



Susan Macchia, NJ, PFN Chair

My daughter, 3 years into recovery, is graduating from high school this June and heads off to college in August. My anxieties aren't off the chart—yet! Now that she's an adult: How do I balance her independence with the ability to support her should she need it? This issue's article, **Estate Planning for your College Child**, discusses several documents your family might consider to ensure adult children have someone to speak for them if they cannot speak for themselves.

The PFN Steering Committee started planning for this October's NEDA Conference in New York City. Last year's "Night without ED" was such a success we will host a dinner for parents, families and friends where we can all meet and provide support to each other throughout the conference. Be sure to sign up for the dinner when making your conference reservation!

Looking Back, A Mother and Daughter's Journey, by Lorri Antosz-Benson, PFN

My name is Lorri Antosz Benson, and I am a survivor of my daughter's eating disorder. Better than that, so is she. We walked that walk for about four years, when she was sixteen through twenty years old. It was probably the most horrific and agonizing four years of my life, but now, three years later, I see it was also when I learned most of my lessons about life. We were lucky- first, because she was able to pull herself out of the black hole that was sucking the life out of her. But also because we were able to take our two separate experiences and put them together in a book to

help family and loved ones, called "DISTORTED- How One Mother and Daughter Unraveled the Truth, the Lies and the Realities of an Eating Disorder." The writing was therapeutic for both of us, and the feedback from readers and knowledge that we are now helping other families is fulfilling.

So what can be learned from my family's experiences? How can other parents, spouses, friends, and families of those battling eating disorders gain from our anguish? For one thing, know you are not alone. You are not the only one who does not understand, who is not sure what you

can do, and who is scared out of your mind as you watch your loved one slide down the slippery slope. You would be surprised to learn how many of us are out there. When my story became more public, people came out of the woodwork—everyone had a story to tell about their sister, their daughter-in-law, their college roommate; I couldn't believe how common this problem is.

One of my most valuable lessons, and the one I think is the most helpful, was about separating your journey from that of your

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Just One Thing

NEDAwareness 2010 Gets People Talking!

"It's Time to Talk About It"...and our collective voice has never been stronger. NEDAwareness Week 2010 was a resounding success, with an increase of over 400% in registered participants representing all 50 states and 23 other countries! Thanks to all the PFN members and volunteers across the country that did *just one thing*, we were able to reach more people than ever with critical eating disorders and body image information and resources.

As a result of unprecedented participation from educators and students at middle schools and junior high/high schools, university departments and student

organizations, non-profit organizations, businesses, mental health practitioners, parents, online communities and many others, NEDAwareness Week garnered national, regional and local media attention for eating disorders as serious mental illnesses. Our fabulous first-ever NEDAwareness Week Partner Organizations helped engage many communities that have not previously participated in eating disorders awareness-raising efforts and we look forward to continued growth in 2011!

NEDA sends a big THANK YOU to all PFN members helping to get the message out: Eating disorders

are serious mental health conditions, but with early intervention, education and access to quality treatment, there is hope. Educating your local schools and organizations does not have to end with the wrap-up of NEDAwareness Week 2010 – NEDA invites you to continue distributing the Educator Toolkit and Parent Toolkit throughout the year.

[Download](#) the Parent Toolkit

[Download](#) the Educator Toolkit

[View Photos](#) from NEDAwareness Week 2010

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Estate Planning for your College Student, by Alexander J. Graziano, Esq.

With a son or daughter heading off to college, probably the last thing on a parent’s mind is estate planning. However, a child over 18 who is attending college, or living away from home for any other reason, presents unique legal issues which parents should consider and address by means of certain simple and straightforward legal documents.

The primary issue with a child 18 or older is that now you the parent no longer have the same legal authority over him or her as when the child was below the age of 18. As the parent of a minor child, you had complete control of his or her welfare, from clothing to shelter to education to medical care. As the parent of an adult child, you have none

(unless your son or daughter gives you that authority.) Anyone who has dealt with the health care system during the last 15 years or so is well aware of the privacy provisions of the federal law known as the Health Insurance Portability and Accountability Act of 1996, (HIPPA). The Act imposes severe penalties for unauthorized disclosure of private health information. As a result, most health care providers broadly interpret the prohibition against disclosure, making it very difficult to obtain information about the patient unless you are that person’s spouse.

What this means to the parent of a college student living away from home is that you are not entitled to information about your child’s

health unless he or she authorizes it.

While authorization may seem like a simple matter, it can become complicated. What if your child is unconscious or mentally incapable of giving authorization? What if he or she simply doesn’t want you to know?

The above issues can be resolved by means of a few key documents. They are:

- Durable Power of Attorney
- Medical Power of Attorney
- Living Will

DURABLE POWER OF ATTORNEY
The creator of a Power of Attorney is called the **Principal**. The

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“You are not entitled to information about your child’s health unless her or she authorizes it.”

“...it became excruciatingly frustrating because it wasn’t my problem to fix.”

A Mother and Daughter’s Journey through an Eating Disorder

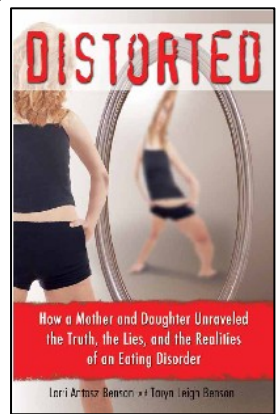
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struggling loved one’s. I wanted so much to just fix the problem, but it became excruciatingly frustrating because it wasn’t my problem to fix. When I thought about it in those terms, I began to handle it very differently. Her road included a giant eating disorder boulder to navigate, and by overcoming it, and figuring it all out, she would grow and enhance herself as a person.

My road had a different boulder blocking the way. My boulder was that my beloved daughter had an eating disorder. Because of the challenges that that particular obstacle presented to me, I learned some of life’s biggest lessons. As awful as that time period in my life was, I definitely grew and even gained some wisdom. That was one of the many lessons I eventually absorbed during our terrible eating disorder adventure. It may have been the hard way, but I learned

to let go. Although it may not be for everyone, I received a great deal of comfort from putting my anguish in God’s hands. My faith opened my mind to understanding things like letting go, realizing Taryn and I had our own paths to travel, and accepting that there were some things I couldn’t change or resolve. It wasn’t in my nature to just step back, and through God, I was able to find the strength to put the frustration aside and be patient. It wasn’t easy, and I didn’t always succeed, but I learned it was what I had to do.

Others may find other sources of strength, through counseling, family support, meditation or any number of avenues. The im-

portant thing is to find a way to understand this is not your battle to win. You are not the star of this game, you are in a supporting role. And the sooner your child, spouse, friend, sister or whoever it may be realizes that the ball is in their court, and their court alone, the sooner they will begin to accept the responsibility of recovery. And you can begin accepting the responsibility of your own journey.



- includes excerpts from "Distorted" by Lorri Antosz Benson and Taryn Benson

Insurance 101—Fully Insured vs. Self Insured Plans, *by Susan Maccia, NJ, PFN*

Families that obtain health insurance through their employer, like mine, are often provided with several health plan options when open enrollment time comes around. We receive a glossy, high quality brochure which explains our options in what we think are clear and concise bullet points - What's the deductible? What's the reimbursement? What's the co-pay? But what that fancy book doesn't tell you is whether or not the plans offered are fully insured or self insured. This will make a difference when it comes to regulations, appeals and the document which spells out your coverage.

Most people are familiar with fully insured plans. Fully insured plans are sold by an insurance company. Premiums are paid

directly to the insurance company and the insurance company uses these premium dollars to pay out on claims.

Self insured plans are funded by your employer: your employer assumes the liability for and pays claims with its own funds. Any premiums you might pay are paid to your employer and your employer in turn pays the claims. Large companies will often hire an insurance or other company to "administer" the insurance plan on their behalf and some companies may administer the plan themselves.

Large insurance companies like Aetna and Blue Cross Blue Shield not only sell health insurance but also provide "administrative" services to employers. Let's say your employer offers 3 different

health insurance plans - one each through Aetna, Blue Cross Blue Shield and Cigna. There's probably no way for you to determine which of these plans are self insured or fully insured. Now you ask: What difference does it make?

1) Regulations: Fully insured plans are subject to federal **and** state laws governing health insurance. Self insured plans are **not** subject to state laws. In the case of self insured plans, state laws which mandate treatment for specific illnesses, such as laws mandating insurance companies cover benefits for eating disorders on parity with medical illnesses, do not apply. During an appeal process, the self insured plan may look towards state laws

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For more information on self insured plans, visit the Department of Labor web site at www.dol.gov/ebsa.



NEDAwareness..... Making a Difference, *by Susan Maccia, NJ, PFN*

My daughter Christine is in recovery 3 years. Over these years we have been a voice for NEDA in various capacities. Knowing four other young women in our town who are struggling with or in recovery from an eating disorder, we thought an event at our local high school might make more of a personal impact. Christine approached the Student Assistance Counselor who offered to form a committee to plan a three day event during NEDAawareness Week.

Day One/Kick Off

We set up a table outside the cafeteria with NEDA balloons, tattoos and brochures. To motivate students to browse the information, Christine created a simple 10 question quiz. Each student who handed in a completed quiz was entered in a raffle for gift cards to local establishments.

Day Two/Art and Self-Expression

With the help and cooperation of the Arts Department, interested

students attended a "Be Comfortable in Your Gene's" art workshop. Students received a life size paper cut out of a pair of jeans. The art instructor encouraged self expression through art using the jeans as a palette. The completed jeans were displayed throughout the hallways of the school.

Day Three/Assembly

Students attended a special presentation by a local therapist which discussed how society has become so focused on appearance, how media influences our perceptions and how devastating eating disorders can be to the person suffering and his/her family and friends.

At the end of our week, we held a "thank you" event for teachers and administrators. We provided CD's with copies of the NEDA Educator Toolkit and Information for Coaches and awarded raffle prizes to students.

It's often difficult to gauge just how much of an impact an event

like this can make, especially with high school teenagers looking forward to the final bell. Imagine my surprise when my daughter came home after an event wrap-up meeting with the news: two students reached out for help!

I'm so very proud of my daughter and, more importantly, she is very proud of herself. We've come a long way from the depths of anorexia to a place where we combine our own unique gifts to reach out and help others. She's learning that making a difference doesn't always mean bringing about world peace, becoming a Supreme Court judge or even being Chairperson of NEDA's PFN. I'm learning to let go, give her space to spread her wings and give her tools to manage her life on her own, knowing the family support net will always be here to catch her if she falls.

NEDAawareness in your community can happen at any time during the year. [Register](#) at NEDA's website.

Insurance 101—Fully Funded vs. Self Funded Plans

(Continued from page 3)

for guidance but is not bound to adhere to state law when making a final determination.

2) Appeals: Under a fully insured plan, appeals are processed and decided by the insurance company. Further appeals normally take place at the state level usually through the state's insurance commission. When that process is exhausted, you might consider filing an individual or class action suit against the insurance company. Under a self insured plan, initial appeals are handled by the administrator with all final appeals decided by your employer's benefit committee. When the appeals process is exhausted, there are very few options left aside from filing a law suit against your own employer. Options might include contacting your US Senator's office (most Senators have case workers

whose job it is to advocate on behalf of their constituents) or the Department of Labor.

3) Governing Documents: Fully insured plans are governed by a Certificate of Coverage. The Certificate of Coverage is similar to a contract between you and the insurance company and details the terms of the health insurance plan. Self insured plans are governed by Plan Document which details the terms of the coverage along with a Summary Plan Description (SPD) which provides a summary of the Plan Document. When appealing a claim denial, you want to make sure you have a complete copy of either the Certificate of Coverage or the Plan Document and Summary Plan Description (SPD).

If you obtain your health insurance from an employer, make sure you have all the information you need

when it's time to make a plan decision during open enrollment. Obtain a copy of the Certificate of Coverage or Plan Document and SPD prior to making a decision on which plan is right for your family. Your employer is required to provide these documents to you at open enrollment. Learning as much as you can about the insurance you have not only helps you make a decision during open enrollment but will make the process of dealing with your insurance company or administrator less confusing .

Be sure to read [NEDA's Parent Toolkit](#) for information on tackling insurance.

NationalEatingDisorders.org



NEDA
CONFERENCE
2010

October 8-10
New York City, NY
**Building Bridges
to Recovery**

Registration opening soon!

The Annual NEDA Conference is designed to address the needs of individuals and families of those affected by eating disorders including anorexia, bulimia, binge eating, ED-NOS, and more. The program also includes sessions for treatment providers and health and educational professionals. Perhaps most importantly, it's a chance to gather together to meet others, share stories and foster connections in a warm, welcoming environment.

Estate Planning for your College Student

(Continued from page 2)

Power of Attorney names an **Agent** (also known as an attorney-in-fact) to act on his or her behalf in legal and financial matters. The principal can grant the agent very broad powers or can limit them to certain circumstances or certain assets.

If your adult child signs and delivers a Durable Power of Attorney to you, you will be able to act on your child's behalf for the purposes listed in the document.

A Durable Power of Attorney continues in full force and effect even if the Principal becomes incapacitated. A Power of Attorney terminates upon death.

MEDICAL POWER OF ATTORNEY

Under a Medical Power of Attorney, your child appoints an agent (you, the parent) to make medical decisions on his or her behalf in the event

he or she is unable to do so. It also allows the agent to communicate with the child's health care providers and receive information about the child's medical condition. This document is often used in conjunction with a **Living Will** (see below) and can help to avoid the privacy issues discussed above in the event the child is unable to make his or her own medical decisions.

LIVING WILL

A Living Will contains two parts. In the first, the child creates an **Advance Directive for Health Care** setting forth his or her wishes regarding the use of life-sustaining treatment (surgery, drugs, therapy, machines which provide life support functions, etc.) and the circumstances under which life-sustaining treatment would be withheld or withdrawn.

In the second part, (sometimes referred to as a **Health Care Proxy**),

the child names a person or persons (you, the parents) to carry out his or her wishes set forth in the first part.

It is important to note that a Living Will **does not** become effective unless and until the patient become unconscious or mentally incapacitated and unable to make health care decisions for himself or herself.

Once your child has created and signed the above estate planning documents, you as a family should review them periodically to ensure that they remain up to date.

Alexander J. Graziano is a partner in the Verona, New Jersey law firm of Graziano & Campi, LLC. He specializes in Wills, Trusts and Estate Administration. He may be reached at 973-857-2525 or alex@grazianolaw.net.



NEDA Network Highlight—MEDA Luncheon Invitation

PFN members and all attendees of the Multi-service Eating Disorders Association's annual conference in Needham, MA are invited to a special luncheon at the conference organized by PFN member, MB Krohel! View the special invitation on our [PFN webpage](#).

"Getting Unstuck: Revitalizing the Prevention and Treatment of Eating Disorders"

April 30-May 1, 2010

Sheraton Needham

For more information about MEDA, a NEDA Network member organization that serves families in the Northeast, and to register for the conference, go to www.medainc.org



Meet NEDA - Susie Roman, Program Coordinator

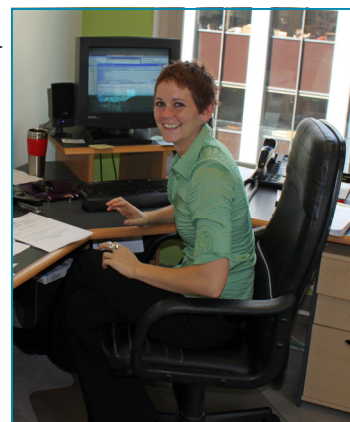
Susie Roman joined the NEDA team in 2008 as the Program Coordinator after moving back to Seattle from Vancouver, B.C. where she received her MA in Women's Studies and Gender Relations from the University of British Columbia (UBC).

While in Vancouver, Susie coordinated UBC's Anti-Violence Week, educational events and awareness campaigns for the Sexual Assault Support Center at UBC. Susie worked for many

years as a workshop facilitator on sexual violence, cultural constructions of gender, systemic oppression, privilege, supporting survivors of trauma, and sexual violence coping mechanisms. Her primary areas of professional and academic focus have included cultural underpinnings of gender and sexual violence, body dissatisfaction among women and young girls, co-modification of the body, the relationship between eating disorders and trauma, and the relationship between eating dis-

orders and sexuality and gender identity.

Susie has been volunteering for two years at the Lambert House, a drop-in center for LGBTQ youth, and enjoys working with at-risk youth. In her free time she teaches and performs Tribal Belly Dance, enjoys taking aerial circus arts classes and loves to hunt through thrift stores.



Just One Thing



PFN is Your Story.....

Starting in May, look for a new story each month from all kinds of different PFN members coming to your email's "virtual kitchen table" that will reach out and touch your heart. It's a conversation we all will look forward to! Lorri Benson will be "at the table", helping us get to know each other better through our stories.

Share your Thoughts.....

If you have an idea for an article, a question you'd like us to research or would simply like to share your story, we'd love to have you participate in our newsletter! Email us at pffnetwork@myneda.org. Be sure to include your full name, email address and daytime phone number so we can contact you! The PFN Newsletter is by parents, family and friends for parents, family and friends!



NationalEatingDisorders.org



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