



# NEDDC e-Bulletin

Issue Five | November 2012

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Dear Reader,

Welcome to the November issue of the NEDC e-Bulletin. This month we are focusing on issues, research and resources of relevance to the family and friends who play such an essential role in the care, support and recovery of people with eating disorders. We have also highlighted some Australian eating disorders research currently taking place as well as opportunities to get involved in NEDC activities. As always we hope you enjoy this edition and if you would like to suggest topics or events to be featured in future editions of the e-bulletin, please contact us at [nedc@thebutterflyfoundation.org.au](mailto:nedc@thebutterflyfoundation.org.au).

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## "Caring" - a lived experience perspective



### Written by Belinda Caldwell

Families have now been shown to be an important element of the recovery process for eating disorder sufferers but the process of caring for this specific illness is extremely challenging, requiring enormous emotional reserves and new parenting skills for many.

In addition, it can result in financial challenges with family members unable to work and, at times, a need for strong advocacy on behalf of your family member in a health system which can appear fragmented and confusing.

I am the mother of Lucy, 17 and I would describe our family's journey as: the most intense and challenging experience of our lives. There is nothing scarier for me than a child who can't do that most basic functions of living- eat.

Our family journey started just before Christmas in 2010 after Lucy returned from trekking in Nepal, where she lost a significant amount of weight. On her return she started exhibiting compulsions to exercise, a need to control what the family were eating, and anxiety so we started taking her to the GP and a psychologist to work out what was happening. By the end of February 2011, she had lost more weight and was admitted to the Royal Children's Hospital in Melbourne after her heart rate measured 35 at the GPs. As a parent, I was shocked at the diagnosis of severe anorexia nervosa. However I was very grateful for the meeting on the day of admission with the psychiatrist after he outlined the severity of the disease, stipulated clearly that there was no research evidence that parents or families contributed to it other than possibly in a hereditary sense and that there was a treatment methodology which was delivering

much more optimistic outcomes that we would have access to through RCH. So we spent no time wondering what they could have done to prevent it, rather learning as much as we could about what we were going to be required to do when Lucy returned home.

After 5 weeks Lucy returned to our care with the support of regular FBT coaching sessions. While medically stable, Lucy was very entrenched in her anorexic behaviours and thoughts. The first meal at home, she just laughed at the notion that we would make her eat. Afternoon tea of toast with avocado and their new friend 'butter' and milk was presented and 2 hours later were eaten after much coaching and refusal to let her leave the couch. Lucy needed a parent to sleep with her at night for 5 months to 'forbid' her from exercising. She would wake up during the night with the compulsion to exercise until she commenced on some medication. She was not allowed in her room on her own, the bathroom door lock was removed and all toilet and showers supervised. Meals would take up to 12 hours of any day in the beginning. If meals were not eaten, then a trip to the hospital ER was undertaken even though we only had to actually go through the doors once: mostly she ate in the car park.

But as the weight went back on, Lucy's mood improved, the endless jiggling slowed and then stopped, the sneaking of food stopped, the endless conversations about how fat she looked, feeling full etc reduced and life started to return to some semblance of normality. 20 months later, Lucy is well on the way to recovery and about to attend schoolies.

At what cost was this recovery? I had to take 5 months of unpaid leave followed by Rob taking 3 months. On my return to work, I continued to find the demands of caring for Lucy intruded significantly the demands of my job as a CEO of an NFP, and I ended up leaving a much loved job. Our family has downsized the family home to reduce financial

pressures so if Lucy relapses, we can afford to have one parent not working. Lucy's older sister had to do her final year of school largely unsupported as we were in the thick of caring for Lucy. I sought counselling support to deal with the trauma of both the demands of caring but also the impacts such as leaving my job.

Would we do it again? Absolutely. While difficult, it has also been a privilege. How many parents get to experience such a pure level of parenting, a raw sense of what you would do for your child if you had to? In many ways it has brought us all closer, we discussed more openly how to deal with issues and developed joint plans of action.

What could have made the process easier? We feel so blessed that our journey was relatively straightforward with minimal hassles with the health system – but only because we were able to access the RCH program as participants of a research study: we would have been 'out of region' otherwise. But I know that isn't the case for many families I have since come to know. Many families have been seeking assistance for a long time before someone takes their concerns seriously. FBT or Maudsley is very sporadically available and other inpatient and outpatient support hugely variable by location. There are some clinicians who still feel anorexia is a mental state that can be snapped out of and parents being the 'food police' is a bad idea. My daughter says now she could never have eaten without us requiring her to and removing her choice to eat reduced her anxiety as she could tell the anorexia she had no 'choice'. She likens it to having two parents and one had to be stronger than the other. Parents and carers need to be supported and empowered in this critical therapeutic role. By doing the caring, we are keeping our kids out of hospital and reducing health care costs hugely.

*Belinda Caldwell is on the conference organising committee for [At Home with Eating Disorders](#), Australia's first eating disorders conference for families and carers. We have more details about this event [later in the e-Bulletin](#).*

## Research article review



*The National Eating Disorders Collaboration collects and provides the latest evidence based research and information available on eating disorders from Australia and around the world. The topics included in our [Research and Resources](#) section are wide ranging and recognise the physical, social and emotional aspects and the broad spectrum of eating disorders. All information has been sourced from the NEDC Resources Review, NEDC Evidence Review, books, fact sheets, treatment guidelines, manuals or programs, reports, web-based programs, multimedia, academic peer reviewed journals and individuals working within the eating disorders sector.*

*Each month in the e-Bulletin we will be highlighting some of the research and information uploaded regularly on our website.*

### **The burden of caregiving tackled with Collaborative Care Skills Training**

Caring for someone with an eating disorder is an enduring and intense process associated with high levels of stress, burden, psychological, and physical strain. Because the age of onset of an eating disorder is typically adolescence or early adulthood, a person with an eating disorder often relies upon a carer such as the parent for significant assistance with their recovery. This often leads to high levels of pressure placed on family relationships, interpersonal dynamics, and the coping resources of the carer.

Research has shown that caregivers of eating disorder patients have higher levels of anxiety, depression, and perceived caregiving burden than caregivers of patients with

other psychiatric illnesses. One study by [Zabala, McDonald, & Treasure \(2009\)](#) showed that of those caring for someone with anorexia nervosa, 50% exhibited high levels of anxiety and depression. This in turn can lead to unhelpful attitudes, behaviours, and emotional reactions on the part of the carer, which can have an adverse impact on the patient, and a vicious cycle develops.

How the burden of caregiving is perceived is influenced by a number of variables, including the caregivers' socio-demographic characteristics, the clinical characteristics of the patient's illness, and the social support and personal resources available to the caregiver. Divorce, symptoms of anxiety or depression, a low level of education, a high level of concern about the patient's eating disorder, along with poor physical quality of life in the patient have been found to be associated with a greater perceived burden of caregiving ([Padierna, et al., in press](#)).

One way to reduce family distress and suffering can be to identify modifiable elements associated with specific difficulties present in the caregiver's role. A better understanding of those things that they can change would provide caregivers with alternative ways of coping through family-based interventions.

To do this, the Maudsley Collaborative Caring model has been developed, which teaches carers the skills required to optimise the management of severe eating disorders ([Sepulveda, et al., 2011](#)). This programme involves modules on coping, medical risk, understanding change, communication, emotion processing, problem solving, interpersonal relationships and managing eating and other difficult behaviours, supplemented with skills-based workshops.

Evidence has demonstrated the effectiveness of the workshops in the UK where the model was developed . A pilot study has recently been conducted to determine if the

workshops can be taught in an Australian setting, by facilitators trained in the delivery of the programme, with similar positive outcomes ([Pepin & King, in press](#)).

Overall results of the study indicate that specific knowledge and coping skills learnt through structured family interventions improve the caregiving experience and significantly reduce psychological distress, levels of expressed emotion, and aspects of perceived burden. There was also a trend towards increased confidence in the carers that their loved one could change.

The other important outcome of the pilot study was that it demonstrated the content of the workshop is transferrable to a different context (i.e. UK to Australia). It also confirmed that a brief yet thorough training in the content and delivery of the workshops coupled with a solid understanding of its foundations and core concepts such as readiness for change is necessary to support carers throughout their participation in the workshops.

Carers are the most important providers of support in the public health system. If they also get the informational and practical support they require it seems plausible that not only will their distress decrease, but they will be able to be more effective providers of support for the person they are caring for.

*The NEDC Clearinghouse contains a number of research articles focusing on [family and carer issues](#) including the Collaborative Care Model highlighted in this article. If you are interested in more information and resources pertaining to this subject check out the [Carers Guide to the NEDC Website](#) later in this e-Bulletin or explore our comprehensive [Research and Resources](#) section.*



**The following are links to organisations that offer support workshops to carers:**

[Eating Disorders Victoria](#)'s Building Hope is a six-week, skills-based learning program comprising 6 two-hour sessions for parents, siblings (15 years and over), partners, other family members and friends of a loved one with an eating disorder.

[The Eating Disorder Outreach Service \(EDOS, Queensland\)](#) is delivering parent/carer skills based training for families affected by eating disorders.

## Carers guide to the NEDC website



The NEDC has a large number of resources available through our website which are designed to meet the needs of many different audiences. We have created this guide below to help **families and carers** find appropriate resources by highlighting suitable content.

Family and friends play a crucial role in the care, support and recovery of people with eating disorders. The effects of an eating disorder are often felt not only by the person experiencing it, but also by their family and network of friends. A carer can be a parent, partner, friend, grandparent, child, sibling, grandchild, neighbour or any other person caring for someone with an eating disorder.

### *Help for families and carers*

Caring for someone with an eating disorder is a big responsibility and comes with considerable personal strain. The follow pages provide information to help equip families and carers with skills and coping techniques.

[Carers](#)

[Stages of change](#)

[Tips for carers](#)

[How to help](#)

[Recognise the warning signs](#)

[What to say and do](#)

[Preventing eating disorders](#)

[Get help](#)

[Family approaches](#)

## ***Other resources***

There are various pathways carers can take to get help and support. The following pages contain information on treatment and support options.

[Centres and services](#)

[Support organisations](#)

[Helplines](#)

[Useful websites](#)

## ***Get informed***

Being as informed as possible about eating disorders will help you identify the warning signs in someone you are concerned about and assist in understanding what they are going through. Our [Eating disorders explained](#) section contains essential information about eating disorders. Of particular use are our informative [Fact Sheets](#) and our dispelling [myths about eating disorders](#) page.

## Australia's first eating disorders conference for families and carers



*At Home with Eating Disorders* is the 1st Australian eating disorders conference for families and carers and is being held on May 23-25, 2013 in Brisbane.

Best evidence for eating disorders shows that the close involvement of families and carers in the care of their loved ones is key to improving early detection, restoration to a healthy weight and maintaining long term wellbeing. For parents and carers, however, the journey can be confusing, challenging and difficult to navigate.

The primary aim of *At Home with Eating Disorders* is to provide families and caregivers of people with eating disorders with access to a range of expert information and knowledge so that they can leave the conference feeling empowered, better informed and more able to support, care for and assist in the recovery of the person with the eating disorder.

The secondary aim of the conference is to provide opportunities to network and connect with others who share a similar experience, in a safe and supported environment.

Keynote speakers include:

- **Professor Daniel Le Grange**, Professor of Psychiatry and Behavioral Neuroscience and Director of the Eating Disorders Center at the University of Chicago Medical Center.
- **Professor Janet Treasure**, Professor of Psychiatry at King's College London and Head of the Eating Disorders Unit at the South London and Maudsley NHS Trust.

Clinicians and people with eating disorders wanting to learn more about the role of families and carers in supporting recovery are also welcomed.

The program and flyer have been [made available](#).

More details can be found on the [event website](#).

## A spotlight on current Australian eating disorders research



There are many [eating disorder research studies](#) currently occurring in Australia and researchers are frequently looking for participants to contribute to this research. The following is a list of current eating disorders research requiring participants. If you know of anyone who might be interested in participating in some of these it would be much appreciated if you could pass these along.

### *Emotions & attitudes towards eating*

**About:** The study aims to investigate eating and body concerns and how they might relate to emotional experience in adults aged 18 years and over.

**Looking for:** anyone aged 18 or older

**Participation involves:** completion of a thirty minute questionnaire (participants have the opportunity to win one of five AUD\$50 iTunes certificates)

**Weblink:** [https://macquariehs.qualtrics.com/SE/?SID=SV\\_5u21RaLQGWRWSTr](https://macquariehs.qualtrics.com/SE/?SID=SV_5u21RaLQGWRWSTr)

### *Dysfunctional eating in a community sample: The role of emotion regulation, impulsivity and reward and punishment sensitivity*

**About:** The study aims to explore an important step in understanding pathways between the Behavioural Inhibition and Approach Systems, emotion regulation and impulsivity within dysfunctional eating.

**Looking for:** Australian residents aged 18 years or older

**Participation involves:** Participants are required to complete several questionnaires, which will take approximately 20 minutes.

**Weblink:** <https://www.surveymonkey.com/s/HN55WJ6>

### *Exploring the Relationship between Self Esteem, Schemas and Eating Disorders*

**About:** It is hoped that this research will increase our knowledge about the way in which schemas (beliefs) are linked to self-esteem and particular eating disorder symptoms. This information will inform the developing schema therapy model for the treatment of eating disorders.

**Looking for:** anyone with an eating disorder diagnosis aged 16 years or older

**Participation involves:** Participants are required to complete a battery of questionnaires which will take approximately 20 minutes

**Participate:** Contact Dr Susan Simpson at [susan.simpson@unisa.edu.au](mailto:susan.simpson@unisa.edu.au) for more details

## Opportunities to get involved



### Become a member!

The NEDC welcomes and actively encourages people who are interested in joining the collaboration.

NEDC membership is a mutually beneficial relationship and a vehicle for partnering, shared learning and ensuring everyone has a voice in the discussion of strategic priorities for improving approaches to prevention and treatment of eating disorders in

Australia. With the assistance of our members, it is the aim of the National Eating Disorders Collaboration (NEDC) to help ensure:

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

To become a member you just need to fill out our [quick online membership form](#). Becoming a member is free but the participation and support of our members is priceless! If you are not yet a member we would love to have you involved.





connect  
share  
discuss

### Join the e-Network!

The [NEDC clinicians e-Network](#) provides an opportunity for clinicians to join in discussion, problem solve, share evidence and network with frontline clinicians and some of Australia's leading experts in eating disorders. If you are a professional in clinical practice with an interest in eating disorders and haven't joined our e-Network yet we would love to [have you involved](#).