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### For further information contact:
Eating Disorders Association
12 Chatsworth Rd, Greenslopes Qld 4120
Phone: (07) 3394 3661
URL: www.eda.org.au
Introduction

Food for Thought was funded by a 2015-2016 Partners in Recovery (PiR) Innovation Fund Grant from Brisbane North PHN. The project was jointly managed by The Eating Issues Centre (TEIC formerly ISIS) and the Eating Disorders Association (EDA).

The Food for Thought project was designed to improve service integration and promote system reform to support the carers of adults with eating disorders. The project focused on five aspects of service integration and system reform: (1) providing improved access to information and resources for carers, (2) strengthening carers’ knowledge and skills by providing concrete tools to assist them in navigating the service system, (3) improving the carer support community through an online and social media presence, (4) increasing the understanding of eating disorders in the primary health network, and (5) engaging health professionals and service providers to improve their understanding of the important role of carers in supporting adults with eating disorders.

This report provides an overview of the project’s objectives, implementation and evaluation.

The need for the project

Research suggests that eating disorders remain under-recognised and poorly treated. Research by The Butterfly Foundation indicates that:

- Up to 95% of people with eating disorders receive no treatment
- Of those who seek treatment, up to 85% find it difficult to access appropriate treatment
- 60% of clinicians experience difficulty referring clients for treatment
- GPs do not generally have the knowledge, experience or skill to treat or diagnose eating disorders
- Including families and carers as integral members of the treatment team is essential for the delivery of effective treatment.

It is widely accepted in the sector that:

- The eating disorder Anorexia Nervosa has the highest death rate of any mental illness
- Many individuals with eating disorders don’t recognise they are unwell
- Eating disorders often co-exist with other mental illnesses, and the other illnesses are more likely to be treated
- The carers of individuals with an eating disorder often find it difficult to get help and support for themselves and their loved one
- The carers of adults with an eating disorder are often excluded from treatment planning
- The service system within the eating disorder sector lacks integration and collaboration; the increasing demand for services and resulting growth in services has meant that it is difficult to maintain service integration and collaboration

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• Referral pathways are often unclear, and this means that navigating successful access to treatment can be difficult for carers and service providers
• Primary health care professionals who diagnose eating disorders and work with the individuals experiencing them can find it difficult to link with the appropriate treatment team; there are well-established eating disorder services available, however, knowledge of these is often lacking
• GPs, who are usually the first point of contact for the diagnosis of eating disorders, often lack the skills and knowledge required to diagnose an eating disorder and are unsure of where and when to refer.

TEIC and EDA were keen to address these issues through a project that focused on providing increased access to knowledge and support for the carers of adults with eating disorders. Consultation with the sector conducted in the early stages of planning the project suggested that:
• Carers find it difficult to understand where and how to access information about treatment pathways and referrals
• Carers frequently struggle to find support for themselves and the person they care for
• Carers are often not fully engaged by health professionals and service providers in the care and support of their loved one with an eating disorder
• Carers lack the information and skills to support their loved one with an eating disorder
• Carers frequently take on a case management role, but do not receive adequate support or recognition for that work.

In response to these identified needs, TEIC and EDA received a PiR Innovation Fund Grant to address system reform and service integration for the carers of adults with eating disorders.

Project goals and objectives

The Food for Thought project was designed to:
• Increase the capacity of carers to navigate the service system by improving consultative networks, building community supports and providing resources
• Promote the inclusion of carers in the diagnosis and treatment of eating disorders by empowering carers with knowledge and tailored tools designed to ensure carers know when to act, where to go to, what to ask for and when to advocate for their loved one
• Provide information to service providers and health professionals about the importance of carer involvement in treatment
• Provide support and information to primary health care providers to improve their capacity for early detection of eating disorders and to improve their ability to recognise, treat and support people with eating disorders
• Build awareness amongst primary health care providers about the importance of involving carers in treatment planning and implementation.
A consultative approach to the project

Food for Thought was designed as a consultative project that involved and engaged carers and individuals with a lived experience of eating disorders, alongside relevant service providers and health professionals. The project’s geographical focus was the North Brisbane region.

Contributing organisations included:

- **TEIC (The Eating Issues Centre)** – which provided project administration, governance support, financial management, human resource management and employment, access to resources and oversight of project deliverables. TEIC was represented in the project’s steering sub-committee and contributed to the community education sessions.

- **EDA (Eating Disorders Association Qld)** – which provided office space and office infrastructure, day-to-day project support, access to the library and resources, access to carers and carer support workers and day-to-day professional support. EDA also participated in the project steering sub-committee and the community education sessions.

- **The Eating Disorders Outreach Service (EDOS)** (a Metro North Hospital and Health Service at the RBWH) – which participated in project planning and content development, and supported the project’s implementation. EDOS provided extensive face-to-face consultation at the project’s commencement, expert review of all materials and resources developed through the project, a facilitator for Eating Disorder Information Sessions, and a staff member to assist with GP enquiries at the General Practice Conference and Exhibition.

- **Local community organisations** Kyabra, Communify, ARAFMI, MIFQ and Carers Qld – which provided venues for project events, participated in meetings about the project’s development, assisted in the dissemination of information and provided feedback about the project’s resources.

- **Specialist organisations** including The Butterfly Foundation, the Centre of Excellence for Eating Disorders (CEED) and the National Eating Disorders Collaboration (NEDC) – which provided information and research, resources and feedback about the project’s direction.

Project consultation also involved working closely with carers, health professionals and service providers. Consultation included:

- **Carers** – a carer consultation group was established to guide, inform and review the project. This group had nine active members, including two with a lived experience of eating disorders. The consultation group met both face-to-face and via email, and contributed to the project’s planning, concepts and resource development. Members of the carer consultation group consulted with GPs about the resources that would be most suitable.

- **Carers** – a carer representative participated in the project’s steering sub-committee.

- **Carers and consumers** – those attending the Recovery Event at the 2015 Body Image and Eating Disorders Awareness Week were consulted about the project’s resources and logo and their recommendations informed the design.

- **Consumers** – a person with lived experience of eating disorders participated in the project’s steering sub-committee.

- **Expert review** – a carer who was employed by EDOS on a short-term project contributed to Food for Thought by providing expert review of the resources being developed.

- **Health professionals** specialising in eating disorders – the Eating Disorders Special Interest Group (EDSIG – a Brisbane-based network of professionals working with eating disorders) and
the Eating Disorders Advisory Group (EDAG – a Queensland policy group for eating disorders) contributed to the project through individual face-to-face meetings and email contributions

- Health professionals and service providers – who participated in initial interviews about the project’s direction.

**Issues identified through consultation and research**

The project was developed through a literature review, a series of small surveys and informal consultation with stakeholders. The literature review included the Queensland needs analysis on eating disorders (published by EDA in 2012), the family consultation focus group and survey (published by CEED in 2015), and research published by The Butterfly Foundation. Informal consultation involved carers, individuals with a lived experience of eating disorders, health professionals and service providers.

The research revealed that:

- Carers seeking information about eating disorders typically search the internet in preference to talking with a health professional
- Carers feel under-involved and unsupported by health professionals and service providers
- Carer involvement is often vital to a person’s recovery
- Carers need to be involved in case management – including being involved in regular conversations with health professionals
- Collaboration across the eating disorder sector could be improved
- The referral pathways and options available for GPs making an initial diagnosis, in particular, need to be improved
- Suggested reasons for the lack of collaboration and referral pathways include high case loads, inadequate resources, lack of specialist training and mentoring, limited forums for sharing information and services, and a self-learning culture that leads to referrals within a limited circle of trusted colleagues
- Many general health professionals lack information about eating disorders and feel they lack the skills and experience required for diagnosis and treatment; in addition, they often do not understand the urgency of seeking treatment
- Health professionals and service providers currently lack information about eating disorders, local referral pathways and local sources of information
- Excellent information is already available and much good work is being done in the area of treatment and support for people with eating disorders. Improved sharing of information and more widespread knowledge of the information already available are needed
- Carers, people experiencing eating disorders, health professionals and service providers need access to local, trusted sources of information to help them locate the most valuable information available online
- Best-practice treatment approaches for eating disorders are poorly understood, both amongst general health professionals and in the wider community; there is a widespread misperception about eating disorders that can impact on diagnosis and treatment.
**Project achievements**

Food for Thought’s achievements fall into three main categories:

1. **Consultation and events**
2. **Social media**
3. **Information resources.**

**Consultation and events**

Food for Thought employed a project worker for 10 months. Project worker Karen Harper liaised with the sector, shared information and helped to build long-term networks. She ensured that carers and health professionals were involved in the development and design of the project’s resources and were ready to use the resources when released. The project worker was the catalyst that enabled all other aspects of the project to be completed. Throughout the project, Karen met with 32 agencies and service providers to discuss their work in the sector, what part they play in the service pathway, and their thoughts about how service navigation could be improved.

**Eating Disorder Information Sessions for service providers**

Food for Thought organised two Eating Disorder Information Sessions in Brisbane, on 16 March (Red Hill) and 22 April (Northlakes). These events were attended by 75 health and community workers (and had a waiting list of 20). Presentations discussed current best practice on eating disorders, evidence-based treatment approaches, the importance of carer involvement throughout the treatment journey, recent developments in treatment and research, and information about local referral pathways and service providers. Event participants included social workers, dietitians, counsellors, psychologists, nurses, school guidance officers and chaplains.

Presenters at these events included Carmel Fleming from EDOS, Melissa Marks from EDA, Fiona Hunt from TEIC, and Food for Thought project worker Karen Harper.

Interest in the Eating Disorder Information sessions was extensive. As a result, an additional Information Session was organised on the Sunshine Coast on 19 April 2016 as an adjunct to this project (supported by Food for Thought, but organised through EDA and run locally).

Participants completed a short survey/feedback form at the end of each session, which indicated that they had improved their knowledge, skills or strategies relevant for working with people affected by eating disorders. At the end of the sessions:

- Most participants rated their ability to identify people with eating disorders as either high (62%) or very high (14%)
- Most participants reported that they knew where to access support and assistance for people affected by eating disorders and for their carers (with 24% rating their knowledge as high, and 58% rating their knowledge as very high)
- Participants agreed that the material provided during the sessions was relevant and useful, and that the concepts were clearly explained
- More than 70% of participants agreed that the event was worthwhile and should be presented again
In response to a question about the topics they would like to learn more about, 47% of participants requested information on how to effectively involve family or other support people, and 57% requested information about treatment methods and approaches.

Events for eating disorder health professionals
Food for Thought, together with The Centre for Integrative Health (CFIH – a private provider of eating disorder related services), organised two events for local health professionals who specialise in treating eating disorders.

The first event brought together a group of 18 practitioners over breakfast on 18 April 2016. The group discussed ways to develop clearer referral pathways and improved service integration. The second event brought together the same practitioners, for a meeting on World Eating Disorder Action Day, on 2 June 2016.

Prior to the 2 June meeting, the practitioners completed a short survey and a service navigation mapping exercise. Their responses suggested that clearer mapping of service delivery within the region would greatly improve the ability of clients and their carers to find the treatment they need. Participants’ survey responses also addressed service navigation and current challenges:
- In response to a survey question about the most important ways of supporting clearer service navigation pathways, participants suggested reinforcing the importance of a constructive therapeutic relationship with the relevant health professional, stronger networks, clear navigation pathways, improved information, services being clear about their own limitations, and improved communication between services
- In response to a survey question about the current challenges or concerns they face in working within the eating disorder sector, most participants selected two responses – a lack of resources, and a lack of professional development specific to the sector.

At the 2 June event, participants worked together to map service and referral pathways that would be suitable for use by GPs and eating disorder health professionals.

This group of health professionals has now merged with the Eating Disorders (EDN), established in 2002. EDN met in July and August 2016, and has committed to quarterly meetings to create greater collaboration within the eating disorder sector. EDN will work together on specific events such as Body Image and Eating Disorders Awareness Week (BIEDAW) in September 2016. Chairing and secretariat duties for the EDN meetings will be shared amongst all participants.

Events for GPs
Food for Thought planned a dinner for GPs in North Brisbane, to help improve their knowledge of eating disorders and their understanding of best-practice treatment pathways. It proved difficult to bring GPs together for a dinner, and the project’s steering sub-committee realised that a special event would reach only a very small group of GPs. In response to this, the steering sub-committee agreed to reach out to GPs through an existing event – the General Practice Conference and Exhibition, in August 2016. That event is discussed in more detail in the following section.
Participation in existing events
Food for Thought participated in three relevant, existing events: two Family Information Days and the General Practice Conference and Exhibition.

Family Information
Days are organised by EDA for carers and extended family to gather information and learn about eating disorders and their treatment. Speakers include a GP, dietitian, counsellor, a person with a lived experience of an eating disorder and a carer. Food for Thought participated in two Family Information Days - at the Sunshine Coast in November 2015, and in Brisbane in February 2016. Food for Thought’s project worker, Karen Harper, provided an overview of the project and surveyed participants.

Food for Thought exhibited at the General Practice Conference and Exhibition from 26-28 August, 2016. The conference was attended by more than 500 primary health care professionals from Queensland. It provided an opportunity to raise awareness, generate dialogue, distribute information directly to GPs and answer specific questions about eating disorders. At the conference, Food for Thought:

- Scheduled eating disorder professionals to be available for consultation (including Nurse Practitioners from the Child Youth Mental Health Eating Disorder Team, a Nurse Practitioner from EDOS and Food for Thought project worker Karen Harper)
- Distributed printed information, including the Potential Eating Disorder Assessment tool developed by the project (Appendix 3) and a resource developed specifically for the conference – Links to eating disorder information for General Practitioners (Appendix 4)
- Distributed 240 USB memory sticks with a wide range of relevant electronic resources collated by the project
- Met with 140 delegates who visited the stand to ask questions and gather information.

The Food for Thought materials received positive responses from GPs and an enthusiasm to incorporate them into practice. Participating at the event generated increased awareness about eating disorders amongst both speaker convenors and delegates. Conversations are already underway about scheduling an eating disorder session for the 2017 conference. A brief report of Food for Thought’s involvement in the conference is included in Appendix 1.

Social Marketing Activities
Food for Thought launched a Facebook page for carers on 4 September 2015. The page was designed as a way to bring together carers facing similar issues in an online community and provide carers with a way to contribute to the Food for Thought project. Carers were invited to provide feedback about where they access information, give feedback on project materials, and provide their ideas about the project’s content.

The page was maintained and updated by Blue Flame Media on behalf of the Food for Thought project.

When the Food for Thought project ended in August 2016, the Facebook page had 695 ‘likes’. Most posts reached around 495 people, with the most popular post reaching 1500 people (this post was a personal story published on World Eating Disorder Action Day). Posts included short videos, personal stories, information for carers, promotion for specific events and information about the project.
The Facebook page provided a way for carers to engage in an online community, give feedback about key topics, seek information and share information. The Facebook page provided an excellent forum for distributing information to carers and seeing what things were most interesting to people. Users of the page were most interested in relevant images and uplifting sayings.

At the conclusion of the Food for Thought project, the Facebook page was rolled into the page maintained by EDA.

A brief report about the Facebook aspect of the Food for Thought project, prepared by Blue Flame Media, is included in Appendix 2.

**Information resources**

The Food for Thought Project developed The Eating Disorders Carers Help Kit – a web-based toolkit designed to provide information and support, and improve the accessibility of existing information about eating disorders. The Carers Help Kit was developed by scanning currently available online information and consulting with carers to review the suitability of existing content and identify shortfalls. The Carers Help Kit brings together the excellent resources already available and provides some new resources to fill the gaps identified by carers.

The Carers Help Kit was developed as an innovative web platform that acts as a portal to information. This means that people browsing the site can stay on the site rather than leave it every time they click a link.
The Carers Help Kit is designed to link carers with the best information available, educate carers about how navigate the system, and empower them with the information they need to ask questions and seek appropriate referrals.

Individual resources produced as part of Food for Thought are included in the Carers Help Kit (as downloadable electronic resources) and are also available in print. These include:

- **Potential Eating Disorder Assessment Tool** – a two-part form for use by both carers/people with possible eating disorders and GPs; the first part asks questions around thoughts and behaviours, and the second part is designed to get GPs undertaking key physical assessment criteria (attached in Appendix 3)
- **What to Expect From Your GP** – a guide that explains how a GP is likely to approach eating disorder assessments, which is designed to help carers and individuals know what to expect and how to book the right appointment (attached in Appendix 5)
- **Eating Disorder Assessment Pathway** – a guide on where to go in North Brisbane to start getting information, diagnosis, referral and treatment for a possible eating disorder (attached in Appendix 6)
- **Eating Disorder Treatment Continuum** – which explains the various health professionals involved in treating eating disorders (attached in Appendix 7).

The online Eating Disorders Carers Help Kit includes the following sections:

- Welcome
- What is an Eating Disorder?
- How to Start a Conversation
- Getting a Diagnosis
- Your Role as Carer
- What To Say & Not To Say
- Treatment
- Keeping Strong For Them
- The Long-Term Case.

The kit (website) is written in accessible, non-medical language, and directly addresses carers. It provides an overview of the important issues under each topic, and links to reliable information including introductory materials, detailed information and research, videos and case studies. It provides pathways and a trusted network that can help carers navigate the system and locate the information they need. While the help kit is particularly designed for carers, the information it includes will also be useful for health professionals and community services.

Current funding enables the kit to be maintained and updated as a separate website for three years. When funding finishes in 2019, the resource will be incorporated into the EDA website.

The Eating Disorders Carers Help Kit was launched on 31 July 2016.
Evaluation

Food for Thought was evaluated and reviewed as the project progressed:

- Evaluation and feedback from the project committee, carers, health professionals and service providers contributed to the project’s direction and to the content and design of the project’s resources. Ongoing evaluation helped to ensure that resources were carefully targeted to carers and tested with carers prior to final production. Ongoing updates and evaluation will occur to ensure continuous improvement.

- Surveys were conducted at the end of the Eating Disorder Information Sessions with health professionals and community organisations. These evaluations suggested that participants became more confident in their ability to identify people with eating disorders, more familiar with the ways to access support and assistance for people affected by eating disorders, more confident and knowledgeable about referrals, and more aware of the importance of carers in treatment and recovery. These evaluations suggested that information sessions should be held multiple times each year.

- The Facebook page was evaluated through usage statistics and engagement which revealed that the page was highly valued by carers. A report about the Facebook page is included in Appendix 2.

- The Eating Disorders Carers Help Kit was launched on 31 July 2016, and has not yet been evaluated. EDA and TEIC will monitor usage statistics and conduct an informal evaluation in early 2017. Feedback from carers who reviewed the site before it was launched included: 'Love the content, wish this was around 3 years ago when we needed it' and 'I do think you did very well and should be pleased with the results'. In August 2016, the site received 658 visitors; 33 of those visitors remained at the site for more than one hour, and 41 visitors stayed for between 30 and 60 minutes. The top downloads were the pathways infographic (26 downloads) and the assessment tool (21 downloads). The site developers completed the SEO setup in late August, and will review it after one month. A survey on the site seeks feedback from visitors, and its results will be analysed in January 2017.

Service integration and system reform outcomes will be gradual, and evaluation will be required over an extended period. The Food for Thought project identified the key issues that need to be addressed in terms of service integration and system reform from the perspective of the carers of adults with an eating disorder:

- Accessible and accurate information available on the internet and easily findable
- A pathway for getting an eating disorder detected and diagnosed
- A pathway and an understanding of treatment options
- Increased understanding and ability to detect eating disorders in primary health networks.

Project sustainability

Food for Thought was a fixed-term project that finished on 31 August 2016:

- The most important aspect of the project’s work was to improve service integration and promote system reform for carers. At its completion, this project has provided a platform from which carers can gain a better understanding of the system and how to navigate it. Many aspects
of the project are sustainable and will have a long-term impact on the support available to those who care for people with eating disorders

- The improved networks and local understanding of referral pathways will extend beyond the life of the project
- The Eating Disorder Network has new members and a stronger networking component
- The resources developed through the project will be available for the long term. The printed information distributed to health professionals and service providers will provide a permanent resource available for their use. Resources will also be available from EDA and TEIC. The website can continue to be readily updated by EDA as new materials around eating disorders are developed nationally or internationally
- The Eating Disorders Carers Help Kit will be available online in its current location until at least 2019. After 2019, it is likely to be rolled into the existing EDA website. Updating the kit will involve minimal work, as the website is designed as a linking and referral tool
- The Facebook page is being rolled into the EDA Facebook page, so its valuable content will not be lost.

**Recommendations**

Through the development, implementation and evaluation of this project we have identified a number of areas that would benefit from future focus. The following recommendations will benefit carers, individuals with lived experience of eating disorders, health professionals, service providers the broader community:

- Ongoing eating disorder information sessions for health professionals and service providers are needed and would be highly valued by people in North Brisbane and wider networks. We currently have a waiting list for future information sessions
- Eating disorder service providers and support organisations would benefit from increased links with similar organisations across Australia, with improved sharing of resources and project outcomes, and the sharing and tailoring of projects which can be implemented locally
- More research and consultation is needed to determine and inform the best case management model for the carers of individuals with eating disorders. The system in its current form is challenging for carers and health professionals due to the complexity of eating disorders and the reluctance of consumers to be engaged in treatment. At present, the bulk of case management falls to carers and any future model should consider their needs as well as the needs of the individual with an eating disorder. It is naive to assume that any case management model can be developed without the inclusion of carers, given that the national standard schema for eating disorders indicates that including carers is essential for the delivery of effective eating disorders treatment. There is a current project underway in Victoria which may give a basis for us to explore the possibility of producing a pilot carer inclusive case management model in Queensland
- Queensland would benefit from a funded coordinator to continue the work which has been started by this project, such as improving service integration and system reform for those with eating disorders and their carers.
### Project income and Expenditure as at 31 August 2016

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<td>Salaries, fees, allowance, admin costs</td>
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### Acknowledgements

Thanks to:

- The carers who contributed through the consultation group or steering committee, and the other many carers that provided thoughts, feedback and their experiences in a formal and informal way. Project worker Karen Harper noted: *I appreciate their input above all else!*
- The staff at Eating Disorders Outreach Service, in particular Carmel Fleming, Elaine Painter and Janice Jack
- The various health professionals in private practice, including Dr Leanne Barron, Cathy Dart and the Centre for Integrative Health
- Angela Taylor from Brisbane North PHN for project support as well as venue supply and organising review of materials
- Belinda Caldwell from the Victorian Centre of Excellence in Eating Disorders
- Staff at National Centre for Eating Disorders Collaboration.
Appendix 1

Brisbane General Practice Conference and Exhibition Report

Brisbane General Practice Conference and Exhibition
August 26 – 28th 2016
Stand 1016 – Eating Disorders Information
Conference delegates 500

Aim of our attendance: GPs are generally the first point of contact for assessment and treatment for people with a possible eating disorder or their families. With this project we have found it hard to get information to GP’s about eating disorders.

Aims:
1. Raise awareness of eating disorders
2. Increase confidence of GPs and PNs to be able to initially assess an eating disorder and to know where to refer or who to talk with for further assistance

Stand 1016 was situated along the path between Lounge and keynote address room. Our busiest time was 11.15am until midday, prior to the keynote session daily. Friday lunch time was busy also. Saturday we saw the same number of people but more gently paced.

Stand size 3 x 3 on a corner (open 2 sides), cost $4,400 incl gst (special rate as full rate $7,700)

Materials Distributed
- 240 – USBs with comprehensive eating disorder information, if we had more they would have been taken (USB included an electronic version of most items below)
- 250 – Understanding Eating Disorders Booklets (EDA)
- 50 – service outlines for both CYMHS-EDT and EDOS
- 50 – GP info sheets for Eating Disorder Assessment Tool, Links and contacts QLD plus GP’s play a vital role
- Postcards – about 300 taken
- NEDC – fact sheets, 17 of each type taken; all GP guides taken
- Printed Bags – about 20 of these taken (we would not take these in future)

Friday 26th 8 – 5pm, Karen Harper all day, Edith (8.30-4pm) and Richard (12-2.30) from CYMHS
60 Stand visitors who had a conversation and showed interest.

Saturday 27th 8 – 5.30pm, Karen Harper all day, Janice from EDOS for most of the day.
60 Stand visitors who had a conversation and showed interest.

Sunday 28th 8 – 5pm, Karen Harper all day, cancelled the other staff due to low conference numbers.
22 Stand visits who had a conversation and showed interest.
Summary of stand visits (there were no formal statistics gathered; this is based on information gathered while talking with conference participants and staff jotting down notes)

<table>
<thead>
<tr>
<th>Day</th>
<th>Brisbane GP</th>
<th>Brisbane NP</th>
<th>QLD GP</th>
<th>QLD NP</th>
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</tbody>
</table>

NP = Nurse practitioner or professional other than GP. For times we did not know difference they are in GP column. Brisbane includes Gold and Sunshine Coast.

Please note that additional to stand visits indicated here, other people did take information without a conversation. Additionally 35 information packs were given out to delegates attending the mental health education sessions at the conference.

We had a couple of specific inquiries around anorexia in the elderly or those with dementia. Also a number of queries around obesity.

Final thoughts:
- It was good to have stall staffed by a range of workers, from broad general knowledge of eating disorders with a state-wide perspective and face-to-face service workers.
- Having information on USB proved excellent, also having a USB which is different was a talking point and people stopped to look.
- Having a stand that did not promote one service particularly seemed to appeal, GPs seemed reluctant to be sold any product or service but were very keen for information.
- A simple potential eating disorder assessment tool to show and offer GPs and PNs as a start place for assessment was very well received; some mentioned finding ways to incorporate it into their practice systems.
- Postcards and walls images did generate conversation, and the postcards were obviously talked about at other stands as we got visitors who had seen them elsewhere.
- In future I would once again use USB for all the material and limit the printed material I take two copies of most things so that you can talk to them and show content. 20 copies of things like NEDC fact sheets, 50 copies of service information. 70 copies of the GP specific sheets like eating disorder potential assessment tool and key links and contacts. I would still take bulk amount of Understanding Eating Disorders booklet.
- Regional workers also identified the PHN newsletter as how they find out about any education or events coming up in their region.

The other advantage of being at GPCE was networking opportunities and raising awareness of eating disorders being a potential topic for future conference sessions.
| Janice from EDOS (having fun) | EDOS explaining information to a Gladstone GP | Edith and Richard from CYMHSEDST |
Appendix 2

Facebook Report

**Audience**

<table>
<thead>
<tr>
<th>MM/DD/YYYY: 01/09/2015</th>
<th>0</th>
<th>(Start)</th>
</tr>
</thead>
<tbody>
<tr>
<td>MM/DD/YYYY: 15/08/2016</td>
<td>695</td>
<td>(End)</td>
</tr>
</tbody>
</table>

- **92%**
- **8%**

**Most Engaged**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>13-18</th>
<th>19-24</th>
<th>25-34</th>
<th>35-44</th>
<th>45-65</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage</td>
<td>2.5%</td>
<td>41%</td>
<td>26%</td>
<td>14%</td>
<td>16.5%</td>
</tr>
</tbody>
</table>

- **1%**
- **22%**
- **37%**
- **15%**
- **25%**

**Location**

<table>
<thead>
<tr>
<th>Location</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brisbane</td>
<td>50%</td>
</tr>
<tr>
<td>Gold Coast</td>
<td>15%</td>
</tr>
<tr>
<td>Sunshine Coast</td>
<td>10%</td>
</tr>
<tr>
<td>QLD</td>
<td>5%</td>
</tr>
</tbody>
</table>

**Talking About**

- 475 reach per week
- 1,500 highest reach

**Rogue Pages**

- Existing: 0
- Claimed: 0

**Feedback:**

- Page has grown steadily over the last 11 months.
- Majority of your followers on the page are Female (90%).
- The highest like rate is from the 19 - 24 category but it is the 25 - 34 age group that interacts with the page the most.
- Brisbane has more than 50% of your audience while Gold Coast and Sunshine coast are also holding a large proportion. The remainder of QLD shares 5%.
- You average weekly reach is 475 but has been as high as 1,500 on topical posts (Men have eating disorders too).
- The post that had the most impact was the "World Eating Disorder Action Day" post - due to it being about the carers and a personal post.
- *Thought for the Day* posts did consistently well with the videos doing the best.
World Eating Disorder action day was yesterday. Brisbane eating disorder service providers held a meeting yesterday looking at how to improve interaction and navigation between service providers and those needing the services.
Men suffer from negative body image and eating disorders too and the statistics are alarming: Approximately 45% of western males are unhappy with their body. 17% are dieting at any given time. 1 in 10 anorexics is male and 3% of young Australian boys use muscle enhancing drugs ie steroids. (2008 National Survey of Young Australians).

Positive body image is important to EVERYONE!
<table>
<thead>
<tr>
<th>Published</th>
<th>Post</th>
<th>Type</th>
<th>Targeting</th>
<th>Reach</th>
<th>Engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td>03/06/2016</td>
<td>World Eating Disorder action day was yesterday. Brisbane eating disorder service providers held a meeting yest</td>
<td></td>
<td></td>
<td>733</td>
<td></td>
</tr>
<tr>
<td>23/06/2016</td>
<td>Timeline Photos</td>
<td></td>
<td></td>
<td>272</td>
<td></td>
</tr>
<tr>
<td>03/07/2016</td>
<td>Just for you. Tag a friend:</td>
<td></td>
<td></td>
<td>504</td>
<td></td>
</tr>
<tr>
<td>28/06/2016</td>
<td>Your thought for this morning :)</td>
<td></td>
<td></td>
<td>302</td>
<td></td>
</tr>
<tr>
<td>11/08/2016</td>
<td>Our Carer’s website is now LIVE! Specifically to help carers navigate and link to a range of helpful online eating</td>
<td></td>
<td></td>
<td>293</td>
<td></td>
</tr>
<tr>
<td>13/06/2016</td>
<td>The Patchwork Project uses embroidery and patchwork to narrate the lived experience of eating disorders throu</td>
<td></td>
<td></td>
<td>301</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 3

Information developed for the GPs conference

Links to eating disorder information for General Practitioners

Guides for GPs

Academy for Eating Disorders – Critical Points for Early Recognition and Medical Risk Management In the Care of Individuals with Eating Disorders. 2012 USA
An easy to read and understand guide including key guidelines, important facts, presenting signs and symptoms, early recognition, assessment, refeeding, goals of treatment, timely interventions, ongoing management, 11 pages.

Eating Disorders: An Information Pack for General Practitioners. 2012 QLD
Comprehensive guide with over 45 appendices. Includes role of GP, diagnosis, assessment, management, referral. 124 pages

Concise guide including general information, screening and assessment, appropriate referral, ongoing treatment and management. 18 pages.

Centers for Disease Control and Prevention Clinical Growth Charts
Clinical growth charts for children and adolescents. 2 to 20 years.
http://www.cdc.gov/growthcharts/clinical_charts.htm

Hunter New England Local Health District NSW 2014.
Provides a complete overview and sufficient detail to be very useful. Has NSW contact information however the clinical information accurate for QLD. 64 pages. Ph: 02 49246620

Professional eating disorder information


NICE National Institute for Health and Care Excellence, UK
Eating disorder pathways – comprehensive guide to various pathways for all the eating disorders based on latest evidenced based treatment options
http://pathways.nice.org.uk/pathways/eating-disorders

Information for patients, families and health workers

Royal Australian and New Zealand College of Psychiatrists – Eating Disorders Your guide to what they are and how they are treated. Aust 2015
A comprehensive outline of eating disorders for people with eating disorders and for those who are concerned or looking for information.

Eating Disorders Association – Understanding Eating Disorders. QLD 2014
A comprehensive booklet on eating disorders for all people and families affected by eating disorders, for the health professionals who support them and for the broader community.

www.EatingDisordersCarerHelpKit.com

Where to find local support and services for eating disorders

Queensland specific services

Queensland Health

Adults
The Eating Disorder Outreach Service (EDOS)
Provides assessment, care and treatment for people and their families affected by eating disorders. EDOS also provide advice, support, training and education for health professionals.
Phone: 07 3100 7500  Email: EDOS@health.qld.gov.au

Children and Youth
The CYMHS Eating Disorder Team
Offers a free and confidential service specialising in the treatment of children and youth up to 18 years of age who have a diagnosed Eating Disorder and are living in the Greater Brisbane Area. Referrals to the service may be made by Mental Health Services, Psychiatrists and Primary Health Providers including General Practitioners.
Phone: 07 3397 9077  Email: CHQ-CYMHS-Greenslopes@health.qld.gov.au

Government Supported Community Organisations

The Eating Issues Centre (TEIC)
Free telephone support QLD wide for people with an eating issue; limited space free counselling for bulk bill eating issue clients; fee paying groups and therapy for eating issues clients.
Phone: 07 3844 6055  Email: info@eatingissuescentre.org.au

Eating Disorders Association (EDA)
Free telephone support and information QLD wide for carers and family of people with an eating disorder; free counselling for carers and families in Brisbane area; information and contact details QLD wide for specialist eating disorders health professionals.
Phone: 07 3394 3661  Email: admin@eda.org.au

Private Health Providers

Eating Disorders Association (EDA)
For a list of private health professionals with experience in eating disorders.
Phone: 07 3394 3661  Email: admin@eda.org.au

Assessment tools

Feed your instinct
An online resource developed in 2016 aimed primarily at parents of children and adolescents. The FYI Eating and Body Image Checklist outlines some behaviour changes that may be noticed. Once the checklist is completed, FYI will generate a personalised report with a summary of the information which can be taken to the GP for further assessment.

Potential Eating Disorder Assessment Tool
Developed in 2016 aimed primarily at adults with potential eating disorders. The tool has questions around behaviours and thoughts followed by key observations to assist a GP in detection.

www.EatingDisordersCarerHelpKit.com

GPs play a vital role in eating disorder detection and treatment
You are usually the first point of contact

“Eating disorder symptoms can go unnoticed by health professionals for long periods unless they have the necessary knowledge and skill to identify signs and symptoms of the illnesses. In many instances, a patient will seek help or treatment for another issue, such as emotional problems or weight loss, without disclosing symptoms of an eating disorder.”
(Hudson, Hiripi, Pope & Kessler, 2007).

A five step guide to ensuring your patient receives the correct treatment in time

1. How to recognise an eating disorder early

“People who are identified and treated early in the course of an eating disorder have a significantly better chance of recovery when compared with those who have been living with an eating disorder for a longer period.”
(Compeence to prevent and treat eating disorders, NEDC 2015).

Consider:
- Do they meet any of the eating disorder high risk factors?
- Do they have any early warning signs – weight loss, preoccupation with food or exercise, body image concerns, emotional problems, infertility issues, and/or over exercising injuries?
- Are parents or carers concerned? It is important to listen to their concerns, as people with an eating disorder are likely to have a high level of ambivalence and fear, and will work to keep the eating disorder secret.

“The inclusion of families and carers as integral members of the treatment team is an essential principle for the delivery of effective eating disorders treatment”
(National standard schema for eating disorders, Appendix 3).

2. What to do when someone presents with risk factors

Start with a general question like:
- “Does your weight affect how you feel about yourself?”
- “Are you satisfied with your eating patterns?”
(Cotton, Ball & Robinson, 2003)

If the response is YES or you are still concerned, use one of these tools:
- Potential Eating Disorder GP Assessment Tool: http://eatingdisorderscarehelpkit.com/getting-a-diagnosis/
- NEDC Eating Disorder: a professional resource for general practitioners (SCOFF p5; Risk Assessment p7):

Get a second or expert opinion – details in section 5. It can also be helpful to establish what they have consumed in the last day or last 5 days.

3. What to do next

- Tell the person your concerns
- Don’t be surprised if they are angry, upset, or in denial if their eating disorder symptoms are questioned
- Discuss a course of action
- Involve the accompanying person (parent/carer) in treatment planning
- Consult with a specialised eating disorder service
  (details under section 5).

High risk factors

- Dieting: a factor common to all eating disorders is dieting
- Gender: 90% of sufferers are female especially around transitions including puberty, pregnancy and menopause
- Age: between 12 - 25
- Physical: those in competitive physical activity where body shape and size are a focus (e.g. dancer, model, athlete)
- Size: underweight, overweight, obese or those seeking to lose weight
- Psychological: traits like perfectionism, obsessive-compulsive, harm avoidance, poor self esteem
- Health Issues: diabetes, PCOS, substance abuse, gastrointestinal disorders and food allergies or yo yo dieting.
You are usually the first point of contact

“Without appropriate skill and expertise, experience in early intervention and treatment for people with eating disorders may do harm, prolonging the duration of illness, building resistance to treatment, and increasing the loss of hope in recovery and the risk of suicide.”

Competence to prevent and treat eating disorders NEDC 2015

4. Moving to treatment

An experienced eating disorder multidisciplinary team is most helpful in treatment, and usually includes a doctor, dietician, therapist and other allied health practitioners. However in some cases a referral to a specialist eating disorders treatment service may be more appropriate (details under section 5).

Contact the organisations below to find experienced practitioners in your area.

5. Assistance is readily available to GPs

The following Queensland health services offer information, advice and support to healthcare professionals as well as treatment and referral options to patients, carers and families affected by eating disorders:

- **Adults** – Eating Disorder Outreach Service (EDOS)
  Phone: 07 3100 7500
  Email: EDOS@health.qld.gov.au

- **Children and Youth** – Children Youth Mental Health Service
  Eating Disorder Team (CYMHS EDT)
  Phone: 07 3397 9077
  Email: CHQ-CYMHS-Greenslopes@health.qld.gov.au

- Additionally you can contact Eating Disorders Association (EDA) for information and contact details for specialist eating disorders health professionals throughout Queensland
  Phone: 07 3394 3661
  Email: admin@eda.org.au

  “Best practice would increase recovery rates from 5 to 8% initially (where almost nobody receives best practice treatment), up to 50 to 80% as enough health professionals are trained and centres constructed, to be able to provide best practice treatment for all new cases as they occur.”

  Investing in need, Butterfly Report 2014

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Eating Disorders

- Affect 1 in 11 Australians - it is possible that 1 in 11 of your patients have an eating disorder
- Are serious medical and mental illnesses
- Affects all genders, age, race and backgrounds
- Are increasing in males
- Have a mortality rate 12 times higher than any other mental illness
- Many people with eating disorders look healthy, yet may be extremely ill.
- Families are not to blame, and can be the best allies in treatment.
- Genes and environment play important roles in the development of eating disorders.

DON’T WATCH AND WAIT

If you suspect that your patient could have an eating disorder take action, ask questions and call for advice as soon as possible.
Appendix 4

Potential Eating Disorder Assessment Tool

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you make yourself sick because you feel uncomfortably full?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you worry you have lost control over how much you eat?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you recently lost more than 5kg in a 3 month period?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you believe yourself to be fat when others say you are too thin?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would you say that food dominates your life?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you try things to manage your weight?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Restricting food intake</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Use of laxatives</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Excessive intense exercise</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Induce vomiting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you feel ashamed at the amount of food you have eaten in one episode?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you ever eat in secret?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you make excuses to avoid family or social activities that involve food?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loss of or disturbance of menstrual periods?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fainting or dizziness?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Changes in emotional and psychological state?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e.g. low self-esteem, stress, anxiety, irritability, depression</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are you waking up sweating during the night?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

This section to be completed by your family member based on observation

<table>
<thead>
<tr>
<th>Observations</th>
<th>Critical Signs/Thresholds Indicating urgent medical attention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood Pressure Lying:</td>
<td>If postural changes of &gt;10mmHg &lt;90mmHg Systolic BP</td>
</tr>
<tr>
<td>Blood Pressure Standing:</td>
<td></td>
</tr>
<tr>
<td>Pulse Lying:</td>
<td>If &lt;50 bpm, &gt;100 bpm or if postural changes of &gt;20 bpm or if irregular</td>
</tr>
<tr>
<td>Pulse Scandling:</td>
<td></td>
</tr>
<tr>
<td>Temperature:</td>
<td>If &lt;35.5 (day/evening)</td>
</tr>
<tr>
<td>Respiratory rate:</td>
<td>If short of breath/ &lt;15 bpm or &gt;20 bpm</td>
</tr>
<tr>
<td>Blood Glucose Level (BGL):</td>
<td>If out of normal range (4-8mmol/L)</td>
</tr>
<tr>
<td>Glucose given:</td>
<td></td>
</tr>
<tr>
<td>ECG: Uwaves, QT interval (QTc = QT / √R)</td>
<td></td>
</tr>
<tr>
<td>Urinalysis 10strip: ketones, pH, specific gravity</td>
<td></td>
</tr>
<tr>
<td>Pathology: including ILFTs, FBC, magnesium</td>
<td></td>
</tr>
</tbody>
</table>

Notes:

Further Information or referral - QLD Health Eating Disorder Outreach Service (EDOS) - 13 3030 7900 for an intake pre-screen, which can provide advice and refer for support and medical practitioners. From 9am-8pm Monday to Friday, EDOS also offer clinics at RBWH Monday morning. A completed BDS will trigger referral if required. Download PESO Eating Disorders: A Professional Resource for General Practitioners. To find an Eating Disorder specialist, visit the Queensland Government website or contact your local General Practitioner. For further information or referral, please contact your local Health Service Provider.

References:
- Eating Disorders Career Help Kit 2015.

www.EatingDisordersCareerHelpKit.com
Appendix 5

What to Expect From Your GP

What to expect from your GP

How a General Practitioner with experience in Eating Disorders may treat an Eating Disorder Client.

1. Long appointment – Upon booking, if the patient’s condition is identified as a potential eating disorder, a long appointment is scheduled.

2. On arrival at clinic, the nurse will complete ECG, pulse, BP (sitting and standing), temperature, urine (10 strip for pH, ketones plus SG).

3. Accompanying person will be invited in. However, if the client/patient refuses, the Doctor will suggest something like ‘Perhaps we could ask them (carer/parent) in later for some general discussion.’

4. If accompanying person does not attend further appointments, ideally the Doctor will regularly have a conversation and update them by phone whilst the patient/client is in the room, so the patient has no concerns about breach of confidentiality.

5. On the second visit, another long appointment is booked and a Mental Health Care Plan or Chronic Health plan is completed.

6. Referrals are usually made for the client/patient to a suitable eating disorder dietitian (public or private), psychologist or therapist, and possibly after 3 months, a psychiatrist. Liaison between health professionals is generally conducted by phone.

7. If medically vulnerable (low BMI or out of balance electrolytes), the patient will be seen at least twice weekly.

8. As the patient improves, a fortnightly appointment will be attended, with bloods done on the off appointment week, with subsequent reduction in frequency as appropriate.

Further information or referral:

QLD Health, Eating Disorder Outreach Service (EDOS) 07 3100 7500 offer an intake phone service which can provide advice and referral for private and public medical practitioners (9am-4pm Monday to Friday). EDOS also offer a clinic at RBWH on Monday mornings; a completed EDOS written referral is required.


To find a General Practitioner with eating disorder experience in your area, contact Eating Disorders Association, phone 07 3394 3661.

www.EatingDisordersCarerHelpKit.com

## Appendix 7

### Eating Disorder Treatment Continuum

#### Eating Disorder Treatment Options Continuum

<table>
<thead>
<tr>
<th>Carer, peer and family / community support</th>
</tr>
</thead>
</table>
| Core treatment team of medical officer, dietitian, therapist and carer aiming at least disruptive model of care

<table>
<thead>
<tr>
<th>Community</th>
<th>Outpatient</th>
<th>Intensive outpatient</th>
<th>Inpatient treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Treatment Goals/Focus

- **Healthy relationship with food and body**
  - Interpersonal therapy
  - Weight restoration
  - Learning healthy coping strategies
  - Relapse prevention

- **Support**
  - Group therapy
  - Preparation for individual therapy
  - Nutritional rehabilitation/weight restoration

- **Nutritional rehabilitation**
  - Therapy
  - Dietetic treatment
  - Intensive treatment
  - Medical stability and monitoring
  - Transfer of care planning
  - Psychiatric stabilisation

#### What Treatment Providers Can Do

- **Prevention and early intervention**
  - Nutritional therapy
  - Psychological and psychiatric interventions
  - Family skills group
  - Delivery of evidence based therapies
  - Cognitive Behavioural Therapy Enhanced
  - Family Based Treatment
  - Maudsley Model of Anorexia Nervosa Treatment for Adults
  - Specialist Supportive Clinical Management

- **Specialist group day programs**
  - Evidence based treatment
  - Family Based Treatment
  - Maudsley Model of Anorexia Nervosa Treatment for Adults
  - Cognitive Behavioural Therapy Enhanced

- **Dietetic treatment**
  - Psychiatric treatment
  - Transfer of care planning
  - Limited therapy

#### Who is Responsible

- **Community mental health NGO including carer and family support**
  - Private and public practitioners
  - Community mental health

- **Private and public practitioners**
  - Community mental health

- **Specialist eating disorder treatment team**
  - Public or private

- **Intensive multidisciplinary inpatient treatment team**
  - Public or private

---

There are specialist eating disorder practitioners in both public and private sector. Call EDA for information and contact details.

- **EDOS (07) 3100 7555**
- **EDA (07) 3394 3661**
- **CYMHS EDT (07) 3397 9077**
- **TEIC (07) 3844 6055**

[www.EatingDisordersCarerHelpKit.com](http://www.EatingDisordersCarerHelpKit.com)