



Eating Disorders Survival Guide

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HOW TO AFFORD APPROPRIATE TREATMENT FOR AN EATING DISORDER: A GUIDE FOR PATIENTS AND THEIR FAMILIES

Assessment of the Problem

The first, most important step in preparing to get treatment for an eating disorder is to obtain a complete assessment so that the eating disorder and any associated mental or physical problems can be appropriately diagnosed. The assessment should be by a health care professional knowledgeable about eating disorders. A list of professionals who have received training in and have experience with eating disorders can be obtained through the Academy for Eating Disorders www.aedweb.org. Referrals for across the nation can be obtained by calling NEDA's Information and Referral Helpline at **800-931-2237** or from NEDA's website www.NationalEatingDisorders.org under the Treatment Referrals section.

Usually, the health care professional who provides the initial assessment will be able to diagnose the eating disorder. A complete assessment will include 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. Often, physical problems are associated with an eating disorder and a psychiatrist, internist, family practitioner or pediatrician may need to be seen if these problems are suspected. The most common physical consequences of eating disorders include osteoporosis (thinning of the bones), heart problems (especially irregular heart rhythms from electrolyte imbalance), kidney problems (resulting from repeated dehydration from starvation or purge behavior), and brain abnormalities (enlarged spaces in the brain). In addition, gastrointestinal problems are common and include constipation, diarrhea, reflux, nausea and heartburn. See Table 1 for a list of recommended laboratory tests. People who have eating disorders often have other associated mental illnesses. These include obsessive-compulsive disorder, anxiety, depression, social phobias, post-traumatic stress disorders and chemical dependencies. The health care professional may be able to detect these psychiatric problems as well.

Determining the Appropriate Treatment

The second step is to determine what level of treatment is needed (e.g. outpatient, inpatient, partial hospital, residential, or intensive outpatient), where this treatment should occur, and which health care professionals should be a part of the treatment team so that recovery is optimal. Criteria for the level of care are outlined in Table 2. The intensity of the level of care will vary according to the type and severity of the illness, including both physiological and psychological factors. Using guidelines developed by the American Psychiatric Association <http://www.psychiatryonline.com/popup.aspx?aID=139471>, the professional who provides the assessment will evaluate what type of treatment is needed, where it should be provided, and who is able to provide this care. A treatment team may include psychiatrists, therapists, counselors, nutritionists and primary care physicians.

At this stage, it is also important to try to get an estimate of the duration of treatment. For example, bulimia nervosa lasting less than six months with no other associated psychiatric disorders (such as depression or alcohol or drug abuse) and no physiological complications from the eating disorder would likely have a treatment length of less than six months. Treatment often includes cognitive behavioral therapy in a group or individual format. However, if the duration of the illness has been longer or there are associated conditions, much more comprehensive treatment may be needed. It is



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important to note that estimates are exactly that – estimates. The actual course of treatment can vary widely from the initial estimate.

The classification Eating Disorder Not Otherwise Specified (EDNOS) includes a wide variety of problems. Most of these patients are as seriously ill as those with anorexia nervosa or bulimia nervosa. The classification EDNOS covers diagnoses in which one or more of the formal criteria for anorexia nervosa or bulimia nervosa are not met. For example, a patient who does not binge but purges regularly and is normal weight does not meet the criteria for bulimia nervosa. Yet, this person is likely to require comprehensive treatment. Many very seriously ill eating disorder patients do not meet the diagnostic criteria for anorexia nervosa or bulimia nervosa but still need treatment and still have tremendous health risks. When seeking insurance coverage, it may be more difficult to explain to the insurance company the need for treatment when the patient does not fit the current diagnostic criteria.

The following list details the information a person with an eating disorder needs to know prior to trying to obtain care. Armed with this information, you can then attempt to access the appropriate treatment through your insurance company or through various community agencies.

Facts to Know

- 1. Eating disorder diagnosis**
- 2. Other psychiatric diagnoses**
- 3. Physiological complications of the eating disorder**
- 4. Level of care recommended (e.g. outpatient, inpatient, partial hospital, residential, or intensive outpatient)**
- 5. Anticipated duration of recommended treatment**
- 6. Professionals needed and their required expertise**

Locating Appropriate Care

If you have insurance, first determine if there are mental health benefits. Then determine what those benefits include. Often these mental health benefits include an amount for inpatient or residential treatment and an amount for outpatient treatment. Most policies also include major medical benefits, which are typically much greater than the mental health benefits. Some companies provide Employee Assistance Programs (EAPs), and sometimes appropriate care is available within these programs. To determine what these benefits are, read your company's summary of benefits, the booklet that comes with your insurance, or you can call the phone number on your insurance card.

Although you may have what appear to be adequate benefits, the next issue is whether or not those benefits can be accessed in order to obtain appropriate care. There are three major types of health insurance policies: indemnity, preferred provider organization (PPO), and health maintenance organization (HMO). Very few people have indemnity policies, but they are usually the most comprehensive with the greatest flexibility. PPOs are typically much more flexible than HMOs. There is usually a deductible (a portion of the charge from the hospital, residential treatment center, or care provider that you pay). And, especially in HMOs, there are reviewers (*who are often untrained clerical personnel or professionals with little if any training in eating disorders*) who decide how much of your benefits will be available to you when a diagnosis is made. This decision is often based on idiosyncratic rules or internal guidelines that do not reflect the needs of the individual case, the current evidence-based treatment modalities, or consensus of expert professionals.



In addition to determining what benefits are available to you according to your policy, it is important to determine what the treatment center or care provider will be required to do to help you access those benefits. This is not always easy to determine in advance. First, find out if the recommended professionals are providers for your HMO or PPO. Ask your insurance company to send you a list of providers and then see if any of the professionals recommended to you are on this list. Refer to the “Questions to Ask When Considering Treatment Options” handout for assistance in evaluating which treatment professionals will best be able to assist you. Once you have selected a treatment provider that best suits your needs, let the professional and their office personnel know the results of your assessment (diagnoses, type of treatment recommended, site of treatment recommended, and estimated duration of treatment). The “Questions to Ask Your Treatment Provider” handout can assist in understanding the treatment process, and for the patient’s family and loved ones, the handout “How to be Part of the Treatment Team: Questions for Parents & Families to Ask” provides helpful inquiries to aid them in the support process.

Your insurance benefits do not match the recommended treatment.

The current mental health care system’s reimbursement policies and ‘managed care’ guidelines make it very difficult for eating disorder 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.

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

- I. Your insurance policy does not provide for adequate benefits for the type of treatment recommended. For example, if you have anorexia nervosa, the binge/purge subtype, and residential treatment is recommended for 60 days, your insurance benefits may be for only 10 days of residential treatment. In this case, first try calling your insurance company and ask to access your major medical benefits or ‘flex the inpatient benefit.’ The reason this is logical is because the semi-starvation that is a consequence of anorexia nervosa is a physiological complication and left untreated will likely result in hospitalization on a medical floor in a general hospital which will ultimately be very expensive. In fact, eating disorders **are** medical illnesses and it is worthwhile mentioning this to your insurance company. Have the evaluating physician or specialist write a letter documenting the level of care needed. Appeal to the medical director of the insurance company if you are denied.

Typically, providing the above information to your insurance company will not result in any change on their part. If this occurs, the next step is to contact the personnel department of the company that purchases the insurance. When you do this it is important to remember several things. First, insurance coverage is called a “benefit” but in fact it is a part of the compensation to the worker who has the insurance policy. It is **not** a gift from the employer. Since they pay for your coverage, they can put pressure on the company to provide the needed service. Furthermore, the insurance company is supposed to hold the funds paid by the employer on behalf of the employee and dispense them according to rules set down by the employer. This decision is often made by an intermediary, namely the HMO or PPO company, but, in fact, they are working at the direction of the employer. Thus, the employer can decide to fire the insurance company (and ultimately the HMO or PPO). The important point for you to remember is that it is actually your employer (or the employer of the person who has the insurance benefits) who has power over what benefits are provided from the HMO or PPO. Thus, your personnel department can be helpful to you. When you begin to investigate this area, you may find that the insurance company blames the employer or the employer blames the insurance company. Remember, the employer pays for the insurance benefits (which often includes hiring an intermediary HMO) and ultimately (although often not immediately) the employer can choose to change insurance companies.



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 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. Refer to the “Securing Eating Disorders Treatment: Ammunition for Arguments with Third Parties” handout for supporting evidence.

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. Other options include contacting your union, if applicable.

Tips for Fighting for Appropriate Insurance Coverage

- Record and document every phone call including names, dates, times, what was discussed and how you were advised. Put requests into writing if they are initially denied.
- KEEP COPIES OF EVERYTHING.
- Be persistent in the appeals process. Many denials can be reversed.
- Call your state's Insurance Commissioner.
- Write letters, CC'ing your insurance company's CEO/President, State Attorney General, State Insurance Commissioner, US and State Congress members, advocacy organizations, your attorney, etc. Be sure to include documentation, evidence and facts.
- Get the media's attention if appropriate. (See #3 Creative Solutions below)
- Ask the Human Resources person at your place of employment, your insurance agent, and/or your union representative to work on your behalf. Give them powerful statistics that help to prove your point. (Use NEDA's “Securing Eating Disorders Treatment: Ammunition for Arguments with Third Parties,” “Facts for Advocates” and “Statistics: Eating Disorders and Their Precursors” handouts.)
- Know your state laws. Insurance company agents won't tell you what they are.
- **Don't give up!** Insurance companies want you to do just that.

2. Despite efforts to obtain needed coverage for the treatment recommended, your insurance company and personnel department are not helpful. Although it is tempting to give up at this point, there are other steps that can be taken. First, let your insurance company know that you have decided to call the state insurance commissioner and then call him or her. It is the commissioner's duty to license, regulate and oversee all insurance companies and other entities engaged in the business of insurance under the authority granted by the insurance laws of the state. Consumer complaints are also investigated through the commissioner's office as consumer protection is an important job of the insurance commissioner.

The following websites provide links to obtain your insurance commissioner's contact information:

State Insurance Departments / Commissioners Websites

National Association of Insurance Commissioners: http://www.naic.org/state_web_map.htm



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Health Insurance Resource Center: <http://www.healthinsurance.org/>

Insurance Claims Consultants: www.insuranceclaimsconsult.com/Ins.Commissioner.htm

When you speak with the insurance commissioner's office, tell them what has been recommended, what steps you have taken to obtain treatment, and the results of these attempts. Be able to provide documentation. Follow up this phone call with a letter explaining the difficulties. Keep a copy of this letter and all communication for your files.

It is likely that the insurance commissioner may not be helpful to you. Thus, the next step is to contact your senators, congressional or house representatives. The following websites provide links to obtain contact information for government officials.

Government Officials Websites

U.S. Senate Directory: www.senate.gov/general/contact_information/senators_cfm.cfm

U.S. House of Representatives Directory: <http://www.house.gov/house/MemStateSearch.shtml>

U.S. Congress and State & Local Officials: www.congress.org/congressorg/home

Congress emails: www.webslingerz.com/jhoffman/congress-email.html

Congress emails, fax and phone (Spanish link also listed below): www.visi.com/juan/congress

Spanish link: ¿Quiere ponerse en contacto con miembros del Congreso en Español?
www.visi.com/juan/congress/index.es.html

If this is ineffective, contact your state governor. You are likely to find that there are people in your legislator's office who can be helpful to you in pursuing appropriate care for your eating disorder.

3. **Creative Solutions.** Some families have gotten their insurance companies to make appropriate decisions by contacting the newspaper or magazines and describing their plight. Others have called help programs on the radio and TV. Be aware that media attention can be an overwhelming experience and exposes the person and family to the public, resulting in a loss of privacy. Take time to think through the consequences going public with your story can have on you or your family (e.g. ability to obtain future jobs or work due to illness). For suggestions on how to work responsibly with the media, consult the "Tips for Responsible Media Coverage" and "Guidelines for Sharing Stories of Recovery" handouts.
4. **Determine if you can afford care even if your insurance company will not pay for it.** Once you know what care is recommended, who should provide it and at what site this care should be provided, find out the stated total charges from the institution and/or professional(s) providing the care. Assess your own financial resources and negotiate a fee or payment plan you can afford with the institution or providers. Obtain the vital and needed care while continuing to pursue reimbursement.
5. **Legal Remedies.** Some families have been able to access help for their loved one by contacting their attorney, if benefits are available through their insurance company but they cannot access these benefits. Others have had to resort to legal actions in order to get their insurance companies to pay for treatment. This process can be long and arduous, but may be a necessary step if your insurance company is delaying or refusing access to treatment. The handout, "Securing Eating Disorders Treatment: Ammunition for Arguments with Third Parties," provides facts to assist in the appeal for the insurance company to cover treatment.

The **Eating Disorders Coalition for Research, Policy and Action (EDC)** is a group of non-profit organizations, treatment centers and other organizations whose mission is to advocate at the federal level for eating disorders to be recognized as a public health priority. The Family & Friends Action Council (FAC), one of the founding members, provides an opportunity to share stories of their family struggles in getting help and coverage for their loved one and



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to fight for greater resources for treatment, research, prevention, education and outreach through congressional briefings and other advocacy activities. For more information on the EDC's Family & Friends Action Council go to <http://www.eatingdisorderscoalition.org/involved/involved.html>.

The **Anna Westin Foundation** www.annawestinfoundation.org provides an example of one family's battle against an insurance company and additional tips on how to appeal to your insurance company.

The **Patient Advocate Foundation** <http://www.patientadvocate.org/> or 1-800-532-5274 provides information and resources, including sample appeals letters and more.

- 6. Benefit of following above steps.** One of the main benefits of following all of the appropriate steps is that it means you have accepted that you or your loved one has a disorder that requires appropriate treatment. Many people with eating disorders and their families deny that they have a serious problem. In addition, many people with eating disorders have low self-esteem that prevents them from assertively insisting on receiving benefits to which they are entitled. Following these steps in an assertive manner, even if your insurance company does not agree to pay for appropriate care, can result in an improved self-esteem. This bodes well for utilizing the treatment that is available to you.

I have Medicare or Medicaid Benefits.

Many hospitals and treatment centers do accept Medicare and/or Medicaid. However, the problem usually is that there are not trained eating disorders specialists in the hospitals and treatment centers that do accept Medicare or Medicaid. If the treatment center is a mental health center, which is funded in part by county, state or federal funds, you can sometimes ask that appropriate care be provided and sometimes there are personnel at the center that are familiar with the treatment of eating disorders.

Are there any treatment programs that help people with no money or benefits?

Yes, but they are not always easy to locate. Some agencies that receive public funds do provide treatment and sometimes that treatment is outstanding. Mental health centers receive a portion of funding from state and federal governments to cover a portion of the treatment of mental health illnesses. They provide some care for people with little or no money. To find more mental health information, visit the SAMHSA's National Mental Health Information Center website (www.mentalhealth.samhsa.gov).

Or contact them at:

SAMHSA's National Mental Health Information Center

U.S. Mail: P.O. Box 42557, Washington, DC 20015

Toll-Free: (800) 789-2647

E-mail: info@mentalhealth.org

Website: www.mentalhealth.samhsa.gov/aboutken/contact.asp

A possible avenue to obtain treatment is through various community agencies. Some examples include family service centers or hospitals with clinics in major cities. Although these facilities do not typically include specialists in eating disorders, they may offer treatment or counseling at no cost or on a sliding scale fee. Some also provide referrals to similar resources in the local area if they cannot meet your needs.

Another possibility for students to obtain treatment is through a counseling center or student health services on their college or university campus. In order to access treatment at these locations, you must usually pay a student health fee with your tuition. This is usually a relatively small amount of money and the treatment you may receive is likely to be worth it. Most counseling centers are very familiar with eating disorders since they occur so commonly among college



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students. Many of the best short-term treatments for eating disorders are available on campuses, and if you are a college student, this may be your best option.

Many Departments of Psychiatry within medical schools have low fee clinics run by psychiatric residents (medical school graduates who have had two or three years of their psychiatric training and are supervised by experienced faculty members). Even if you are not a student at the college where the medical school is located, you may be able to be treated by a resident who is closely supervised and obtain excellent care. The way to access treatment is to call the Department of Psychiatry within the medical school and ask if they have low fee clinics run by the residents, and if they will accept a patient with an eating disorder. Inquire about sliding scale fees and ask directly about what type of supervision the residents have available to them.

What about no-fee research treatments?

Sometimes treatment can be obtained in the context of a research program. Often there will be research studies underway at a college or university near you, and there may be announcements of these studies in the newspaper. It is worthwhile calling the Eating Disorder Program at a university or college near you and asking if they know of any research projects underway and then contact the Study Coordinator for the research program. For current research studies, go to the Treatment Referrals section of NEDA's website.

Other research studies can be found by searching for "Eating Disorders" on the National Institutes of Health Clinical Trials website www.ClinicalTrials.gov.

It is important to remember that although there may be no fee for part of the treatment, there may be fees for certain non-research portions of the study and there are inclusion and exclusion criteria. Also, because it is a research project, it means that the treatment offered is usually not the current standard of treatment. Nonetheless, most standard treatments were initially the focus of a research study and, hence, you may benefit.

What about self-help groups?

Self-help and support groups are often useful, but there are times when they can be dangerous. Asking the following questions can help you decide if the self-help group is likely to help you.

1. Does the facilitator or the leader of the group encourage you to seek professional treatment as well as a self-help group?
2. Are most of the people in the self-help group also in treatment with professionals?
3. Does much of the discussion revolve around exchange of information? For example, does the group bring in speakers that teach about some of the consequences of semi-starvation and how to decrease these complications?
4. Is there a central theme that maintaining a healthy body weight is the goal?
5. Does the group avoid simplistic or faddish ideas about how to recover?
6. Does the group talk about common problems and try to solve them?
7. Does the group avoid exchanging information about "how to purge" or "how to diet"?
8. Are members of the group actually improving in terms of normalizing their eating patterns and decreasing purge behavior?
9. Do you have a sense of support and belonging when you go to the group?

If the answers are "yes" to all or most of these questions, the group may be of benefit.



What about trying to recover on my own?

It is unknown how many people recover without professional treatment or without significant family assistance. There are self-help books that often help people in the recovery process, but it seems unlikely that most people can get well completely on their own. It is recommended that professional guidance and/or care be sought.

Some self-help books that have been found useful include:

- Anorexia Nervosa: A Guide to Recovery (1998) by Lindsey Hall and Monika Ostroff, Carlsbad, CA: Gurze Books.
- Bulimia: A Guide to Recovery (1998) by Lindsey Hall and Leigh Cohn, Carlsbad, CA: Gurze Books.
- The Body Betrayed: A Deeper Understanding of Women, Eating Disorders, and Treatment (1995) by Katheryn J. Zerbe, MD. Carlsbad, CA: Gurze Books.
- Eating Disorders Source Book (1999) by Carolyn Costin, MA. Los Angeles, CA: Lowell House.
- The Starving Family: Caregiving Mothers and Fathers Share Their Eating Disorder Wisdom (2005) by Cheryl Dellasega, PhD. Fredonia, WI: Champion Press, LTD.
- Surviving an Eating Disorder: Strategies for Family & Friends (1997) by Michelle Siegel, PhD, Judith Brisman, PhD, & Margot Weinschel, PhD. New York, NY: HarperCollins Publishers, Inc.
- When Dieting Becomes Dangerous: A Guide to Understanding and Treating Anorexia and Bulimia (2003) by Deborah M. Michel, PhD, Susan G. Willard, LCSW, et al. New Haven: Yale University Press.

NEDA's Reading List and links to other websites providing useful information can be found under the Links & Resources section of NEDA's website.

Conclusion

Keep trying to get better and trying to locate people to help you. Although there are many barriers to accessing professional treatment, it can usually be accomplished by patients who are committed to recovery. Care providers themselves are energized when the patient wants to recover and can often assist in finding the help you need. Many primary care physicians and pediatricians are relentless in trying to find help for their patients and your interest in recovery will encourage them to continue to try to help you.

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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)

**Also refer to the American Psychiatric Association (APA) & DSM IV-R for more detailed information.
<http://www.psychiatryonline.com/popup.aspx?aID=139471>

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 mellitus

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 but not suicidal
- 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

