

**Letting Others Know What Helps: How Young People with  
Eating Disorders can Explain their Preferences to Others**

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### Abstract

This paper primarily represents the views of young people with eating disorders who would like family, friends and professionals to understand what they find helpful and unhelpful but also presents alternative perspectives. A framework is proposed to aid such communication with examples to illustrate how this might be implemented and how this links to a cognitive behavioural approach. The benefits and challenges are described. Finally, suggestions are made for constructive communication regarding what is helpful and unhelpful and applicability to other contexts.

**Keywords:** Adolescent, anorexia nervosa, communication, eating disorder.

This paper describes a framework for use with young people with eating disorders to help them communicate what they find helpful and unhelpful and examples are given using this framework. The benefits and potential challenges of communicating on this issue are described and suggestions are made for constructive communication.

Since 2002, young people with eating disorders have been supported to run workshops at our national conference and at several of these events they have chosen to speak about what they find helpful and unhelpful. They clearly want their voices heard and feedback from the audiences of health professionals, young people and families has been that this information is invaluable and therefore it should be shared.

All involved in the care and treatment of adolescents with eating disorders want to be helpful, not unhelpful, but the question remains, how do we know what to do for the best? To help us understand how to approach the treatment of eating disorders generally we have treatment guidelines such as those produced by the National Institute for Clinical Excellence (NICE 2004). As noted in the NICE (2004) guidelines and by Treasure and Schmidt (2002) the evidence base for the effectiveness of eating disorders treatments is very weak. Guidelines for management are based mainly on expert clinical opinion (Gowers & Bryant-Waugh 2004). What follows is brief summary of some of the key recommendations.

The regular use of medication is not justified for the treatment of eating disorders and should be reserved for cases complicated by co-morbid diagnoses (Gowers & Bryant-Waugh 2004). There is limited evidence from randomised controlled trials suggesting that psychotherapy is more effective than non-specific routine follow-up by a junior psychiatrist (Dare, Eisler, Russell, Treasure & Dodge 2001). Whilst no psychotherapy has been shown to be beneficial over others, the important factors appear to be an enduring therapeutic relationship and empathic engagement (NICE 2004). Garner & Garkinkel (1997) report that there is some evidence for the

use of Cognitive Behavioural Therapy (CBT) in the treatment of anorexia nervosa and the framework suggested here does parallel some such techniques as shall be noted throughout. For young people, it is believed that the involvement of parents in treatment is crucial (Lock, Le Grange, Agras & Fairburn 2001) and the NICE (2004) guidelines recommend the use of family interventions. A key component of treatment is weight restoration and where possible it is recommended that this occurs on an outpatient basis with inpatient treatment reserved for cases of anorexia nervosa where there are serious complications related to co-morbid diagnoses and high physical or psychiatric risk (Nicholls & Bryant-Waugh 2003). Eating disorder sufferers are often ambivalent about recovery and it is therefore sometimes necessary for professionals to take control of decision-making. However, the goal remains to move towards working collaboratively with the young person. Interventions such as Motivational Enhancement Therapy (MET) are often employed to help the individual move to a position where they are more prepared to contemplate change (Gowers & Bryant-Waugh 2004). In addition, eating disorders treatment for young people should address developmental and psychosocial issues specific to adolescents (Kreipe et al. 1995) and should consider social and educational needs (Nicholls & Bryant-Waugh 2003).

In terms of knowing what is helpful on a more individual level, one can usually tell when the 'wrong' thing has been said or done but it can be far more difficult to know what is the 'right' thing to do. Many parents can no doubt relate to knowing that something they said or did was 'wrong' but being unsure what that was, feeling bemused, confused, anxious and wondering what to try next. It is understanding at this individual level that will be addressed here. The premise of this paper is that understanding requires communication.

The context is that of an 11-bedded regional inpatient unit for 11-18 year olds with eating disorders, which also offers outpatient and day patient treatment locally. Patients typically stay on the inpatient unit for approximately 4 months. The young people represented here mostly have a diagnosis of anorexia nervosa, therefore reference will be to anorexia nervosa and anorexic thinking throughout, although the ideas presented could just as easily apply to bulimia nervosa or other eating disorders.

In the early days of developing involvement in our service, patients' views tended to be expressed in the form 'it's unhelpful when you say or do this' with the underlying implication 'now we have told you, you should stop doing it'. As might be expected, this feedback was often met with defensiveness and counter-arguments that the young people were trying to be too controlling of others' behaviours. Involvement and collaboration on the unit has developed from this starting point, as has the framework proposed here, by supporting the young people to work together with us on a different method, which encourages explanations of the reasons behind the dislike of certain comments or behaviours and the suggestion of alternatives, thus taking a more empowering and less critical approach.

In my role as Head of Patient and Parent Involvement in this service, and as a former member of the clinical team, I have found that the young people want those close to them, for example family members and the professionals working with them, to have more understanding of, and be more sensitive to, the kinds of comments and behaviours that they find

unhelpful. 'Unhelpful' can mean lots of different things. These might include:

- Distressing.
- Making things more difficult.
- Raising anxiety levels.
- Reminding of worries, fears and negative things.
- Triggering thoughts and feelings that make the 'anorexic voice' stronger, harder to ignore or to resist.
- Too challenging to cope with in the given situation.

It is acknowledged that there may be many other perspectives on this topic and that parents, siblings, health professionals, friends, teachers and so on might have alternative views about hearing sufferers' preferences for how those close to them should behave in order to be helpful. An examination of a dialogue between these perspectives would be illuminating but is beyond the scope of this paper, although I attempt a brief outline of some of the possible arguments from both sides. Nevertheless it is right that young people's views are expressed here and this presents an opportunity for others holding different views to respond.

The thinking reported here is the result of several years of increasing patient and parent involvement within this service, where the emphasis is on striving for a culture of collaboration and partnership. Empowerment of young people and their parents is sought through information provision, recognition of their expertise and utilising this to produce materials, deliver training to professionals, develop and facilitate support networks and influence service decisions. The involvement of young people and parents is co-ordinated and supported by the Head of Patient and Parent Involvement, a part-time post created for this purpose. The views expressed here come from a variety of sources including:

- Presentation material and feedback forms from workshops at our annual national conference, which have involved 11 young people.
- Exit satisfaction interviews with 14 young people and questionnaires from 21 young people.
- 51 feedback forms from young people involved in group-work on friendships and rehabilitation, which included explaining the illness, and communicating what is and is not helpful, to friends (Davies 2004).
- Notes from discussions with 2 young people specifically focused on this paper and the issues addressed here.

### **What is it Like Having Anorexic Thinking?**

The young people consulted over this paper felt it was important for the readers to understand what it is about anorexic thinking that makes it necessary to communicate about what is helpful and unhelpful. The following is a brief account of anorexic thinking based on how a young person with anorexia nervosa has described it. The young person produced a list of points, which have been drawn together into prose with her words shown in single quotation marks.

Anorexia involves 'a constant battle of thoughts and feelings'. 'Malnutrition causes irrational thinking' such that 'twisted thoughts seem normal to the sufferer'. 'There are constant thoughts about food, for example counting calories obsessively', and a 'constant fear of gaining weight'. 'You worry about what others think of you and the way your body looks.' 'You worry about what others are eating compared to you', how others look and so on and this comparison is linked to a 'lack of self-confidence and very poor self-image'. 'You feel angry towards the illness for taking your life away' but also 'feel anorexia is there when you are struggling'. Anger is even directed towards food 'for causing so much pain'. 'You never see what other people see even if you try really hard to see it!' 'It makes you take other people's comments the wrong way.'

As this young person highlighted, the constant battle and distorted thinking make the abnormal seem normal and vice versa, meaning that everyday comments and behaviours can be taken the wrong way and cause emotional distress. The fact that abnormal thoughts seem normal to the young person makes challenging these thoughts in therapy very difficult, particularly as approaches like CBT are dependent on some level of recognition that the problem thoughts are not normal, rational nor based on sound evidence.

### **The Framework**

The following framework is proposed to enable young people to communicate to those close to them the things that they find unhelpful due to the impact of anorexic thinking. The development of this framework began with young people preparing to lead a workshop at one of our conferences in which they wanted to tell the delegates what they regarded as unhelpful. In my role of supporting the preparations for this workshop, I was able to help them consider how it might be useful to their audience to provide more explanation of why certain things are seen as unhelpful. Reflecting on how, having gained this knowledge, those close to the young people could still be left feeling that they only knew what not to do rather than what they could actively and positively say or do, led to the addition of a step whereby young people suggest an alternative comment or behaviour. Each step in the framework appeared to require a deeper level of thought on behalf of the young people, as they were mostly very adept at expressing their dislikes but explaining the reasoning behind these required more thought. Furthermore, thinking of alternatives that would be tolerable, and could even be positive proved more of a challenge but one on which most were willing to embark. Exploring why the alternatives suggested were preferable seemed a logical final step in the framework to provide a fuller understanding. It is intended that the framework be used beyond the context of a workshop presentation, taught to young people so they can use it themselves in situations they encounter as individuals or as a peer group, or worked through with help from a professional or carer.

The suggested framework is as follows:

1. Identify what it is that they find unhelpful.
2. Provide an explanation of why this is the case (focusing on what it makes them think and feel).

3. Suggest what might be a more helpful comment or behaviour in the given situation.
4. Explain the reasons why this alternative is preferable.

### **Examples Using the Framework**

The following are examples from one young person of what she finds helpful and unhelpful, explained using this framework.

1. 'People commenting on what you're eating is unhelpful.
2. Because you don't want to think about what you have to eat, it's hard enough already.
3. It's more helpful to make normal conversation while you are eating.
4. Because it helps you to think about something other than the fact you're eating.'

Here the young person identifies distraction as a helpful intervention whereby negative automatic thoughts that can preoccupy the individual and impede their progress (Freeman 2002) can be replaced by alternative thoughts on another subject.

1. 'Asking questions about what you have to eat is unhelpful.
2. Because it is upsetting to think about it.
3. It is more helpful for conversations about food to be positive things like "this tastes nice", things that would be said normally.
4. Because you need to learn how to have conversations about food that are normal and not obsessive.'

In this case normalization and developing balanced thoughts (Greenberger and Padesky 1995), as used in CBT, are employed.

1. 'Saying "you look well" is unhelpful.
2. Because it makes you think that you must look healthy and therefore must be fat when that's not the case.
3. It's more helpful to comment on fashion rather than physical appearance.
4. Because it's nice to know that people like what you're wearing and it gives you confidence.'

The young person here articulates some of the negative automatic thoughts triggered by this comment and suggests a means of avoiding a situation that causes this triggering of thoughts.

Developing this last example further, other thoughts suggested in the young people's conference workshop material that might arise from a remark such

as 'you look well' include 'they think I'm greedy', 'they think I'm totally better, they think it's gone', 'if they think it's gone they might think I got better too quickly, they might think that I was never ill, that I was attention seeking or something', 'they think I got better because I didn't have the self-control or discipline to lose more weight', 'I failed at being ill, I never got thin enough or to a low enough weight, I have failed' and 'I fail at everything'. This highlights the importance of young people sharing such insights, as people unfamiliar with eating disorders are unlikely to predict that commenting on someone looking well would cause them to feel they have failed at everything.

It may be possible to add a further stage between steps 2 and 3, focused on exploring the explanation of why something is unhelpful and challenging the thinking behind this. Young people presenting at one of our conferences argued that offering a rational alternative view could be helpful. In CBT terms, this would translate as challenging negative automatic thoughts and achieving balanced thoughts. Examples of helpful responses to challenge anorexic thoughts, as suggested by the young people, include the following:

- "You look well" is supposed to be a compliment. In reality you did look awful when you were at your most ill.'
- 'People who don't have a good knowledge of the illness may think that it goes away straight away but you know that it's not like that and other people with a good knowledge will too.'
- 'People who don't have an eating disorder won't think you have failed. To them there is no such thing as being "good enough" at being ill. Being ill is always a bad thing and getting better quickly is the priority.'
- 'When you're ill there is no such thing as accomplishing being thin enough or a low enough weight. Your illness will never be satisfied.'

### **Possible Benefits**

Based on the experience of patients sharing their views of what is helpful and unhelpful, it is suggested that there are benefits from both the young person's perspective and the perspective of the person receiving the information, including enabling avoidance of some triggers to negative automatic thoughts and developing some more balanced thoughts through challenging.

For the young person there may be a positive impact on their self-confidence as a result of being consulted and having their expertise recognised. They may experience an increase in their perceived self-worth through attempts to understand them. A sense of personal effectiveness might also be acquired as they learn to express their preferences to successfully bring about change. As young people explained in one of their workshops, 'knowing that they are listened to will give a patient increased confidence and help them to feel cared for, factors which eventually make them feel stronger against the illness'.

There might also be therapeutic benefits for the young person. For example, discussion of the young person's preferences may help them to discern whether the origins of these are anorexic or anti-anorexic. As suggested in Maisel, Epston and Borden's (2004) book, questions that can be asked to distinguish these origins include 'is it something I/you would like (to do) if I/you didn't have fears around it?'. If the answer is 'yes', the preference is anti-anorexic and should be pursued. Anorexic preferences might also be identified and could result in a decision to not participate in such preferences thereby avoiding reinforcing the eating disorder's control. Furthermore the young person can learn to not be overwhelmed by the rush of thoughts and feelings triggered by a particular comment but rather to process and challenge these thoughts instead. As noted above, this kind of communication can help the identification of negative automatic thoughts and thinking errors (Freeman 2002) and the process of gathering further information through discussion with another person could help shift these interpretations (Greenberger and Padesky 1995) to more balanced thinking. An alternative way of understanding a situation, presented by someone the young person trusts, could provide a constructive challenge to the anorexic thought.

Young people presenting at our conference have explained that 'by being able to understand and recognise anorexic thinking at work, others can help the young person find methods of stopping the thought pattern before it results in a destructive behaviour'. This idea is also supported by the experience of numerous sufferers who have felt that 'what has been most useful in gaining some traction against the problem has been coming to know the voice of the problem...and the tactics and strategies it uses to imprison them' (Maisel, Epston and Borden 2004: 12-13). Having someone alongside to support them with this process can be helpful for the young person.

For professionals, family and friends there are likely to be improvements in relationships due to better communication. Increased knowledge and understanding of the situation, from the young person's perspective, can inform practice, enable the avoidance of unnecessary conflict based on misunderstanding and allow interventions to be tailored more appropriately. It can also remove some of the anxiety around what to say and do, provide the individual with a sense of empowerment, facilitate engagement and increase the young person's motivation.

### **The Potential Challenges**

Again, based on experience to date, the following difficulties and opposing views have been highlighted. Some relate to the expectations that may be put on those close to the young person. For example, whilst most parents welcome the idea of insight into their child's experience and have expected such information to be useful and empowering for them, some have expressed concern that the young person's preferences could become a set of 'dos and don'ts' or rules they are expected to follow. Families often report feeling that they have to 'walk on eggshells' and worry about having further things they have to do or avoid. Similarly, some parents and professionals have felt that as control tends to be an aspect of anorexia nervosa, there is potential for this to become just another area where young people are able to be controlling.



The importance of being realistic about the extent to which people can avoid saying or doing unhelpful things is also an issue. Whilst professionals, families and friends might make a particular effort to be sensitive, out in the 'real' world young people have to be able to cope with difficult situations where people are less likely to know what is the right thing to do. It could be argued that the focus should be on challenging anorexic thinking rather than what could be seen as giving in to it. As noted above however, this process might actually lead to better understanding of anorexic thinking and to challenging this, whereas dismissing the young person's stated preferences without such consideration could in fact be more collusive and leave less scope for therapeutic work where thoughts can be more actively challenged.

From what I have seen of this communication in practice, I argue that it is important for the young people to feel that those closest to them want to understand and to help. If they do so, it seems to help relationships and provide a trusted support network for the young person, which is a good foundation for facing the necessary task of challenging the anorexic thoughts. There are therefore two central aspects to this work: (1) helping those close to the young person to be helpful or more sensitive and (2) helping the young person prepare to deal with things they may find unhelpful or difficult.

### **Tips for Managing this Process Successfully**

The following might be useful approaches:

- Be open with the young person about the different perspectives others might have and how to avoid colluding with the desire for anorexic control.
- Clarify with the young person what it is that they want people to know, to whom they want to communicate this information and their expectations of what will happen once this information is known.
- Involve those close to the young person in this discussion, particularly family members, such that they are not left feeling that the young person, perhaps in collusion with professionals, has set them up to behave differently without consultation.
- Emphasise to the young person the importance of providing positive feedback to those who try to help them. Even if they have actually got it wrong, the young person can encourage them by expressing gratitude for their efforts before going on to explain why something they said or did was actually unhelpful.
- Take an individual approach. Eating disorder sufferers do not unanimously agree on what is and is not helpful. However as one of our young people pointed out, 'even though every patient is, and should be treated as an individual, many of the thought patterns are very similar'. Some of the more universal themes, such as not saying 'well done' for completing a meal, could be communicated more widely, although they still need to be checked out with individuals. For example, young people on our unit have produced information leaflets for friends and schools, suggesting what is

helpful and unhelpful in supporting them, and each leaflet contains space for individuals to adapt it to their own needs and preferences.

### **What Can Others Learn from this Approach?**

It might be that young people and adults in other areas of mental health are less affected by people saying and doing the 'wrong' thing and have less need for such an approach. However, most individuals do have needs and preferences that, if met, would be experienced as helpful and supportive and may facilitate therapeutic engagement, family and social relationships and boost the individual's confidence. This paper argues for the benefits of sharing these needs and preferences with those closest to the individual and addresses one approach to communicating these.

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