

HEMO HINTS

Don't forget to take care of yourself! Have some quality time alone...or go on a date with Your partner or friend.

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INALEX EXCHANGE

A MONTHLY NEWSLETTER DEDICATED TO FAMILIES LIVING WITH A BLEEDING DISORDER

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Caronna's Corner - Our Independence Joe Caronna—President, Inalex Communications



Fireworks, family barbecues, apple pie and the American flag. These are all symbols of Independence Day. It's a time of year

when we all celebrate our independence. We celebrate the independence from the tyranny of British rule, the independence of a free democratic country.

As the father of a child with hemophilia I think of his independence and how he will grow up to be a man. I think back to a day not so very long ago when boys with hemophilia, just like my son, were very dependant on others.

Long before clotting factor was covered by insurances, it was "paid" for with blood credits. To get these credits, blood drives would be held and you had to depend on others for blood donations. This was a very difficult time because hemophilia had bad connotations. Hemophilia meant if you got cut, you would bleed to death. So families were very reluctant to tell others their child had hemophilia. You really had to depend on close family and friends to donate blood.

In New Jersey, as well as other states in the country, the generations before us fought long and hard to get our clotting factor covered by insurance, so we would not have to depend on blood drives and blood donations. This was a step toward independence.

Before clotting factor, this generation of men also had to depend on emergency rooms for treatment. There was no home care delivery of clotting factor. You couldn't go to your refrigerator and get factor replacement. These men went to the waiting room of the ER and had to wait hours for plasma and later cryoprecipitate to be defrosted and pooled together.

This dependence on emergency rooms made some men go days or even weeks without treatment. They would depend on RICE for their bleed and that's why so many men from certain generations have severe joint problems.

This dependence turned into independence for hemophiliacs when lyophilized clotting factor was introduced. Hemophiliacs and their families were now free to travel; something we now take for granted but was practically impossible for older generations of hemophiliacs.

While this new product held devastating consequences for an entire generation, this devastation made an entire community come together and fight for safer products.

Not only did this generation fight for safer products, they fought for the right to have our clotting factor delivered right to our doorstep. In fact, here in New Jersey, we have passed an all-encompassing Standard of Care bill; the first of it's kind in the

entire country.

Our community fought hard to get these Standards passed so among other items; factor MUST be delivered to a patient in New Jersey within 3 hours.

As our forefathers laid the groundwork for independence from tyranny, this older generation of hemophiliacs and their families laid the groundwork for the independence my child enjoys today.

There is no need to go to the ER for a bleed, unless of course it is life threatening. We can now infuse factor in the comfort and convenience of our home, safe in the knowledge that if we are out of product, we can get it within 3 hours.

My son Alex enjoys the freedom and independence of playing sports, going to camp; in fact, doing anything he wishes to do. And he also has the knowledge that his product is safe from blood borne disease. There is no limitation to his independence.

Just as we take our freedom and independence for granted these days, we tend to take hemophilia for granted and the quality of life our children are so lucky to experience. So on this special holiday when we celebrate are independence, please take a minute to think about the generations of hemophiliacs that came before us and like our forefathers.. **fought for our independence.**



Dr. David Kundtz
 is on the
 Inalex faculty
 and is the author
 of the
 acclaimed:
 “Quiet Mind: One
 Minute Retreats
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Are You Thinking Positively and Rationally?

Have you ever felt really stressed about something, only to see the stress vanish when you talk the situation through with a friend?

Quite often, our experience of stress comes from our perception of a situation. Often that perception is right, but sometimes it isn't. Sometimes we are unreasonably harsh with ourselves, or jump to wrong conclusions about people's motives, and this can send us into a downward spiral of negative thinking.

Thought Awareness, Rational Thinking and Positive Thinking are simple tools that help you to change this negative way of thinking. This page teaches you how to use them.

The most commonly accepted definition of stress is that it occurs when a person believes that "demands exceed the personal and social resources the individual is able to mobilize". In short, it's when we feel out of control.

When people feel stressed, they have made two main judgments: First, they feel threatened by the situation, and second, they believe that they're not able to meet the threat. How stressed someone feels depends on how much the situation can hurt them, and how closely their resources meet the demands of the situation.

Perception is key to this as (technically!) situations are not stressful in their own right. Rather it is our interpretation of the situation that drives the level of stress that we feel.

Thought Awareness: You are thinking negatively when you fear the future, put yourself down, criticize yourself for errors, doubt your abilities, or expect failure. Negative thinking damages confidence, harms performance and paralyzes mental skills. Unfortunately, negative thoughts tend to dart into our consciousness, do their damage and dart back out again, with their significance having barely been noticed.

Since we barely realize that they were there, we do not challenge them properly, which means that they can be completely incorrect and wrong. Thought Awareness is the process by which you observe your thoughts and become aware of what is going through your head.

A general approach to Thought Awareness comes with logging stress in a Stress Diary. When you analyze your diary at the end of the period, you should be able to see the most common and the most damaging thoughts. Tackle these as a priority using the techniques below. Here are some typical negative thoughts you might experience when preparing to give a major presentation:

- Fear about the quality of your performance or of problems that may interfere with it;
- Worry about how the audience (especially important people in it like your boss);
- Dwelling on the negative consequences of a poor performance;
- Self-criticism over a less-than-perfect rehearsal.

Thought awareness is the first step in the process of managing negative thoughts, as you cannot manage thoughts that you are unaware of.

Rational Thinking: The next step in dealing with negative thinking is to challenge the negative thoughts that you identified using the Thought Awareness technique.

Look at every thought you wrote down and challenge it rationally. Ask yourself whether the thought is reasonable. What evidence is there for and against the thought? Would your colleagues agree or disagree with it? Looking at the examples, the following challenges could be made to the negative thoughts we identified earlier:

- **Feelings of inadequacy:** Have you trained yourself as well as you reasonably should have? Do you have the experience and resources you need to make the presentation? Have you planned, prepared and rehearsed enough? If you have done all of these, you've done as much as you can to give a good performance.
- **Worries about performance during rehearsal:** If some of your practice was less than perfect, then remind yourself that the purpose of the practice is to identify areas for improvement, so that these can be sorted out before the performance.
- **Problems with issues outside your control:** Have you identified the risks of these things happening, and have you

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Spotlight on Men in our Community - Josh Valance

This month, the Spotlight is on Josh Valance of Melbourne, Fla

I was born in 1963 in Cherry Hill, New Jersey. I have factor 9 Hemophilia severe, Hepatitis C aggressive. I'm married to Mary, my beautiful wife for 13 years and I have a 6 years old son John.

Growing up was hard for me because of my hemophilia. I didn't think I could be a normal kid because of it. My father wasn't in my life, and my mother was a stewardess so she did a lot of traveling. Because of this, my mother thought it better if I lived with my grandparents for 20 years in Toronto.

When I was young, I was treated on fresh frozen plasma. I had to go to the emergency room, for sometimes 4, 5, 6 hours. I remember laying there and the nurse coming in saying things like "Please, you can't be doing that", "You can't be moving around", of "Don't wiggle around so much!". It wasn't pleasant, until I was able to take the factor, and boy was it a God sent!

I was sick of hearing my grandparents trying to explain to the medical staff that I needed treatment, even though they can not see blood. They would try to explain that the blood is inside and the nurse would then determine that there was no real problem, and would go to me when they could; leaving me to wait for hours at a time before I was treated.

What a relief to be able to sit at home and infuse myself at

my own leisure not having to worry about waiting for the plasma to thaw. Now with the new products, I don't have to wait. Wonderful!!!

When I was in school, my family was against me playing sports. I would hear "You're a hemophilic, you should not be doing what those other kids are doing", is all I heard. I decided to break the rules and go and play sports. I went and played baseball, and even tried hockey, wrestling, and martial arts. I quickly learned that not all sports are made for a hemophilic. I learned the hard way. Not a good way to learn, but I did learn.

The message here is that I didn't let anything stop me. I would just be a kid, play my sport, infuse when I had to and most of all, have fun. I think it's important to do so because you only have one life and you have to make the most of your life.

A dear friend once told me before he died; that you either get busy living or you get busy dying. Having hemophilia...well I decided a long time ago that I'd rather live than die. I seen too many of my brothers fall to things like hemophilia, AIDS, hepatitis. So life is important, and we have to get up and live life to the fullest, and I owe a lot to my wife Mary.

Mary and I met on Halloween night in 1994 at a party. I was at a very low point in my life. I didn't expect to meet Mary that night, and then later fall in love and get married. Thirteen years later, I can honestly say that I wouldn't trade my life for the world.

I have a 6 year old son named John. He was diagnosed with bipolar severe and autism. Up until recently, my son was in a treatment center for 2 months. It does hurt me that my son has a disability. I thought that when he was born, and he was a boy, hemophilia was finally over, and no more disabilities. And now that he's disabled I have two reasons to advocate - one for myself and one for my son.

I now volunteer a lot of time to my community. I'm proud to say that I was recently appointed on the Hemophilia Federation of America. I also started, with a friend of mine who has a hemophilic son, an organization called "Blood Angels". The purpose of the organization is to support the hemophilia community. We're there to help each other. For example, if someone needs to talk, we have a network that we can call one another. If there is a crises, or if they just depressed and need to talk to someone, we're here.

I think the young people today need to realize how fortunate they are. I'm 44 years old and I see more and more of my older blood brothers who have severe joint issues, and I see these young people today and I say god bless them because they have the advancements in hemophilia where they can go out and be a kid and do what a normal kid does despite having hemophilia.

I have no regrets in my life. If I could do it again, I would do the same, only with a bit more moderation. So message to my fellow brothers and sisters is to live life to the fullest and **to get busy living or get busy dying!**



"When I was in school, my family was against me playing sports, I would hear, "You're a hemophiliac, you shouldn't be doing what those other kids are doing!"

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Are You Thinking Positively and Rationally? (con't)

taken steps to reduce the likelihood of them happening or their impact if they do? What will you do if they occur? And what do you need others to do for you?

- **Worry about other people's reactions:** If you have prepared well, and you do the best you can, then you should be satisfied. If you perform as well as you reasonably can, then fair people are likely to respond well. If people are not fair, the best thing to do is ignore their comments and rise above them.

When you challenge negative thoughts rationally, you should be able to see quickly whether the thoughts are wrong or whether they have some substance to them. Where there is some substance, take appropriate action.

Positive Thinking & Opport-

unity Seeking. By now, you should already be feeling more positive. The final step is to prepare rational, positive thoughts and affirmations to counter any remaining negativity. By basing your affirmations on the clear, rational assessments of facts that you made using Rational Thinking, you can use them to undo the damage that negative thinking may have done to your self-confidence. Continuing the examples above, positive affirmations might be:

- **Problems during practice:**

"I have learned from my rehearsals. I can deliver a great performance. I am going to perform well and enjoy the event."

- **Worries about performance:** "I have prepared well and rehearsed thoroughly.

I am well positioned to give an excellent performance."

- **Problems issues outside your control:** "I have thought through everything that might reasonably happen and have planned how I can handle all likely contingencies. I am very well placed to react flexibly to events."

- **Worry about other people's reaction:** "Fair people will react well to a good performance. I will rise above any unfair criticism in a mature and professional way."

In the examples above, successfully overcoming the situations causing the original negative thinking will open up opportunities. You will acquire new skills, you will be seen as someone who can handle difficult challenges, and you may open up new career opportunities.

Inalex Communications

38 East Ridgewood Avenue, #244

Ridgewood, NJ 07450