FOCUS ON: EATING DISORDERS

"FOCUS ON: EATING DISORDERS" is the first in a series of reports by the Attorney General aimed at raising public awareness about the day-to-day problems that some New York consumers face in accessing health care. Each edition of "FOCUS ON" will spotlight one particular problem with the health care system that has been brought to the Attorney General's attention through consumer complaints to his Health Care Helpline. "FOCUS ON" will also provide useful advocacy tips to help consumers advocate effectively for their health care rights.

EATING DISORDERS AND THE HEALTH CARE SYSTEM

Case History: Sixteen-year-old Sharon was admitted to a hospital for treatment of extremely low body weight, low blood pressure and malnourishment as a result of anorexia. After 15 days, her health plan denied continued treatment and she was discharged. She immediately began to lose weight again and was re-admitted to the hospital. After several unsuccessful, relatively short hospitalizations, her plan approved inpatient care at an out-of-state facility that specializes in eating disorders. But within a month her health plan denied further inpatient care over the objections of her doctor, stating that only outpatient care was medically necessary. Her parents fought back by challenging the decision and ultimately won their appeal.²

In many ways, eating disorder patients are victimized twice -- once by this devastating disorder, and then again by a health insurance system that is not equipped to handle these complex and misconstrued conditions. A basic understanding of the disease is helpful to fully comprehend this dynamic.

Currently, over 5 million people in the United States have an eating disorder, 85-95% of whom are adolescent girls.³ Anorexia and bulimia are the predominant types of eating disorders. Anorexia is characterized by an intense drive for thinness, a distorted body image and an extremely restricted food intake.⁴ It is also among the deadliest of all mental health disorders with an aggregate mortality rate of nearly 6% - - 12 times the average mortality rate for all causes of death among females ages 15-24.⁵ The incidence rate among young girls is 3%,⁶ making anorexia the third most common chronic illness in this population.⁷ Bulimia manifests itself through binge eating, followed by various forms of purging, such as vomiting, extreme exercise and use of laxatives.⁸ Eating disorders are often characterized by an abnormally strong desire for control, which is displaced onto food, and can be precipitated by a particularly stressful life event.⁹

Although eating disorders are largely rooted in psychological issues, it is usually the life-threatening physical manifestations of the condition - low body weight, potassium depletion, malnourishment, dehydration and low heart rate and blood pressure - that initially bring the

patient into the health care system. And because some eating disorder patients can become adept at hiding or denying their self-destructive behavior, ¹⁰ medical and psychological intervention often does not occur until the physical effects of the disorders become acute.

Patients with eating disorders and their care-givers face two primary problems when dealing with health care coverage for these disorders - 1) inadequate mental health coverage offered by health plans and 2) health plan denials of care as "medically unnecessary" based on insensitive and uninformed utilization review policies and procedures.

Inadequate Mental Health Coverage

Case History: After receiving care at a hospital for bulimia, thirty-year-old Mary enrolled in a facility strictly for eating disorders, where she received psychological and medical care. Because her treatment was mostly psychological, her health plan applied the 30-day cap for mental health coverage. Once her coverage was exhausted, Mary's parents scraped together enough money to continue her medically necessary care - at a cost of \$400 a day.

While New York law does not mandate that all health plans and policies offer mental health benefits, it does require that such benefits are "made available" to consumers, who can then choose to buy such benefits or not. State law requires group health plans to make available coverage that includes at least 30 days of inpatient mental health care and \$700 of outpatient care per calendar year. Individual health plans must make available coverage for at least 30 days of inpatient coverage annually and 30 non-emergency, and 3 emergency, outpatient visits to a mental health professional. Some health plans offer more generous coverage for mental health benefits, but many offer only the minimum coverage required by New York law, which is often insufficient to fully treat the condition.

While mental health coverage is usually limited, coverage for physical or physiological care can be unlimited or subject to relatively high caps. With eating disorders, the line between physiological and psychological treatment can be blurred when the patient is admitted to the hospital for medical treatment (low weight, malnourishment, low heart rate), but receives mental health counseling during the hospital stay. The classification becomes critical because it will ultimately determine the extent of coverage - if it is mental health, then the hospital days count against the already minimal cap on mental health coverage.

The legal standard in New York involves a balancing test between the medical and psychological components of treatment to determine which constitutes the majority of the care for purposes of coverage caps. The case of Simons v. Blue Shield and Blue Shield of Western New York¹⁴ involved a young girl with anorexia who was admitted to the hospital for severe malnourishment, dehydration, low body weight and low blood pressure. She was fed through a feeding tube and then her diet was monitored until her weight and vital signs improved. Because she received

some psychiatric counseling and evaluation and the eating disorder was considered a psychological disorder, the insurance company applied the 30-day mental health cap, rather than the 90-day medical care cap, and the patient was required to pay for the days exceeding the cap.

The court ruled that the underlying reason for the hospital admission was the girl's deteriorating physical condition, regardless of the psychological cause of her physical condition. The judge stated that: "It is the physical condition, and the treatment required to deal with that condition, which is crucial, not the reason for the disorder." As a result, the longer hospitalization coverage for medical care was applied and the patient was covered for her entire hospital stay. The Health Care Bureau has held plans accountable to this legal standard in resolving disputes between health plans and consumers about whether care was primarily physiological or psychological in particular situations.

Caps on mental health coverage also provide no room for error for patients with eating disorders when it comes to choosing the right health care provider. Not all eating disorder facilities are the same, and no single facility is appropriate for all cases. Several factors must be considered, including the severity of the disorder, the co-existence of other disorders, suicidal tendencies and the patient's own personality and treatment history. One week in the wrong facility under a plan that has a 30-day cap means that the patient has potentially wasted almost one-quarter of the annual coverage. Before long, the patient is faced with a loss of benefits at a time when the road to recovery has just started.

Case History: 14-year-old Sally was unsuccessfully treated for bulimia at two facilities chosen by her health plan, even though her therapist had recommended treatment at another. By the time Sally was admitted to the facility recommended by her therapist, she had used 23 treatment days, leaving only 7 days of covered care. When the benefits were quickly exhausted, her parents paid the remaining costs out-of-pocket.

Once the mental health cap is met and coverage is exhausted, patients and their care-givers are left with two potentially devastating options - either pay the full cost of continued treatment out-of-pocket or forego treatment and risk a relapse. Paying for care out-of-pocket is cost-prohibitive for most families because rates at inpatient facilities can range from \$400 to \$1000 each day. As a result, families may be forced to resort to drastic financial measures to pay for continued treatment, such as re-mortgaging a house. Families that manage to pay are often left with tremendous medical bills.

Discontinuing treatment risks a relapse. And in some cases, the overall costs to the health plan can actually be greater. If a patient relapses into the disorder's destructive behavior pattern - binging, purging and starving - the concomitant physical deterioration may lead to even more expensive hospitalizations, as well as a cycle of treatment and relapse that can be fatal. If plans

were to provide more generous mental health coverage, expensive emergency hospitalization could be avoided, leading to better outcomes for patients and decreased costs for plans.

Inadequate and Insensitive Medical Necessity Review

Case History: Eleven-year-old Alan was admitted to the hospital for anorexia and depression. He weighed 54 pounds and had to be nourished by a nasogastric feeding tube. After Alan was moved to a hospital equipped to treat eating disorders, his health plan only approved coverage for two days of hospitalization because he had gained some weight back, even though he was still on a nasogastric feeding tube. Fortunately, his parents filed an external appeal 16 and the plan's medical necessity denial was overturned with the help of the Health Care Bureau, allowing Alan to receive additional treatment in the hospital.

Regardless of whether a health plan has a cap on mental health care, treatment care programs for eating disorder patients are still subject to the health plan's Utilization Review ("UR") process. This process determines if treatment is actually covered because it is medically necessary.¹⁷ Unfortunately, health plans sometimes deny treatment as no longer medically necessary (and therefore no longer covered) well before the patient's actual treatment is complete.

Once the physical manifestations of the disease are treated and a normal weight is attained, the patient can appear to be outwardly healthy. This misperception can be compounded by the fact that eating disorder patients become skilled at hiding their destructive behavior, such as sneaking food and privately purging. As a result, an untrained eye may miss the underlying psychological issues that have not been fully treated and prematurely determine that continued treatment is no longer medically necessary. Tragically, cost containment pressures and a general misunderstanding of the disease can lead health plan personnel to err on the side of less treatment.

CONSUMER TIPS

The Attorney General has developed the following tips to aid consumers in accessing care:

- Read your health benefits booklet carefully and check with your health plan to confirm treatment caps, if any, and whether pre-authorization is required before treatment begins.
- Request your health plan's clinical review criteria for eating disorder treatment. These criteria are used by the plan to determine if your care is medically necessary and, therefore, covered by the plan. Most plans are required to give you these criteria upon your written request.¹⁸

- Document all phone calls to health plan personnel, with names, times and substance of conversations. Keep a paper trail of everything you and your doctor send to the plan.
- Research and choose a facility or other health care provider carefully. Don't be pressured into accepting the preference of the health plan. Research what level of coverage you have for out-of-network providers. Remember: New York law provides HMO members with the right to full coverage for out-of-network care if the health plan does not have a participating provider with expertise in the treatment or service needed.¹⁹
- Appeal denials of care. Very few people appeal, but most of those who do appeal win more coverage. So, always appeal any denial of coverage for care you and your doctor think is necessary. Make sure that you get a clear explanation of the reasons for your plan's denial and ask your doctor for a letter explaining why you need the care.
- Visit eating disorder websites for information, support and advocacy tips:
 www.annawestinfoundation.org (Anna Weston Foundation)
 www.aedweb.org (Academy of Eating Disorders)
 www.nationaleatingdisordersassociation.org (National Eating Disorders Assn).
 www.anad.org (Nat. Assn. of Anorexia Nervosa and Assoc. Disorders)
 www.eatingdisorderscoalition.org (Eating Disorders Coalition)
- Get help with your insurance problems. Call the Attorney General's Health Care Bureau Helpline at 1-800-771-7755 (option 3).

ENDNOTES

- 1. The HCB Helpline provides assistance and information to New York health care consumers. Helpline Intake Specialists and Mediators provide helpful information and referrals, investigate individual complaints and attempt to resolve disputes so that each consumer obtains access to the health care to which the consumer is entitled.
- 2. All names have been changed to protect confidentiality. In this and other case examples, we may have combined facts from different cases to create a complete case scenario.
- 3. Becker, Grinspoon & Herzog, "Eating Disorders," *The New England Journal of Medicine*, 1999; 340(14): 1092-98; see also, National Institutes of Mental Health. Eating Disorders, NIH Publication No. 01-4901 (2001)
- 4. American Psychiatric Association Work Group on Eating Disorders. Practice Guideline for the Treatment of Patients with Eating Disorders, *American Journal of Psychiatry*, 2000; 157 (1 Suppl): 1-39.
- "Eating Disorders," Becker, Grinspoon & Herzog, The New England Journal of Medicine, 1999; 340(14): 1098-8, citing Sullivan, P.F.. (1995) "Mortality in Anorexia Nervosa," American Journal of Psychiatry, 1995; 152(7), 1073-1074.
- 6. "Eating Disorders," The New England Journal of Medicine, supra.
- 7. "Eating Disorders in Adolescence: A Position Paper for the Society for Adolescent Medicine," *Journal of Adolescent Health*, 1995; 16:476-480.
- 8. American Psychiatric Association Work Group on Eating Disorders. Practice Guideline for the Treatment of Patients with Eating Disorders, *American Journal of Psychiatry*, 2000; 157 (1 Suppl): 1-39.
- 9. Eating Disorders. *Diagnostic and Statistical Manual for Mental Disorders*, Fourth Edition (DSM-IV), American Psychiatric Press, Washington, D.C., 2000.
- 10. National Institutes of Mental Health. Eating Disorders, NIH Publication No. 01-4901 (2001).
- 11. Insurance Law §§ 3221 and 4303
- 12. Ibid.
- 13. Ibid.
- 14. Simons v. Blue Cross and Blue Shield of Western New York, 144 A.D.2d 28 (1st Dept. 1989)
- 15. Ibid. at pp. 33-34.
- 16. New York's UR law allows utilization review denials to be externally appealed to a clinical peer reviewer. <u>See</u>, Title II of Article 79 of the Insurance Law and Title II of Article 49 of the Public Health Law.
- 17. While each plan has its own definition of medical necessity, generally a service is deemed medically necessary if:
 - it is appropriate and required for the diagnosis or treatment of the patient's sickness, pregnancy or injury; and
 - it is safe and effective according to accepted clinical evidence reported by generally recognized medical professionals or publications; and
 - there is not a less intensive or more appropriate diagnostic or treatment alternative that can be used in lieu of the service or supply requested.
- 18. Public Health Law § 4408(2)(j).
- 19. Public Health Law § 4408(1)(k).