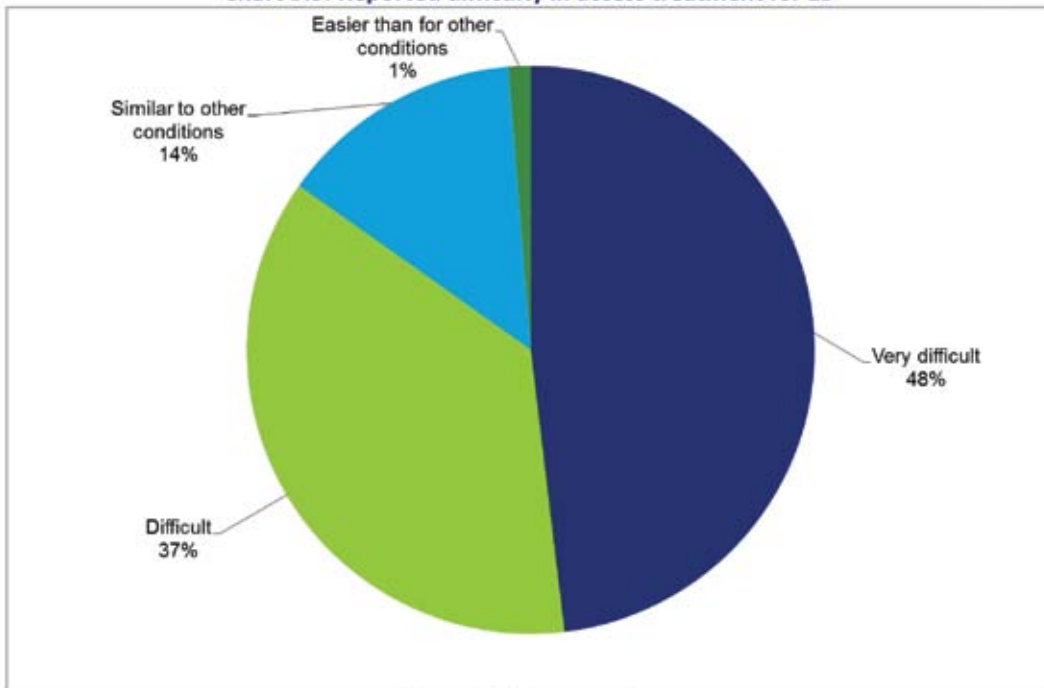
Chart B.8: Distribution of other conditions in participants with comorbidities



Source: 2012 survey results.

Of concern was that 85% (67 respondents) found accessing appropriate treatment (including both finding the right professional(s) and obtaining appointments) difficult or very difficult (Chart B.9).

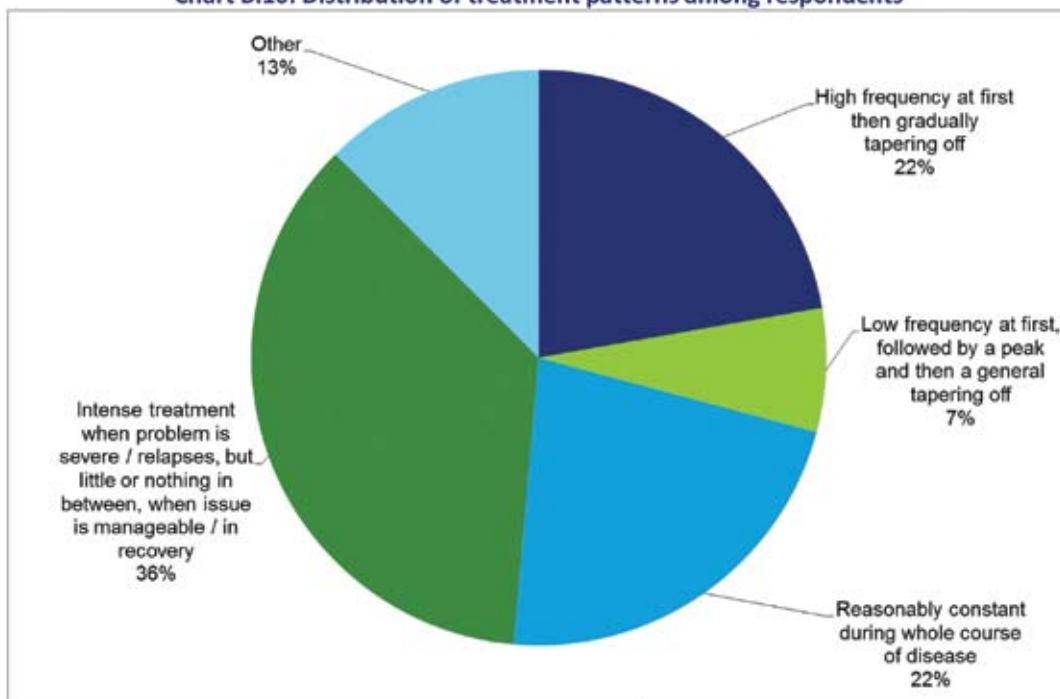
Chart B.9: Reported difficulty in access treatment for ED



Source: 2012 survey results.

The most common treatment pattern (36% of respondents) was intense treatment when their condition was severe, but little otherwise (Chart B.10). However, the second most common pattern (22%) was tied between reasonably constant treatment over the course of the disease, and high frequency of treatment at first then gradually tapering off.

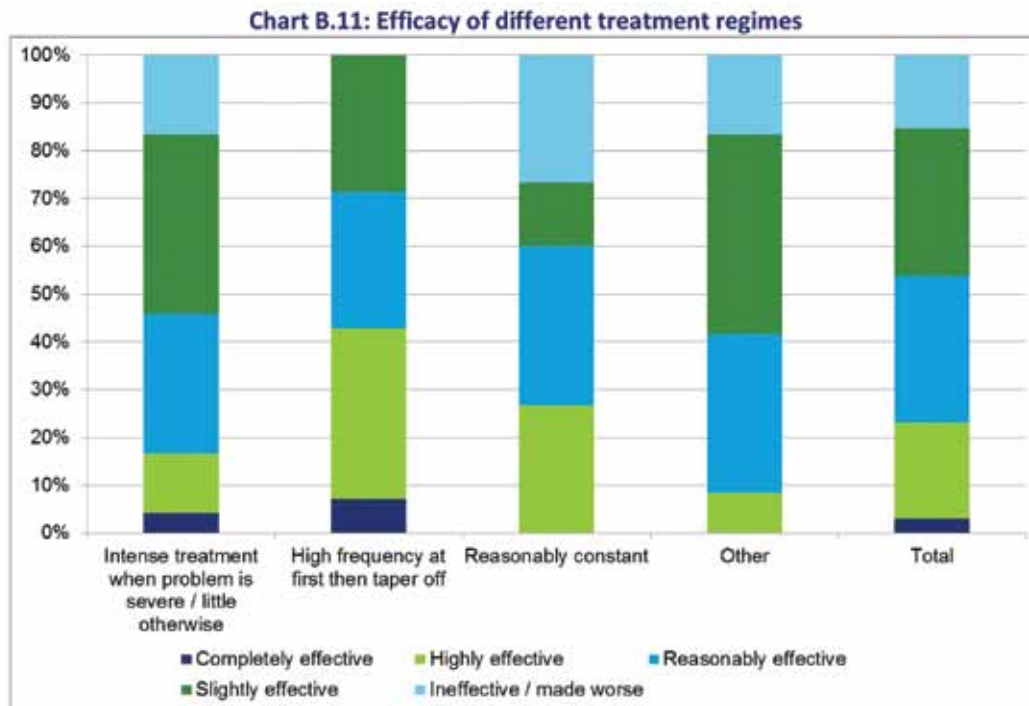
Chart B.10: Distribution of treatment patterns among respondents



Source: 2012 survey results.

Appendix B :: Survey information

Consumer and carer opinion on the efficacy of treatment received was mixed (Chart B.11). Early intervention when ED symptoms are first noted (as characterised by “High frequency at first”) appears to be the most effective treatment or may reflect a less severe patient group. This approach had the highest rate of complete success, and no recorded instances of making patients worse off. Similarly, the somewhat related “Intense when severe” regime had a higher success rate and a lower failure rate than treatment which was not tailored to severity (“reasonably constant”).



:: Notes

LIMITATION OF OUR WORK

General use restriction

This report is prepared solely for the internal use of The Butterfly Foundation. This report is not intended to and should not be used or relied upon by anyone else and we accept no duty of care to any other person or entity. The report has been prepared for the purpose of estimating the economic and social cost of eating disorders in Australia. You should not refer to or use our name or the advice for any other purpose.



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