Outline of session

- Why?
  - What carers & families are saying
  - Clinical evidence
  - Policy directions
- How, where & when?
  - What’s happening in Victoria (& NSW)
  - Setting & meeting standards – helpful resources
  - What do you want to do?

Introduction & Questions

- What is the ethos in your services re family & carer engagement?
- Enablers & barriers to family & carer engagement?
- What are the specific challenges in ED recovery?
- Are there challenges that are specific to ED’s?
- What do we know from other illnesses & recovery about the need for/value of involving carers & families?

What Carers & Families are Saying

- Education – to increase their understanding and expectations of eating disorders and strategies on how to help their loved one
- Recognition of their role – inclusion in the treatment plan and engagement as part of the treatment team
- Support – in maintaining their own mental and physical health and well being
- Peer Support – connecting with other carers and families who are going through or have gone through similar experiences

This Could Include.....

- GP’s and other health professionals establishing treatment teams that include carers and families
- Psychoeducation from the treatment team
- Support groups for carers and all family members
- Specific strategies for their loved ones including young adults and partners

When we first saw our GP, she knew exactly what was happening with our son. She explained the condition, assured us there was help, and set us up with a fantastic treatment team.
The treatment team taught us everything we needed to know to support our child back to recovery.

When I thought it was all too much, the wonderful people in my peer support group were there to listen.

The specialist took the time to explain to me what my wife was going through, and how I could help her, while also taking care of myself.

National Agenda

• The right type of treatment – access to safe treatment that addresses all aspects of illness through integrated, evidence based multi disciplinary care

• Earlier access to treatment – early in subclinical presentation, illness and subsequent episodes of illness – to reduce the impact of illness and the risk of suicide and to support sustainable recovery

• Enabling sustainable recovery – the work of recovery takes time and occurs in the context of everyday life. Families play a vital role in helping people to identify risks, seek help, engage with treatment and sustain recovery

National Agenda - Meeting Needs of Families & Carers

At a minimum, families and carers need to be:

• Identified as the key people providing assistance to the person with an eating disorder

• Informed about eating disorders and specific treatment options and provided with opportunities to share information with the treatment team

• Referred to health, education and support services to meet their own needs

National Agenda - Meeting Needs of Families & Carers

Families and carers who play an active role in the provision of care need to be:

• Included in team decision making about treatment plans

• Educated to ensure that they have the skills to carry out their role

• Relieved – access to respite services such as in-home meal support

• Mentored - supervision and personal support to enable debriefing

• Peer support – opportunities to learn from other families and carers and provide mutual support

• Siblings support – formal and informal support for siblings who may experience disruption in their daily lives, and distress.
Key messages from policy & research

• Contemporary Mental Health care is client & family-centred
• NICE guidelines
• Prof. Janet Treasure - i.e. Best practice
• All evidence-based practices include a support/family system involvement. (FBT, SSCM)
  e.g. MOSAIC trial says they would have done more and earlier.
• Family Centred Practice, Open Dialogue

What keeps AN going (Treasure 2017)

Valued Nature of AN
Thinking Style
Other
Social & Emotional mind
Impact of AN on others
How Close Others
Keep AN going
Mismatch between challenges & resources

Traits/personality
Strengths
Events/challenges
Support

What you bring to AN

NICE Guidelines - May 2017

Communication and Information:

1.1 When assessing people with an eating disorder, the need to have a detailed understanding of the nature and extent of the problem is paramount. This requires a comprehensive assessment of the individual’s physical, psychological, and social functioning.
1.2 Work with patients and their families to develop a shared understanding of the problem and its underlying causes.
1.3 Foster an environment in which patients and their families feel supported and encouraged to participate in treatment planning and decision-making.

Support for people with eating disorders:

1.13 The need for a comprehensive and effective support system is critical to the success of treatment. This includes access to psychological and medical care, as well as social support from family, friends, and community. Other interventions may include medication, nutrition, and exercise.
1.14 The importance of providing ongoing support and follow-up care cannot be overstated.

Open Dialogue

The key elements of dialogue practice in open dialogue: Resilience criteria

Social Network Perspective

- Those who define the problem should be included in the treatment process
- A joint discussion and decision on who knows about the problem, who could help and who should be invited into the treatment meeting
- Family, relatives, friends, fellow workers and other authorities

Impact of AN on others

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Engaging Families & Carers

- What does policy say to guide service development?

Service Development in Vic & Carers/Families

Policy frameworks

1. Carers Recognition Act 2012
   - Acknowledges the important role of carers and outlines the responsibilities & obligations of services

2. Mental Health Act 2014
   - Affirms the role of carers, e.g., in Advanced Care planning where Nominated person can act on the advanced care (for when acutely unwell, not end of life issues) for the consumer

3. Victoria’s 10 year Mental Health plan (2015-25)
   - Lived experience (consumers and carers) to be part of services at all levels - that the design, development & delivery of services is all co-produced

4. The Mental Health Workforce strategy 2016
   - Places lived experience workforce as a central part of the workforce

NSW Policies

- NSW Family and Carer Mental Health Program
- NSW Carers (Recognition) Act 2010
- NSW Carers Strategy 2014 – 2019
- NSW MH ACT 2014

VICTORIAN MENTAL HEALTH ACT 2014 - Carers & families

Key messages:

- The Mental Health Act 2014 recognizes & supports the important role of carers in the assessment, treatment & recovery of people with mental illness.
- The Act also recognizes & supports the important role of parents in the treatment and care of children & young people.
- The Act provides for the appointment of a nominated person to support & represent the interests of a patient & to receive information about the patient’s assessment, treatment & recovery.
- The Act sets out when a person’s health information may be disclosed to a family member of a person with mental illness.
- The Act recognizes & supports the important role of carers & other key support people in the assessment, treatment & recovery of people with mental illness.
OBJECTIVE 4: CO-DESIGN & CO-DELIVERY WITH CONSUMERS AND CARERS

Engaging Families & Carers

- How, Why & When
  - What’s happening in Victoria
  - What do you want to do?
  - Setting & meeting standards – helpful resources

What CEED is Doing

- Championing FC & FF treatment in Victoria
  - Service development & workforce capacity development in offering:
    - family centred treatments: FBT & MFT
    - Family focussed – CCSW

- Championing co-design & co-production
  - funded carer consultant position in CEED team
  - Co-design & production seminars & training
  - Use of carer & consumer advisory groups, & advisors
  - Co-design & production psycho-ed resources for carers & clinicians

CEED Carer Consultant Role – 2014 onwards

5 key components:

- Case consultation - part of internal CEED team clinical discussions & planning
- Case consultation - Carer Case consultation - to Victorian MH Services
- Training for clinicians - providing lived experience perspective
- Systemic & service planning with the CEED team
- Resource development - for use by carers & clinicians

CEED Carer Consultant Role

Planning for 2017-18:

- Develop & trial an inpatient Carer Consultant role
- Develop a Starter Pack for families undertaking adolescent eating disorders treatment
- Awareness raising & promotion across all mental health services- of the needs for carers, families & individuals, the services & resources available & gaps to be addressed

What steps are Vic services taking

- Public CAMHS/CYMHS services since 2011 offer EB – FC treatment as first line treatment for EDs (AN)
- 2016-2017 Piloting of Multi-Family Therapy in CAMHS/CYMHS; project to embed MFT in services (2017-2018) [Alfred CYMHS, EH CYMHS, Barwon EDP]
- Several services have initiated carer consultant roles 2016 & 2017 [Alfred CYMHS, EH CYMHS]
- Offer CDCP forums for clinicians & families [Alfred CYMHS]
- CDCP parent support & psych-ed programs [RCH ED Program]
- Piloting of ED home outreach service with team consisting of clinicians & carer consultant [Alfred CYMHS]
- Adult ED services implementing & embedding CCSW as part of service components (BETRS, Barwon EDP, RMH EDP, Monash WRC)
Resources

A PRACTICAL GUIDE FOR WORKING WITH CARERS OF PEOPLE WITH A MENTAL ILLNESS

Group Discussion - What do you want to do?

- Involving carers more & earlier in treatment
- Involving carers in service development
- Involving carers in workforce development

- Discussion - using the Mind templates, discuss in small groups what steps your services have taken, and what next could they do?