



# Navigating the System: Consumer Tips for Getting Treatment for Eating Disorders

Compiled for the National Eating Disorders Association by Margo Maine, PhD

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Eating Disorders are very serious, potentially life-threatening problems. The current mental health care system's reimbursement policies and 'managed care' guidelines make it very difficult for eating disordered patients to receive treatment. These illnesses are multi-determined, with possible physical or genetic predisposing factors, in addition to multiple psychological issues. The illness process leads to significant physiological changes requiring medical treatment in addition to psychiatric treatment but the reimbursement system does not allow for a holistic approach, wherein the costs of treatment might be more fairly shared between medical and psychiatric insurance benefits. Furthermore, some companies have very specific and inadequate guidelines for treatment, which fall far short of the current recommendations by the American Psychiatric Association (2000).

Consequently, patients, families, and practitioners frequently have to fight to get the appropriate and necessary treatment. The following suggestions may help.

1. The most important first step is to have a complete assessment. This includes a medical evaluation to rule out any other physical cause for the symptoms, to assess the impact the illness has had to date, and to determine whether immediate medical intervention is needed. See Table 1 for specific tests. Equally important is the mental health assessment, preferably by an eating disorder expert to provide a full diagnostic picture. Many people with eating disorders have other problems as well including depression, trauma, obsessive-compulsive disorder, anxiety, or chemical dependence. This assessment will determine what level of care is needed (inpatient, outpatient, partial hospital, residential) and what professionals should be involved in the treatment.
2. Pursue the recommended level of care. Ask your insurance company, HMO, and health care providers for recommendations for programs or specialists.
3. Find out about local resources for treatment by calling the National Eating Disorders Association Information and Referral Helpline at (800) 931-2237 or visit the "Referral" area of the web site [www.NationalEatingDisorders.org](http://www.NationalEatingDisorders.org).
4. If your company does not provide a benefit for the recommended level of care (some policies have inpatient and outpatient, but no residential or partial hospital benefit), ask them to 'flex the inpatient benefit.' Appeal this to the medical director of the company if you are denied. Also, speak to your employer, union, or human resources department. As they pay for your coverage, they can pressure the company to provide the needed service. Have your physician or specialist who evaluated your loved one write a letter documenting the level of care needed.
5. Record the date/time/name of all your communications with the insurance company. Put your requests in writing if they are initially denied. Keep copies of everything.
6. Insurance and managed care companies are governed by state laws but most states mandate an appeals process. Usually, you must file an "internal appeal" with the company. First, request a letter from the company stating that they have denied the coverage you are seeking. (You need this denial in writing). Also request an explanation of their appeals process. Read the membership book from the insurance or managed care company—if the service you need is clearly excluded, appealing the denial will be

For more information, contact the National Eating Disorders Association at 603 Stewart St., Suite 803, Seattle, WA 98101  
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## Navigating the System continued

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- pointless. A letter to the medical director documenting the need for treatment and risks of not receiving it may, however, cause the company to re-examine their policy.
7. If this is unsuccessful, write to the state insurance commission and/or speak to an attorney. Provide copies of all documentation.
  8. Consider getting the care recommended by arranging to self-pay, while you continue to pursue reimbursement.
  9. If the insurance company approves treatment, but not in a specialized program, appeal this decision. Or, ask that the treating clinicians obtain supervision and training from experts in eating disorders. If this treatment does not result in significant improvement, ask that specialists provide further treatment.
  10. If you have no insurance, local mental health clinics or departments of psychiatry at medical schools may be useful resources. Also, you can apply for state assistance, Medicaid, through your local Department of Social Services or for Medicare if you meet the criteria for disability. There are some research programs, which provide treatment for no cost, but you must meet strict criteria. Contact your local major universities or medical schools to find any local research or studies for eating disorders. Research studies are often posted on the National Eating Disorders Association web site [www.NationalEatingDisorders.org](http://www.NationalEatingDisorders.org).
  11. Visit the following web sites for other information about eating disorders or to join in their advocacy efforts:
    - [www.NationalEatingDisorders.org](http://www.NationalEatingDisorders.org) - National Eating Disorders Association sponsors outreach programs, treatment referrals, advocacy, and informational literature.
    - [www.EatingDisordersCoalition.org](http://www.EatingDisordersCoalition.org) – Several organizations have formed the Eating Disorders Coalition for Research, Policy and Action to improve access to care and funding for Eating Disorders at the federal level.
    - [www.aedweb.org](http://www.aedweb.org) - The Academy for Eating Disorders is a professional organization with a membership directory of eating disorders specialists.
    - [www.AnnaWestinFoundation.org](http://www.AnnaWestinFoundation.org) – The Foundation provides education and advocacy for the treatment of eating disorders.
    - [www.MentalHealthScreening.org](http://www.MentalHealthScreening.org) - The National Mental Illness Screening Project sponsors an annual screening program for eating disorders.
    - [www.something-fishy.org](http://www.something-fishy.org) - Something-Fishy provides information about eating disorders, their causes and complications.

Patient Advocate Foundation  
753 Thimble Shoals Blvd., Ste. B  
Newport News, VA 23606  
800.532.5274  
757.873.8999 fax  
[www.patientadvocate.org](http://www.patientadvocate.org) – Information &  
resources including sample appeals letters.  
[help@patientadvocate.org](mailto:help@patientadvocate.org)

The Center for Patient Advocacy  
1350 Beverly Rd., Ste. 108  
McLean, VA 22101  
703.748.0400  
800.846.7444  
703.748.0402 fax  
[www.patientadvocacy.org](http://www.patientadvocacy.org)

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**TABLE 1--Recommended Laboratory Tests**

### Standard

- Complete Blood Count (CBC) with differential
- Urinalysis
- Complete Metabolic Profile: Sodium, Chloride, Potassium, Glucose, Blood Urea Nitrogen, Creatinine, Total Protein, Albumin, Globulin, Calcium, Carbon Dioxide, AST, Alkaline Phosphates, Total Bilirubin
- Serum magnesium
- Thyroid Screen (T3, T4, TSH)
- Electrocardiogram (ECG)

### Special Circumstances

15% or more below ideal body weight (IBW)

- Chest X-Ray
- Complement 3 (C3)
- 24 Creatinine Clearance
- Uric Acid

20% or more below IBW or any neurological sign

- Brain Scan

20% or more below IBW or sign of mitral valve prolapse

- Echocardiogram

30% or more below IBW

- Skin Testing for Immune Functioning

Weight loss 15% or more below IBW lasting 6 months or longer at any time during course of eating disorder

- Dual Energy X-Ray Absorptiometry (DEXA) to assess bone mineral density
- Estradiol Level (or testosterone in males)

**TABLE 2--Criteria for Level of Care**

### Inpatient

Medically Unstable

- Unstable or depressed vital signs
- Laboratory findings presenting acute risk
- Complications due to coexisting medical problems such as diabetes

Psychiatrically Unstable

- Symptoms worsening at rapid rate
- Suicidal and unable to contract for safety

### Residential

- Medically stable so does not require intensive medical interventions
- Psychiatrically impaired and unable to respond to partial hospital or outpatient treatment

### Partial Hospital

Medically stable

- Eating disorder may impair functioning but not causing immediate acute risk
- Needs daily assessment of physiological and mental status

Psychiatrically stable

- Unable to function in normal social, educational, or vocational situations
- Daily bingeing, purging, severely restricted intake, or other pathogenic weight control techniques

### Intensive Outpatient/Outpatient

Medically stable

- No longer needs daily medical monitoring

Psychiatrically stable

- Symptoms in sufficient control to be able to function in normal social, educational, or vocational situations and continue to make progress in recovery.

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