A companion to the National Framework for Recovery Oriented Mental Health Services

INSIGHTS IN RECOVERY

A consumer-informed guide for health practitioners working with people with eating disorders

The Butterfly Foundation in partnership with the Mental Health Commission of NSW 2016

Mental Health Commission of New South Wales

Butterfly Foundation for Eating Disorders

thebutterflyfoundation.org.au

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For further information about the Insights in Recovery research project and the **Insights in Recovery** Guide please contact the Butterfly Foundation, Butterfly Research Institute;

103 Alexander Street, Crows Nest NSW 2065

BRI@thebutterflyfoundation.org.au

FOREWORD

ACKNOWLEDGEMENTS

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The Insights in Recovery Project gratefully acknowledges the time, effort and passion that both professionals and participants have brought to this process. Special thanks go to the Principle Researchers, Frances Cook and Elektra Walter of the Butterfly Foundation. Special thanks also go to Lesley Cook of Partners in Practice, and Dr Jocelyn Lowinger, the key authors of the Insights in Recovery Guide.

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Professor Phillipa Hay (Chair)

Ms Lesley Cook

Ms Katrina Davis

Dr Sarah Maguire

Associate Professor Paul Rhodes

Dr Elysa Roberts

Ms Kathy Thompson

Dr Lauren Waters.

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Insights into Recovery from Eating Disorders: Summary of Recovery Needs and Practices

Need	Practice
A shared understanding of recovery Recovery means breaking free of illness to be myself and finding and liking who I am – not just my body but who I really am as a person. The starting point for recovery oriented practice for health professionals working with people with eating disorders is engagement with the person, listening to their identity as people who are more than their illness and listening for their motivation for change.	The core of recovery oriented practice for people with eating disorders may be summarised as: **Help me...** the whole person in the context of my family and friends, my life and dreams **To feel...** help me to deal with my thoughts and feelings in a positive way **Safe...** help me to feel understood, less afraid and more hopeful in my journey through recovery

Help me to talk about my eating disorder
 	
I felt deeply ashamed about what was going on for me and that made it very difficult to talk about my eating disorder.
 	
If symptoms are ignored or dismissed as not serious, you can lose hope and motivation for recovery and feel as if you are not good enough.
 	
When I was first diagnosed it was really important that my health professionals helped me to understand about eating disorders.
 	
I needed to know eating disorders are serious and complex illnesses –but I also needed to have hope.
	One of the hardest things in recovery can be making a start, especially when working with a new health practitioner. Support disclosure and help people to understand the serious nature of their illness:
	
	• Use a screening tool such as SCOFF to invite disclosure of eating disorder concerns
	• For someone who is being diagnosed for the first time, provide information as needed on:
	  ◦ the different types of eating disorders – Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder and Other Specified Feeding and Eating Disorders (OSFED);
	  ◦ the different dimensions of recovery and why several different health professionals may be involved in their treatment;
	  ◦ recovery as a non-linear process that takes time; and
	  ◦ how the person can define their own goals for recovery.
	• If concerns are identified intervene early rather than waiting for symptoms to become severe
	• Help the person to find their own motivation for recovery.

Need	Practice
Help me to feel safe The most important feelings during my eating disorder were fear, shame and guilt. Absolute fear invaded every area of my life. I don't think that everyone gets how low your self esteem goes with an eating disorder. If people didn't pay attention to what I had to say then I would take it on board that I wasn't interesting enough. It helps me when health professionals establish trust and allow me to voice the concerns that I would normally try to keep hidden. Please remember I am being very vulnerable in front of you. I need a real relationship not just instructions.	A sense of safety is important for engagement. To support this: • Provide good general professional practice including compassion, calmness, honesty and care • Listen without judgement allowing people to voice their concerns • Listen to and acknowledge the distress that people experience without allowing the eating disorder to control how treatment progresses • Offer a sense of humour to alleviate tension • Be firm and empathetic around what constitutes appropriate behaviour in the treatment setting • Focus on the thoughts associated with eating disorders more than weight and appearance • Focus on things other than food that are motivating to build a new life • Increase opportunities for positive behaviours that are unrelated to food • Provide a physically warm, comfortable and relaxing environment • Offer maximum privacy • Foster a community atmosphere.

Need	Practice
Be aware of the words you use Please be careful with the words you choose. Anything someone says about me can send me into total shame. Language is important. There are expressions in everyday use that are taken for granted. Socially, we comment on appearance. Health professionals comment on signs of illness or recovery. When heard through the filter of an eating disorder these expressions can take on an unintended meaning.	Using positive, mindful language can support recovery efforts. As a practitioner: • Invite disclosure using evidence based screening tools • Use person-first language that acknowledges the person as more important than the eating disorder • Use accurate descriptive language rather than labels • When talking about self-control or willpower focus the conversation on the context of using willpower for recovery efforts. Care must be taken not to reinforce willpower as a mechanism for facilitating disordered eating • Notice and comment on achievement in all elements of recovery not just on weight and eating • Use positive and motivating language that builds hope • Ask open questions and allow for choice wherever possible • Try to avoid making comments about weight or appearance as these can be easily misinterpreted as complimenting the eating disorder • Shift the focus of discussion from food and exercise onto a wider view of all facets of recovery • Substitute words like 'try' and 'could' for words like 'should' and 'must' to move away from language that may feel controlling or induce feelings of shame • Use descriptions that accurately reflect what is happening for the person. Avoid simplistic labels such as 'non-compliance' • Try to ask questions rather than make direct comments, for example; 'are you feeling well today' or 'how are you feeling today' rather than 'you look well today'.

Need	Practice
Help me to find my identity It's easy to forget who you are in treatment. If people can't relate to who I am as a whole person what happens to my identity? It really helps me to feel like a whole person when you ask about my thoughts, listen to me talk without expressing judgement, and value what I have to say..	Strengthening self-identity is an important part of recovery. As a practitioner: • Learn about your patient as a person - their interests, hobbies, likes and talents • Talk to their family to learn more about them • Provide opportunities to help reconnect the person to their interests • Build a strong therapeutic relationship through genuine connections and letting your patients see you as a whole person.
Help me to make safe choices As I recover provide opportunities for me to learn how to make safe and healthy choices. It's important that I feel some control in my recovery. I need real guidance but I still need to own my own goals and progress. So please increase opportunities for positive behaviours that are unrelated to food.	Helping people learn to make safe choices promotes recovery. To facilitate this: • Empathise with each person in their unique situation. This does not mean you have to agree with them; attempt to see the world through their eyes and let them know you 'get it' • Provide clear meaningful reasons for treatment (and other) decisions • Actively include people in the development of their treatment plan and match the types of choices relating to eating behaviours to the stage in the treatment process. Where choices are constrained for safety reasons reinforce empathy and clear, meaningful explanations • Build in choices in areas of life unrelated to eating behaviour • Encourage autonomy building behaviour and communication from parents and peers • Avoid coercive language, controlling rewards, inducing guilt or shame • Provide access to palatable food. When eating is a goal of treatment food needs to be desirable • Provide healthy food choices wherever possible • Provide skills based learning on the

Need	Practice
Help me to find healthy support for recovery My eating disorder was born out of the need to cope with things I wasn't ready to cope with. Not feeling good enough is the underlying issue and I need help for this issue not just the eating behaviour. I need support during all the stages of recovery. Lack of support during recovery can increase the risk of recurrence. So help me identify social goals that support getting back into regular life.	Healthy support in all aspects of daily life is important. To facilitate this: • Work to establish trust through use of empathy and encourage help-seeking • Create opportunities for well-matched and safe peer support • Train peer-support workers to provide safe peer support • Help people with eating disorders learn how to develop safe relationships with appropriate boundaries • Encourage people to build (or rebuild) relationships with family and friends • Provide information on safe online communities.
Learn with me A partnership for recovery is not a one sided prescription of what I have to do. You don't need to have all the answers. We can work it out together. I think the best way to learn about recovery from an eating disorder is from people who have experienced recovery.	The best way to learn about recovery from an eating disorder is from people who have experienced recovery. • Provide professional development in eating disorders for all staff • Involve people who have recovered from different eating disorders in the provision of training and mentoring for professionals • Enable collaborative treatment involving different professionals and family members.

INTRODUCTION

Recovery Oriented Practice for Eating Disorders

Eating disorders are serious mental illnesses associated with significant physical complications. They carry the highest mortality rate of all psychiatric illnesses (Arcelus, Mitchel, Wales & Nelson, 2011). Eating disorders represent the 12th leading cause of mental health hospitalisation costs within Australia (Mathers, Vos & Stevenson, 1999, Deloitte Economics 2012).

Eating disorders have a high prevalence, with approximately one in 20 Australians currently having an eating disorder (Hay et al., 2008), and carry a substantial cost of care.

People of any age and gender can have an eating disorder
They may present in any healthcare setting
Every health professional has a role in eating disorder recovery

Restoration of physical, behavioural and psychological health can be achieved by people with a lived experience of an eating disorder with appropriate treatment (Bardone-Cone et al., 2010).

Only one in 10 men and women receive appropriate treatment
(Noordenbox, 2002).

There are many reasons for this, one of which is an inherent characteristic of the illness itself. People with eating disorders often experience a strong ambivalence towards treatment.

On average it takes seven years to achieve the diagnostic criteria for full recovery (Strober, Freeman & Morrell, 1997; Wade et al., 2006) and relapse and recurrence are significant issues during those years (Keel et al., 2005).

Even after cessation of symptoms recovery requires strategies to sustain motivation and healthy behaviours for the long term.

Person-centred care, tailored to suit that person's illness, situation and needs, is the most effective way to treat someone with an eating disorder (Hay et al., 2014). Understanding recovery from the patient's perspective helps health practitioners to tailor person-centred care and improve outcomes.

Simple everyday practices make a difference

The Insights in Recovery Research Project

Gaining insight into consumer experience is essential for effective implementation of mental health recovery policy. Exploring what motivates people to engage in recovery and how they understand recovery in their lives may usefully contribute to the development of effective practice.

Insights in Recovery was a consumer participatory research project translating knowledge from lived experience into a framework of recovery oriented practice for health professionals working with people with eating disorders. This was a co-designed and co-managed research project involving shared leadership between specialists in eating disorders and people with lived experience. The substantive component of the project involved extensive consultation with consumers.

The personal approach to recovery is now central to mental health care policy and standards in Australia. There is very little in the literature on the usefulness of the personal approach to recovery for people with eating disorders; however some authors (For example; Dawson, Rhodes & Touyz, 2014) have proposed that the personal recovery model could be beneficial to people with eating disorders.

The focus of this project was on identifying recovery oriented practices that any healthcare professional could utilise in any healthcare setting.

The substantive component of the project involved extensive consultation with consumers. 104 participants shared their narratives of recovery through an online survey. Thirteen of these participants also contributed through focus groups. The majority of participants were female (95%). All eating disorder diagnoses were represented in the sample however the majority had experience of anorexia nervosa (72%).

Experts in eating disorders treatment and health professionals with no prior knowledge of eating disorders played a role in translating what people with eating disorders want health professionals to know into guidance that is relevant to mental health services.

The process of recovery is something experienced by all who are faced with difficulties, and people with eating disorders identify components of recovery that are very similar to those identified by the personal recovery movement.

Important issues for participants included developing a sense of identity, experiencing personal agency in recovery, supportive relationships, choice and a sense of control, confidence and hope. Participants wanted to be seen as an individual person first rather than feeling categorised by their illness.

Recovery was understood to be a process of regaining a satisfactory life that was no longer dominated by thoughts of food or the punitive eating disorder voice. The narratives strongly emphasised the persistence of eating disorder thoughts after treatment and the need for access to on-going help to learn to manage these thoughts. There was an emphasis on gaining early access to eating disorders treatment, and treatment for the fatigue and physical consequences of eating disorders as factors contributing to social inclusion.

A disconnect in communication between health professionals and people with eating disorders was noted with notable impact on motivation for recovery in the early stages of help seeking. Feeling understood, safe and valued in treatment settings emerged as a strong theme.

Overall the data collected in the Insights in Recovery project supports the use of the personal recovery model and implementation of the National Framework for Recovery Oriented Mental Health Services (2013) as relevant to people with eating disorders.

This project has highlighted areas where recovery oriented approaches for people with eating disorders may require a different emphasis. Of particular note is the need for:

- positive professional responses to help seeking and self-disclosure and the prioritisation of early intervention
- an understanding of recovery as a long term process that addresses eating disorder thoughts and quality of life issues
- a focus on the thoughts associated with eating disorders rather than priority given to weight and appearance
- service settings and healthcare practices that promote feelings of safety to enable people to engage in the hard work of recovery
- a health workforce with knowledge of eating disorders recovery informed by the experience of people with eating disorders.

Findings from this study have informed the development of this resource on recovery oriented practice as a companion to the National Framework for Recovery Oriented Mental Health Services (2013).

The Insights in Recovery project was implemented by the Butterfly Foundation in partnership with the Mental Health Commission of NSW and supported in part by the Ian Potter Foundation.

Every health care practitioner has a role to play in the treatment and support of people with eating disorders. The multi-disciplinary treatment team brings together people with valuable knowledge, expertise and experience to work with the person with an eating disorder to help them achieve recovery.

This Guide outlines some of the basic practices that people with eating disorders have found helpful in their recovery and the background knowledge about eating disorders that was or would have been useful at the outset of their illness. The principles in the Guide are intended to support health practitioners in their important role in assisting recovery from eating disorders.

Eating Disorders

Eating disorders are serious mental illnesses associated with significant physical complications. The group of psychiatric illnesses includes anorexia nervosa, bulimia nervosa, binge eating disorder, and 'other specified feeding and eating disorders' (APA, 2013). People with eating disorders have disturbed eating behaviours and distorted beliefs, with extreme concerns about weight, shape, eating and body image. These disorders have been shown to have one of the highest impacts on health related quality of life of all psychiatric disorders (AIHW, 2008).

Recovery oriented practice is relevant to people with all forms of eating disorder.

While most of the people who contributed to the Insights in Recovery project had experience of anorexia nervosa; people with bulimia nervosa, binge eating disorder and atypical anorexia also participated. There was no discernible difference in responses based on diagnosis. This Guide therefore refers to the whole group of eating disorders.

Best Practice in Treating Eating Disorders

The Royal Australian and New Zealand College of Psychiatrists have published **Clinical Practice Guidelines for the Treatment of Eating Disorders** (Hay et al., 2014). These include a focus on treatment that promotes personal recovery. The principles in the Insights in Recovery Guide compliment this clinical document, focusing specifically on how professionals can meaningfully promote recovery-oriented practice for people with eating disorders.

The Clinical Practice Guidelines for the Treatment of Eating Disorders include the following:

- Person-centred informed decision-making
- Involving family and significant others as partners in the assessment and treatment process
- Least restrictive treatment context, where treatment is offered in the setting that is best suited to the individual's needs and preferences
- A dimensional and culturally informed approach to diagnosis and treatment
- **Recovery-oriented practice** which includes mental health care that:
- recognises and embraces the possibilities for recovery and wellbeing created by the inherent strength and capacity of all people experiencing mental health issues
- maximises self-determination and self-management of mental health and wellbeing
- assists families to understand the challenges and opportunities arising from their family members' experiences
- provides evidence-informed treatment, therapy rehabilitation and psychosocial support that helps people to achieve the best outcome for their mental health, physical health and wellbeing
- works in partnership with consumer organisations and a broad cross-section of services and community groups
- embraces and supports the development of new models of peer-run programs and services
- maximises choice
- supports positive risk-taking
- recognises the dignity of risk (i.e. the individual's right to make treatment choices that the treating health care team might not see as being the most effective decision)
- takes into account medico-legal requirements and duty of care
- promotes safety.

[1] 'Positive risk taking identifies the balance between the positive benefits that can be gained from risks and the possible negative consequences. It relies on a 'strengths approach' identifying the capabilities and wishes of the person who is taking the risk. Supporting positive risk taking enables people with mental illness to exercise a level of power in decision making about their own life (Morgan, 1996; 2013; 2014).

Personal Recovery

The most widely used definition of personal recovery was framed by Anthony (1993):

"…a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. Personal recovery is the process of change through which people improve their health and wellbeing and their quality of life."

The journey of personal recovery is a unique and individual process of change as the person works towards living what they define as a satisfying and meaningful life (Glover, 2010). Recovery "... means different things to different people. But most people agree that a person in recovery is working to take back control of his or her life and achieving her or his own goals and dreams" (Copeland, 2006).

The National Standards for Mental Health Services (The Department of Health, 2010) acknowledge "that each individual is an expert on their own life and that recovery involves working in partnership with individuals and their carers to provide support in a way that makes sense to them."

The stories of recovery that appear in this Guide are based on data collected by the Insights in Recovery research project from people who have recovered or are in recovery from an eating disorder. They represent the most common themes that occur in individual narratives of recovery. The experience of an eating disorder is highly individual; many people may not necessarily experience all of the concerns described in this Guide.

There is no single solution that suits every person with an eating disorder and it is therefore vital to consider and apply the perspectives of the individual, as they are the ones who decide how they engage in treatment and work towards recovery (Yu, Agras & Bryson 2013).

Understanding Recovery

Recovery should always be the goal of treatment, defined in ways that are meaningful to both the person and their treatment team (NEDC, 2012). A general, clinical definition of recovery that may be used as the basis for negotiating personal recovery was defined by Bardone-Cone and colleagues (2010):

Criteria for Recovery

1. **Diagnosis** – no longer meeting diagnostic criteria
2. **Behaviour** – no longer engaging in eating disorder behaviours
3. **Physical health** – weight within healthy BMI range and/or improved general health measures
4. **Psychological** – positive attitudes to one's self, food, the body, expression of emotions and social interaction
5. **Practical** – quality of life including capacity for engagement in work or education, and leisure

(Bardone-Cone, et al., 2010)

Personal Recovery Goals

For people with eating disorders, the idea of recovery is not just about diagnostic criteria, but about self-acceptance, having a social life, having a relaxed attitude to food and being able to express emotions (BjöRk & Ahlström, 2008).

Personal recovery means building a better future founded on the person's present circumstances. Every experience of recovery starts from a different place and leads to a different personally defined concept of recovery (Dawson, Rhodes & Touyz, 2014); there is no standard or universal goal to be achieved.

Progress in Recovery

Recovery is a process that may take an extended period of time, both during and after participation in treatment (NEDC, 2012). For people with different types of eating disorders recovery has been described as a 'long journey' (Reynen, 2012) and a 'complex process' with no single 'correct' pathway (Hay & Cho, 2013).

Relapse and recurrence are significant issues, with rates of relapse ranging from 22% to 51% across studies of people with anorexia nervosa and bulimia nervosa (Keel et al., 2005).

Set-backs and relapse are a common part of the process of recovery and not major obstacles to recovery (Reynen, 2012). The personal choice to pursue recovery must be made repeatedly throughout the recovery process.

Key Points for Practice

The way that the person and their health professional understand and talk about recovery has an impact on the possibility of recovery (Dawson, Rhodes & Touyz, 2014).

People need to know about eating disorders and understand they have a serious and complex illness. They also need to have realistic expectations for recovery.

For the patient who is being diagnosed for the first time, provide information on:

- The different types of eating disorders – Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder and Other Specified Feeding and Eating Disorders (OSFED)
- The different dimensions of recovery and why several different health professionals may be involved in their treatment
- Physical recovery – restoration of healthy eating behaviours and restoration of weight where this is required
- Psychological recovery – self-identity, meaning in life, coping skills, hope
- Functional recovery – building social skills and other practical life skills
- Recovery as a non-linear process that takes time. *"It's a bit like snakes and ladders – many pathways on and off recovery. But even if you skip off, there is always another pathway back on".*
- Recovery as realistic, personally achievable outcome where the person can define their own goals and expectations. *"Professionals have to believe in recovery. Don't tell us that we have to manage this for the rest of our lives. There is no motivation in that".*

Links to the National Framework for Recovery Oriented Mental Health Services

Domain 1: Promoting a culture and language of hope and optimism

Understand the philosophical underpinnings of recovery and its origins in the consumer movement. Maintain knowledge of current issues in recovery literature and research.

Domain 2: Person 1st and holistic
Capability 2A: Holistic and person-centred treatment, care, rehabilitation and psychosocial and other recovery support

In acknowledging and accepting the centrality of people with lived experience in their own recovery, mental health services seek to create environments enabling people to direct their own lives and meet the needs they have identified.

Mental health care acknowledges and is tailored to people's preferences, life circumstances and aspirations, and to their family and personal supports.

Mental health services recognise and account for the multiple elements that affect individuals' wellbeing including personal beliefs, cultural background, values, social and family contexts, physical health, housing, education and employment.

A recovery story

Recovery starts from the moment you want to recover.

Recovery begins when you find someone or something to relate to – something more important than the eating disorder. It is a life changing experience that isn't just about weight and eating.

Recovery is about dealing with ongoing eating disorder thoughts, learning strategies to control your sources of stress and resolving the underlying issues that started the eating disorder. It's about the freedom and flexibility to get through the day without being dominated by food.

So recovery means breaking free of illness to be yourself and finding and liking who you are - not just your body but who you really are as a person.

Recovery is about regaining a fulfilling life and working towards your own life goals.

Starting the journey of recovery

Progress can feel frustratingly slow but even if I go backwards I can still move forwards again towards my goals. Recovery is unique to the individual and ongoing. There can't be any prescriptive guidelines for recovery because everyone is different. It's a process of experimentation – of trial and error – and there needs to be room to try different approaches. The idea of being in recovery is useful. It reflects the ups and downs of life.

I needed to know what recovery really involved because I believed that no one recovered. I had no understanding of the steps needed for recovery. I thought I could get over my eating disorders by myself initially but after a couple of years of treatment I realised I couldn't. Unrealistic expectations of recovery (that it is quick, easy or predictable) make you feel as if you are failing at recovery and are de-motivating.

When I was first diagnosed it was really important that my health professionals helped me to understand about eating disorders. I needed to know eating disorders are serious and complex illnesses –but I also needed to have hope. It gave me hope to have someone help me believe that recovery was possible for me no matter what my diagnosis is or how long (or short a time) I have been unwell.

When you look at treatment programs you get the impression that recovery is all behaviour based. It's all about weight and eating not about the thoughts but this isn't real. Please don't set me up to fail by setting unachievable goals or stopping my treatment too soon.**:**

SUPPORTING DISCLOSURE

A recovery story

I didn't like the place I was in before I got sick, that's why I developed an eating disorder. But for me body image is not the real issue. It's all about the thoughts – the internal battle. I had underlying emotional issues, like not feeling good enough, that manifest as body image problems. With an eating disorder it's not just your appetite for food that is affected. You lose the appetite for living.

I felt deeply ashamed about what was going on for me and that made it very difficult to talk about my eating disorder. My life was dominated by fear. I felt I had to be perfect to be accepted. I felt I couldn't seek help because I didn't deserve it.

When I did finally seek help it wasn't always easy to convince my health professionals I had a problem. I felt I had to become really severely unwell in order to be worth noticing and get support. So getting sicker to get noticed became like a goal, a trophy to achieve. I felt intimidated and scared of what would happen in treatment.

Every time I tried to get treatment and failed I felt a sense of failure and hopelessness. I don't think that everyone gets how low your self-esteem goes.

Appearance isn't a good indicator of illness

The thing is, appearance isn't a good indication of the severity of illness and you cannot tell if someone has an eating disorder just by looking at them.

Don't dismiss the early symptoms…illness does not have to be 'severe' and at crisis point to be taken seriously.

Anyone could have an eating disorder. Screen for eating disorders by asking questions about my thoughts and feelings about food and about myself. Asking about thoughts…is the priority, more than the behaviours. I am probably not going to tell you all about the behaviours anyway, not until I trust you.

It's important to investigate the possibility of an eating disorder even when people have atypical symptoms. Even if you think someone doesn't quite meet the criteria you expected they still need help. If symptoms are ignored or dismissed as not serious, you can lose hope and motivation for recovery and feel as if you are not good enough. If people didn't pay attention to what I had to say and who I am then I would take it on board that I wasn't interesting enough.

Key Points for Practice

Invite disclosure

Fear and shame are commonly held feelings for people with eating disorders and may affect help seeking. People may not be explicit about their symptoms. It is important to take every presentation of an eating disorder – or possible eating disorder – seriously.

Using a screening tool helps you as the health professional to raise the subject and gives the person permission to talk about issues which cause them embarrassment and anxiety.

Opportunistic screening for eating disorders is a simple, safe and inexpensive approach that has the potential to enhance general health in people who are screened as well as identifying people who have or are at high risk of developing an eating disorder.

Evidence based resources exist to support screening including the simple five question SCOFF and the Eating Disorders Screen for Primary Care (ESP) tools.

- For more information on screening tools visit www.nedc.com.au

Intervene early

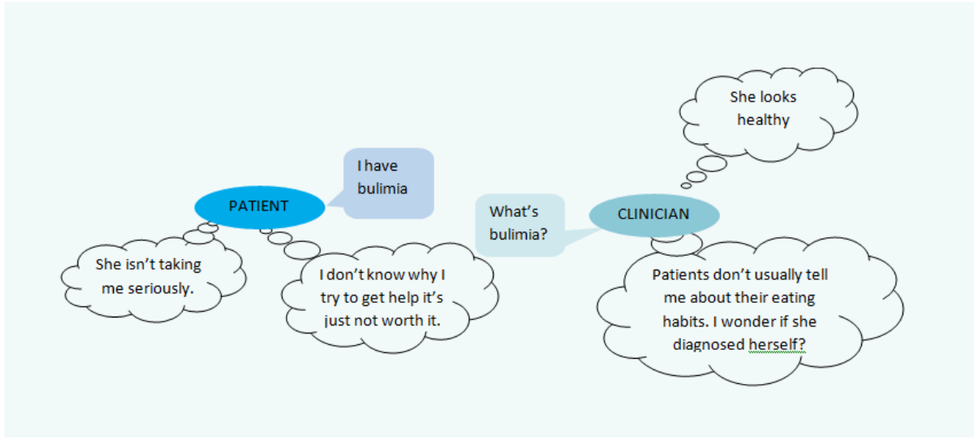
Early intervention is important to reduce the impact of eating disorders. Eating behaviours, thoughts and feelings sit on a continuum and a person who doesn't fulfil DSM criteria may still need help.

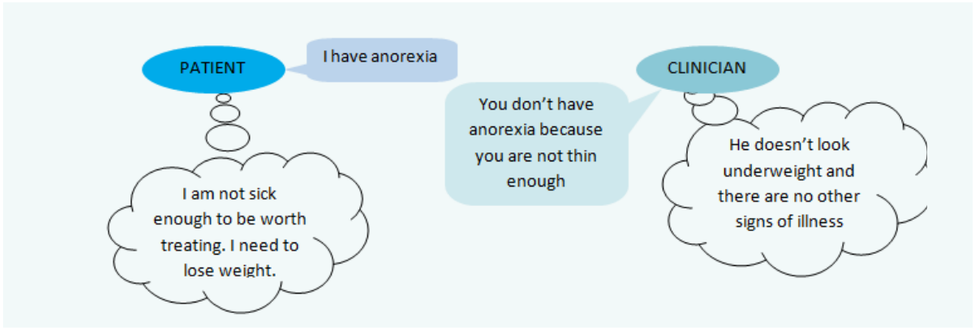
Screening is likely to identify people with disordered eating. This is the regular engagement in destructive eating or weight loss behaviours including binging and purging and is the most common step before development of an eating disorder.

While not sufficient to meet the current diagnostic criteria for a clinical disorder, disordered eating is a serious health problem in its own right contributing to medical and mental health problems and significantly increasing suicidal thoughts and behaviours in adolescents.

Communication

Worry about weight and dieting are so common today that it can be difficult to know how seriously to take a person's concerns. Professional caution, when heard through the filter of an eating disorder, can take on an unintended meaning.





Examples of this disconnect in communication from the Insights in Recovery research include:

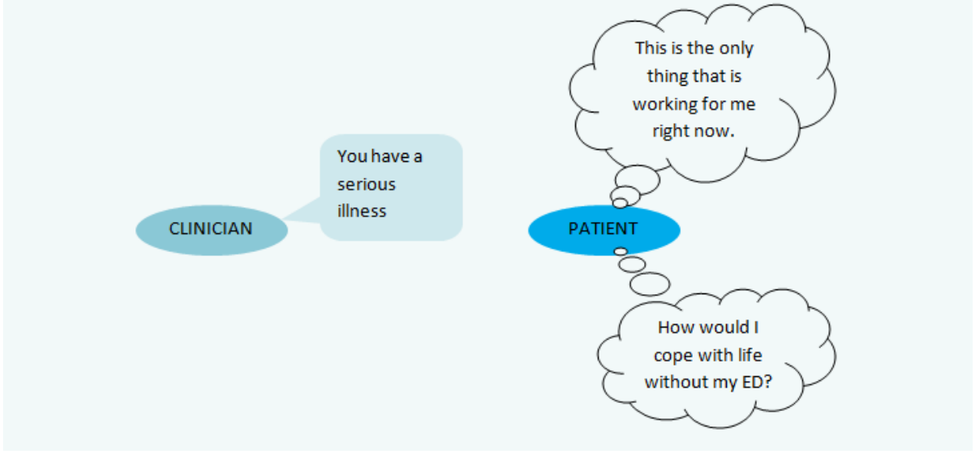
"Please don't tell me I am too fat to have anorexia"

"You can't tell how sick a person is by looking at them. Don't judge me on my appearance"

"I had one doctor ask 'What's bulimia?' Bulimia and binge eating disorders are STILL EDs – not just anorexia. It can be just as serious and damaging."

"It's such a huge thing to ask for help. Don't shut me down when I am asking for help."

Equally, a clear diagnosis of an eating disorder may meet with unexpected responses from the person.



When people are ambivalent about change, they have 'two sides'; the part that wants to change and the part that is against change.

It is important to help the person to find their own motivation for change, treatment and recovery. To aid this process, motivational interviewing techniques are helpful.

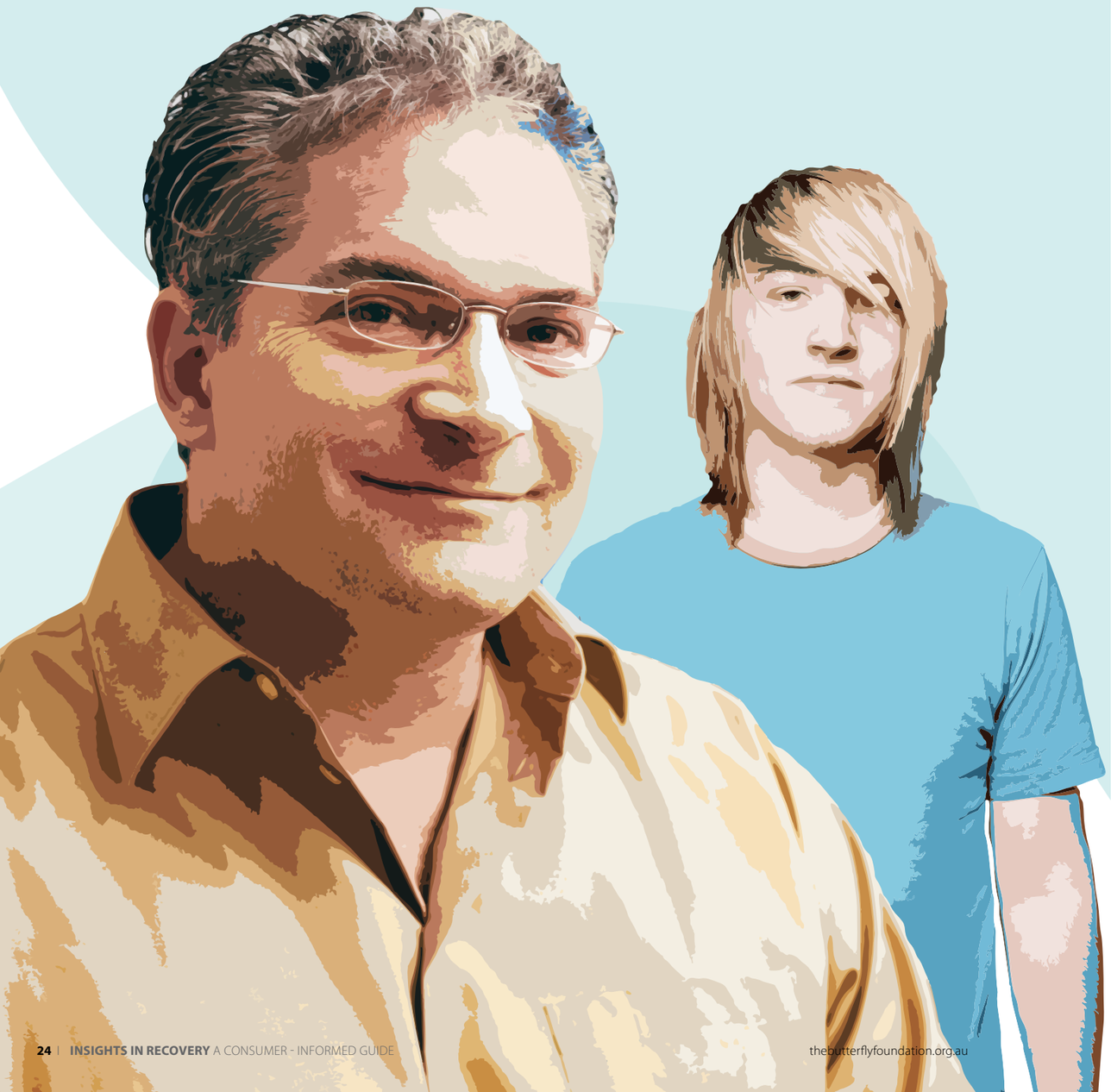
Motivational interviewing is a counselling style helping clients explore and resolve their ambivalence. It acknowledges that direct persuasion is not an effective method for resolving ambivalence and focuses instead on building a collaborative partnership where the motivation to change is elicited from the person.

Links to the National Framework for Recovery Oriented Mental Health Services

Domain 1: Promoting a culture and language of hope and optimism

Language matters. Services can make a significant contribution to and actively encourage people's recovery efforts by embedding and communicating a culture of hope, optimism, potentiality, choice and self-determination.

PROMOTING SAFETY



Why feeling safe matters

Feeling safe emerged as a strong theme from the Insights in Recovery research. People related safety to person-centred care, communication between themselves and their health professionals and to the service setting.

Person-centred care is care in which the person feels valued and respected. People want to receive care that is based on an integrated understanding of their lives and that enables them to continue working with the clinician in a positive relationship (Stewart, 2001).

In Australia, person-centred approaches are supported by the Australian Charter of Healthcare Rights, the Australian Safety and Quality Framework for Healthcare, National Standards for Mental Health Services and the National Framework for Recovery Oriented Mental Health Services.

A collaborative and empathic therapeutic relationship plays a key role in the experience of person centred care. In general, people who experience this relationship positively generally have better treatment outcomes (Martin, Garske, & Davis, 2000; Hewitt & Coffey, 2005). This has been found to be especially true for people with eating disorders (Knauss & Schofield, 2009).

Verbal communication plays a critical role in establishing feelings of trust and respect in therapeutic relationships. Communication involves more than the language used; it starts from the way in which health professionals listen and respond to what the person is able to share. It also includes non-verbal signals of safety and acceptance which are expressed in the physical service setting as well as by the health professional.

"Help me to feel safe"

One over-arching message was defined from all of the consumer information collected in the Insights in Recovery project.

This message was endorsed by people participating in the review process as an important request to all healthcare professionals. It provides a framework for understanding all of the suggested practices in this Guide.

Help me... the whole person in the context of my family and friends, my life and dreams

To feel... help me to deal with my thoughts and feelings in a positive way

Safe... help me to feel understood, less afraid and more hopeful in my journey through recovery

Helping people to feel safe is a theme in practice recommendations throughout this Guide.

A recovery story

The most important feelings during my eating disorder were fear, shame and guilt. Absolute fear invaded every area of my life. I felt I had to be perfect to be accepted and of course I knew I wasn't perfect. I was so afraid that I would do something wrong or not be good enough. Not meet other people's expectations and that included what I thought my clinician expected from me.

I was afraid I wouldn't get better and I was afraid of getting better. I was afraid that people would find out that I wasn't good enough. The fear would sometimes be exacerbated by panic.

I don't think that everyone gets how low your self esteem goes with an eating disorder. If people didn't pay attention to what I had to say then I would take it on board that I wasn't interesting enough.

I needed people who were gentle with me and nurtured me. People who made me feel valued, welcome and safe. But I also needed firm clear boundaries to help me feel safe. I needed to feel accepted as a person without people engaging with or encouraging my eating disorder self.

It helps me when health professionals establish trust and allow me to voice the concerns that I would normally try to keep hidden.

Key points for practice

Therapeutic Relationships

The development of a good therapeutic relationship is essential. People with a lived experience identified the following examples of this in practice:

- follow good general professional practice including compassion, calmness, honesty and care to help people with eating disorders to feel safe
- listen without judgement, allowing people to voice their concerns
- listen to and acknowledge the distress that people experience without allowing the eating disorder to control how treatment progresses
- use a sense of humour to alleviate tension
- be firm and empathetic on what constitutes appropriate behaviour in the treatment setting
- focus on the thoughts associated with eating disorders more than weight and appearance
- focus on things other than food that are motivating to build a new life
- increase opportunities for positive behaviours that are unrelated to food.

Service settings

The physical service setting and the structure of programs can help people to feel safe and open to engagement. For example:

- provide a physically warm, comfortable and relaxing environment
- offer maximum privacy
- foster a community atmosphere.

"Showing up and knowing what the room would look like - quiet, private, warm, same smell, same cup, same chair etc. really helped to creating a feeling of containment and safety to be able to talk about big things and scary things."

Links to the National Framework for Recovery Oriented Mental Health Practice

Domain 1: Promoting a culture and language of hope and optimism

Language matters. Services can make a significant contribution to and actively encourage people's recovery efforts by embedding and communicating a culture of hope, optimism, potentiality, choice and self-determination.

LANGUAGE MATTERS

Why language is important

In recovery it is important to use language that helps people *"feel valued, important, welcome and safe" as well as using language that "communicates positive expectations and promotes hope and optimism"* (Australian Health Ministers' Advisory Council, 2013).

Person first language (for example, 'a person struggling with anorexia') demonstrates the eating disorder is not as important as the person as an individual and as a human. This reduces stigma, is empowering and supports people to develop a sense of self-identify. Person-first language also uses accurate descriptions of a person's struggles rather than simplistic labels such as 'non-compliance' (Symanski-Tondora, Miller, Slade, & Davidson, 2014).

Recovery from eating disorders involves a number of inter-related dimensions (Palmer, 2014): developing healthy eating patterns and attitudes; resolving underlying psychological issues and building a positive sense of self-identity and self-worth and re-engaging in life.

It's important to acknowledge progress in all of these areas. Focusing on weight can be unhelpful and many people *"dread being thought of as 'better' or 'recovered' just because they have put on weight"* (Palmer, 2014, p. 89). There is more to recovery, and this needs to be acknowledged.

Coercive language, controlling rewards, and inducing guilt or shame reinforces external motivation, rather than helping move a person to an internally motivated autonomy (Kaap-Deeder et al., 2014).

A recovery story

Language is important. Please be careful with the words you choose. Anything someone says about me can send me into total shame.

Shift the focus of discussion away from food. Take the focus off food and focus on the other things that are motivating to help me build a new life. For example, avoid making remarks about weight or appearance. Even saying 'you look good today' may be interpreted as a comment about weight. Listen to the distress that I may be experiencing but don't negotiate with the eating disorder.

And please do not compliment the eating disorder in any way. Congratulate me on achieving social milestones as well as behavioural milestones.

Positive language is also helpful and reflects a belief that recovery is possible for everyone no matter what their diagnosis is or how long (or short a time) they have been unwell. Make positive suggestions such as 'you could' or 'try this' rather than using 'should' and 'must' especially in relation to food and exercise. Asking open questions helps me recognise the issues for myself..

Key points for practice

Words are powerful. Using mindful, positive language can affect recovery efforts by focussing attention on hope, growth, empowerment, and building self-identity. To mindfully use language to focus attention on recovery, health professionals can:

- use person-first language that acknowledges the person as more important than their eating disorder
- use accurate descriptive language rather than labels
- when talking about self-control or willpower focus the conversation on the context of using willpower for recovery efforts. Care must be taken not to reinforce willpower as a mechanism for facilitating disordered eating
- notice and comment on achievement in all elements of recovery not just on weight and eating
- use positive and motivating language that builds hope
- ask open questions and allow for choice wherever possible.

Things to Avoid

For a person with an eating disorder, therapeutic conversations can be fraught. Keep in mind to avoid comments that can reinforce the eating disorder.

- Try to avoid making comments about weight or appearance as these can be easily misinterpreted as complimenting the eating disorder
- Shift the focus of discussion from food and exercise onto a wider view of all facets of recovery
- Substitute words like 'try' and 'could for words like 'should' and 'must' to move away from language that may feel controlling or induce feelings of shame
- Use descriptions that accurately reflect what is happening for the person. Avoid simplistic labels such as 'non-compliance'.

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inks to the National Framework for Recovery Oriented Mental Health Practice

Domain 1: Promoting a culture and language of hope and optimism

Language matters. Services can make a significant contribution to and actively encourage people's recovery efforts by embedding and communicating a culture of hope, optimism, potentiality, choice and self-determination.

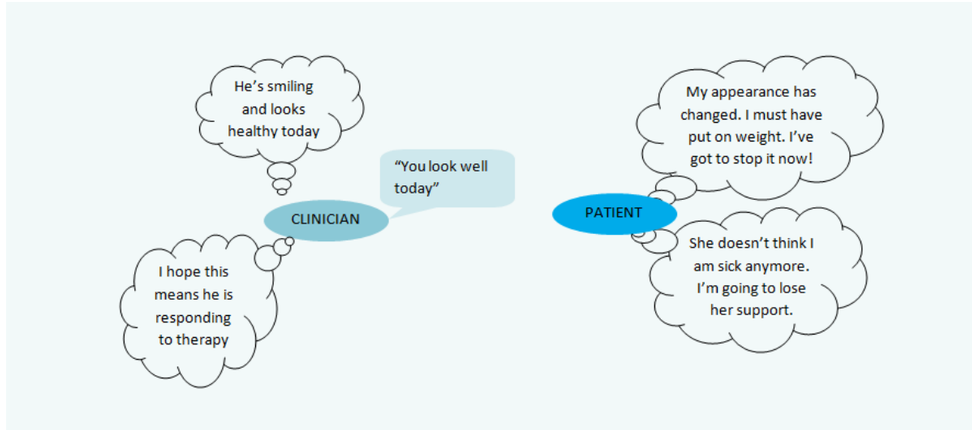
Domain 3: Supporting personal recovery

Staff interactions with people using mental health services promote increased personal control. Mental health services have a responsibility to respect people as partners in decisions affecting their mental health care. People's personal experiences, understandings, priorities and preferences shape decision making concerning service responses.

Communication

There are expressions in everyday use and in healthcare practice that we take for granted. Socially, we frequently comment on appearance. For example; "you're looking well". As health professionals we comment on signs of illness or recovery, for example; "you're looking better today" or "I can't see any signs of..."

When heard through the filter of an eating disorder these expressions can take on an unintended meaning. The diagrams below are based on feedback from participants in the Insights in Recovery project.



The following quotation is an example of this disconnect in communication from the Insights in Recovery research relating to food:

"It is unhelpful to talk about food. My mind is consumed by this all the time. Take the focus off food and focus on the other things that I find motivating to build my life."

The everyday nature of these expressions makes it difficult to monitor their use all the time. Asking questions can be a simple way in which health professionals can improve communication with the person with an eating disorder.

Ask a question, rather than making direct comments. For example, 'are you feeling well today' or 'how are you feeling today' rather than 'you look well today'.

Finding identity

Why identity development is important

People with an eating disorder often struggle with elements of their self-identity (Corning & Heibel, 2016).

Identity formation is thought to contribute to the development of eating disorders (Claes et al., 2015; Stein & Corte, 2008) and re-discovering of self-identity has been shown to form an important part of recovery from eating disorders (Smith et al., 2016).

Clinicians can promote recovery through building trust, making connections and seeing the patient as a whole person separate from the eating disorder (Smith et al., 2016). These are elements of a strong therapeutic alliance, which has been shown to improve outcomes in treatment of eating disorders (Hay & Touyz, 2015).

"Recovery-oriented practices are those that recognize the strengths of service users and empower them within the mental health system... recovery-oriented practices emphasize shared decision making, respect for service user goals, and the recognition of the full humanity of all persons in care relationships" (Atterbury, 2014).

A recovery story

We are people too – we may be a friend, a colleague or a family member with our own underlying issues, insecurities or dreams stifled by our eating disorder.

It's easy to forget who you are in treatment. If people can't relate to who you are as a whole person what happens to your identity?

When you engage in some ordinary everyday conversation rather than just talking about the eating disorder it really helps me regain a sense of self that is distinct from my eating disorder.

I need to find myself not think about myself as a stereotyped eating disorder. It helps when you see me as a person even when I can't see myself as anything other than my eating disorder.

It really helps me to feel like a whole person when you ask about my thoughts, listen to me talk without expressing judgement, and value what I have to say. It helps me rediscover who I am when you learn about who I was before the eating disorder and talk to the people who are important in my life to learn more about me.

My parents can be really good at tapping into what I used to be like and helping me to re-connect with my interests – waking up the real me.

Please remember we are being very vulnerable in front of you. We need a real relationship not just instructions. When you share a little about yourself with me I start to see you as a person and not so intimidating. It can be small stuff like knowing that you have a dog.

This type of interpersonal exchange is vital to help me value myself.

Key points for practice

Developing a sense of self-identity is an important part of recovery from eating disorders.

To help people learn to strengthen their self-identity health professionals can:

- learn about your patient as a person - their interests, hobbies, likes and talents
- talk to their family to learn more about them
- provide opportunities to help reconnect the person to their interests
- build a strong therapeutic alliance through genuine connections and letting your patients see you as a whole person.

Links to the National Framework for Recovery Oriented Mental Health Services

Domain 2: Person 1st and holistic

Putting people who experience mental health issues first and at the centre of practice and service delivery; viewing a person's life situation holistically.

Domain 3: Supporting personal recovery

3B: actively support people to recognise and draw on their strengths to build recovery skills and capacity for self-management of their mental health

INTEGRATE CHOICE

Why integrating choice is important

Recovery is characterised by regaining 'normal' levels of control or choice over eating (Smith et al., 2016).

Freedom to choose and personal control are core features of autonomy (OED Online, 2016). Striving for autonomy forms an important part of recovery from eating disorders (Smith et al., 2016) and fostering autonomy has been linked to improved wellbeing and improved outcomes in people with eating disorders (Kaap-Deeder et al., 2014; Verstuyf, Patrick, Vansteenkiste, & Teixeira, 2012).

In contrast feeling incapable may inhibit recovery for people with anorexia nervosa (Dawson, Rhodes & Touyz, 2014).

Autonomy is a core psychological need and is different to independence; varying degrees of dependence and guidance are required depending on where each person is in their recovery journey (Kaap-Deeder et al., 2014). Autonomy is about identifying with the importance of change and taking ownership over the change process. Building autonomy means fostering intrinsic motivation for change and moving away from externally imposed controls (Kaap-Deeder et al., 2014; Verstuyf et al., 2012).

This is an important concept as providing choice and control to people on issues directly related to their eating disorder differs for every person and depends on where they are in their treatment journey. To illustrate this tension; for some people handing over control of the illness can bring relief and having too much choice is problematic, while for others handing over all control brings anxiety and they may feel unsafe. Therefore the level of control required and associated need for autonomy and responsibility over eating changes as treatment progresses (Smith et al., 2016).

The person with an eating disorder may experience conflicting needs: 'I want to be trusted' and 'I want choice' versus 'I don't know what to do' and 'I can't do it alone'. This can make it difficult to provide treatment that is understood as a positive response to the person's needs.

Even in situations when individual choices are constrained, health professionals can still foster autonomy by *"empathizing with the patients' frame of reference and by providing a clear and meaningful rationale for a request"* (Kaap-Deeder et al., 2014, p. 587). When choices directly related to eating disorder behaviour are limited, research shows having choices over areas of life not governed by the eating disorder is empowering and can result in improved wellbeing (Smith et al., 2016).

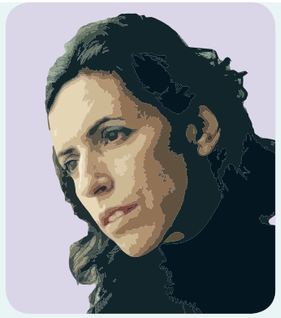
Impaired autonomy may be related to the development of an eating disorder (Verstuyf et al., 2012). Attitudes that do not foster autonomy remove a sense of a person's free will by using coercive language, controlling rewards, and inducing guilt or shame. These types of communication reinforce external motivation rather than helping move a person to an internally motivated autonomy (Kaap-Deeder et al., 2014).

Key points for practice

Helping people learn to make safe choices about their eating promotes recovery. The types of choice provided are dependent on their stage in the treatment process and the individual need for autonomy and choice at that time. Choice can be promoted through encouraging active participation in treatment decisions.

To help foster a sense of autonomy and promote choice in people with eating disorders, health professionals can:

- empathise with each person in their unique situation. This does NOT mean you have to agree with them – it means attempting to see the world through their eyes and letting them know you 'get it'
- provide clear meaningful reasons for treatment (and other) decisions
- actively include people in the development of their treatment plan and match the types of choices relating to eating behaviours to the stage in the treatment process. Where choices are constrained for safety reasons reinforce empathy and clear, meaningful explanations
- build in choices in areas of life unrelated to eating behaviour



A recovery story

Learning together

It helps me when you are open to learning about eating disorders in partnership with me and work with me to frame treatment goals and negotiate milestones that have meaning for me. So please help me to take ownership of my recovery.

A partnership for recovery is not a one sided prescription of what I have to do. If you meet me half way we can work this out together. You don't need to have all the answers. It's OK to refer me somewhere if you can't do everything yourself. Collaborative treatment involving different professionals and family members is very helpful.

Effective health professionals are validating, open minded and provide tailored individual therapy. The most helpful clinician I ever had wasn't an expert in eating disorders.

He said 'I know nothing about eating disorders so you will have to help me out'. He was completely open. Another time I had this really nice nurse in triage. She asked questions. She was very open and she was kind.

As I recover provide opportunities for me to learn how to make safe and healthy choices. It's important that I feel some control in my recovery. Psychologists and psychiatrists have such huge presence. You feel like you have to do what they say but this doesn't help you to learn to make choices and do things for yourself. Realistically, without development of these capabilities, I may be unable to continue my recovery in my daily life.

Things that help me feel I have choice include asking what I am comfortable with as the next step in recovery and allow me to share my views and to disagree with you.

I need real guidance but I still need to own my own goals and progress. So please increase opportunities for positive behaviours that are unrelated to food. Help me take ownership of my own recovery and let me have a say in everything, although I know that is pretty hard to do without letting the eating disorder have too much to say.

So help me learn the difference between me and the eating disorder voice by querying those that appear to be eating disorder thoughts like "is that your eating disorder speaking".

- encourage autonomy building behaviour and communication from parents and peers
- avoid coercive language, controlling rewards, inducing guilt or shame.

"Having a say in everything. I know that is pretty hard to do without letting the eating disorder have too much to say. You need to focus on the person and not the eating disorder voice".

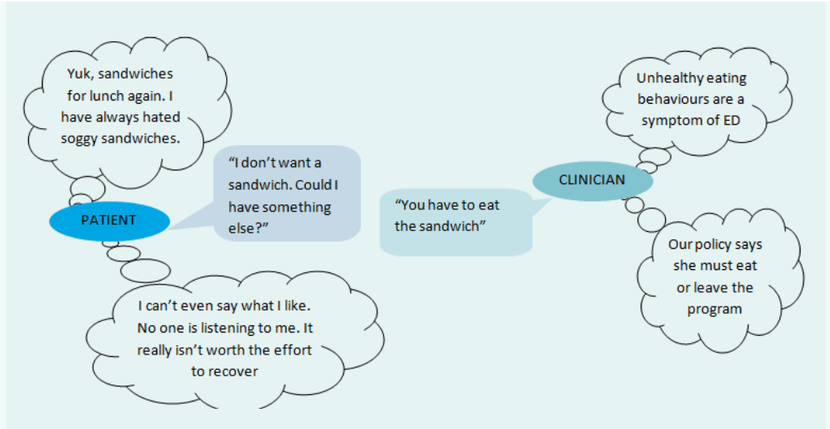
Program Practices

The way eating disorder programs integrate food and meals into their activities can help people to feel safe and to exercise healthy choice. For example, provide:

- access to palatable food. When eating is a goal of treatment food needs to be desirable
- healthy food choices wherever possible
- skills based learning on the preparation of food and on social eating.

Communication

In eating disorder programs, eating the meals provided is often a non-negotiable part of treatment. How we integrate choice and communicate about these aspects of treatment is important for recovery.



The following quote provides an example of this disconnect in communication from the Insights in Recovery feedback:

"It used to shit me when people told me it was my eating disorder talking or my eating disorder behaviour when it was really just my personal preference. Like being told to eat sandwiches when I really don't like sandwiches. That bit isn't my ED, it's me."

Links to the National Framework for Recovery Oriented Mental Health Services

Domain 2: Person 1st and holistic

Putting people who experience mental health issues first and at the centre of practice and service delivery; viewing a person's life situation holistically.

Domain 4: Organisational commitment and workforce development

The physical, social and cultural environment of a service inspires hope, optimism and humanistic practices.

HEALTHY SUPPORTS

Why healthy supports are important

Therapy for eating disorders is important however people with eating disorders identify a much wider range of factors that contribute to personal recovery including personal relationships, meaningful activities and positive life experiences (Espindola & Blay, 2009; Hay & Cho, 2013; Reynen, 2012).

The right type of support (whether from health professionals, peers or family) is an essential element of recovery (Dawson, Rhodes, & Touyz, 2014; Smith et al., 2016). Support promotes help-seeking, hope, development of coping skills, feelings of acceptance as well as ease a sense of isolation (Smith et al., 2016).

Trying to maintain change during the transition from treatment to self-management in daily living can be challenging. Follow up support and peer support are both identified as important adjuncts to treatment enabling people to sustain the outcomes of treatment (Federici & Kaplan, 2008).

People with eating disorders experience support through feeling understood (Dawson et al., 2014). Support from health professionals is perceived as helpful when they enable a sense of trust and connection as this promotes help seeking and disclosure of problems.

Peer-support in inpatient settings can be a form of non-judgmental acceptance, which helps people feel better understood and is highly valued by people with eating disorders.

Peers also can become effective role-models for development of coping skills and this provides a source of hope for recovery (Smith et al., 2016). Building supportive relationships with non-peer friends, family or even pets can also help promote recovery (Hay & Cho, 2013).

However, unhelpful support can impede recovery (Smith et al., 2016). Support from health professionals is perceived as unhelpful when they have not built up trust or when people feel misunderstood. Further, peers can be a negative influence and promote unhelpful behaviours.

For example, 'envy' of peers' appearance or behaviour can make behaviour worse and impede recovery. Also, needing to support distressed peers can become a distraction to their own treatment and recovery (Smith et al., 2016). Similarly, the inappropriate support found through pro-anorexia websites can foster anti-recovery views (Haas, Irr, Jennings, & Wagner, 2011).

- **For more information on support for consumers and carers, visit the Butterfly Foundation website www.thebutterflyfoundation.org.au**

Key points for practice

Recovery happens in daily life more than in the clinical setting. Healthy support is important across all stages of recovery and it is important to provide the right type of support. Sources of support include health professionals, peers, family and friends.

To help people with eating disorders feel supported health professionals can:

- work to establish trust through use of empathy and encourage help-seeking
- provide training to peer support workers that demonstrates how to provide safe peer support
- create opportunities for well-matched peer support
- help people with eating disorders learn how to develop safe relationships with appropriate boundaries

- encourage people to build (or rebuild) relationships with family and friends
- provide information on safe online communities.

"You need an intentional social support team. It doesn't have to be immediate family; it can be friends or peers. You need someone there with you for the long term. You can't get over an ED by yourself".

A recovery story

I think of myself as recovered but I still think a lot about food. Are you still recovered if you have some eating disorder thoughts? I expected it all to be gone and it's not.

My eating disorder was born out of the need to cope with things I wasn't ready to cope with. Not feeling good enough is the underlying issue and I need help for this issue not just the eating behaviour.

I need support during all the stages of recovery. Lack of support during recovery can increase the risk of recurrence. So help me identify social goals that support getting back into regular life.

The right kind of formal peer support is an integral part of treatment. Support healthy peer friendships within group treatment settings, match peer group members for similar stages of recovery and train peer leaders who have a variety of different experiences of illness.

I want to be safe so teach me how to maintain safe boundaries when forming relationships and show me how to have safe online access to peer support where face-to-face support is not practical.

As well as peer support, I also need access to out of hours support and support from family and friends in the long term.

Links to the National Framework for Recovery Oriented Mental Health Practice

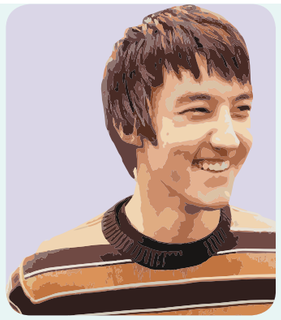
The development of healthy support is referred to in the National Framework for Recovery-Oriented Mental Health Services across all Domains.

Links to the National Framework for Recovery Oriented Mental Health Services

Domain 4: Organisational commitment and workforce development

4D: Workforce development and planning. Ongoing learning, skill development and reflection for recovery-based practice is built into an organisation's professional development processes and continuous quality improvement.

Informed by Lived Experience



A recovery story

Everyone including clinicians and researchers has a long way to go in really understanding what's happening in an eating disorder.

It really helps me when my health professionals have an up to date knowledge of eating disorders. That doesn't mean they have to know it all at the start. Sometimes the most helpful professionals are the ones who admit they don't know and are prepared to learn about eating disorders in partnership with me.

I think the best way to learn about recovery from an eating disorder is from people who have experienced recovery.

Key points for practice

- Provide professional development in eating disorders for all staff
- Involve people who have recovered from different eating disorders in the provision of training and mentoring for professionals
- Enable collaborative treatment involving different professionals and family members.

Next steps for professional practice

Professional development is an important step in effectively responding to eating disorders. Information on opportunities for development in Australia can be found through a number of organisations including but not limited to:

- The National Eating Disorders Collaboration (NEDC); an initiative of the Federal Department of Health, providing a nationally consistent, evidence based approach to eating disorders. www.nedc.com.au/professional-develop
- Centre for Eating and Dieting Disorders (CEDD); an academic and service support centre resulting from a collaboration between the Boden Institute of Obesity, Nutrition, Exercise & Eating Disorders at the University of Sydney and NSW Health. www.cedd.org.au
- Australia New Zealand Academy for Eating Disorders (ANZAED); the peak membership body representing and supporting the activities of professionals working in the field of eating disorders and related issues in prevention, treatment and research. www.anzaed.org.au/

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thebutterflyfoundation.org.au

Butterfly
Foundation for Eating Disorders

THE BUTTERFLY FOUNDATION - SYDNEY
103 Alexander Street Crows Nest NSW 2065
Phone: +61 2 9412 4499 Fax: +61 2 8090 8196
Email: info@thebutterflyfoundation.org.au

THE BUTTERFLY FOUNDATION - MELBOURNE
1430 Malvern Road Glen Iris VIC 3146
Phone: +61 3 9822 5771 Fax: +61 3 9822 5776
Email: info@thebutterflyfoundation.org.au

For support: 1800 ED HOPE – 1800 33 4673 or email: support@thebutterflyfoundation.org.au

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