

## **THALASSEMIA AND FEARS**

### **TIF News, Issue No 4, February 1992**

I must admit that this year I went through a great crisis. I said to myself: I am alive. Yes technology and medical advancements have helped me to stay alive. I have reached my 32nd year of life. So what I am alive? Is it really worth living? Is it worth struggling everyday to stay alive? Do I have a purpose in my life that makes all this suffering worthwhile or am I struggling because I am afraid of dying? Or is it maybe that I am used to it and I think that I have to do it because others say so? Is it because I know that I am going to die that I am trying to stay alive or is there any deeper, more interesting reason for which I am alive?

When I was younger I was a lot more optimistic. I thought life was beautiful people were nice and kind hearted. I later realized that I must not take anything for granted. Life is nothing until we make it into *something, as existential* philosophers say. This means that I am responsible for what I make out of my life. I have to struggle not only to survive physically but also I have to struggle to find my own answers to all of my questions.

This realization overwhelmed me with great dreadfulness. I got terribly *anxious, scared, angry and depressed*. I often contemplated about giving it all up. Why fight more for my life? Isn't It already enough? Committing suicide would be easy. I would just stop using my pump. This is what quite a few of us do. The doctors just say: well she was not compliant with treatment and the issue is easily brushed to the side and under the carpet.

In a class I teach on "Attitudes towards Death & Dying" I asked my students to write an essay on their attitudes towards the idea of their own death. The essays were very interesting and I quote just a paragraph from two of the papers.

..."One single thin thread is what unites life with death or keeps them apart and this is time. Nothing seems more threatening to us than the fear that time is running out, leaving us helpless not ever being able to find a way of stopping this. One thing is certain, the more time passes, the closer we get to death. One struggle that could not be more desperate for us, it seems worse than actual war, fighting against the thought that each new day only brings us closer to death. It seems rather pessimistic since it sounds as all we are waiting for, from the moment we are born, is death, but people fortunately or unfortunately, have managed to do something with this long interval between birth and death in order to forget this ugly truth. Life would become a nightmare if we were constantly fully aware of death. We therefore choose to pretend that death is something we have no connection with"....

The second student says:

.... "Death is God's great joke on man, says Robert Frost. An ironic big joke, I would add. By being given the unique privilege of "being" we instantly undertake the burden of facing the stressful possibility of "stop being". I have just used the word "possibility" to indicate that it took me a considerable amount of time (years) to realize that there is no way of escaping death. I used to believe that there was something that would, just at the last moment, intervene and save me. It seemed very distant for "it will be ages until death knocks on my door"."....

These are very typical thoughts of healthy young adults about death. As you understand it is very common and "normal" for people to deny the certainty of death, or as my student

wrote "to forget this ugly truth". However, for people like us with a chronic life threatening illness the task of "pretending that death is something we have no connection with" or that "it will be ages before death will knock on our door" is very difficult to almost impossible. We have the special privilege to have to fight for our uncertain existence every day of the year and to be constantly reminded of our limitation in keeping death away from our territory. This is dreadful but at the same time could be the opportunity for a more full, true, authentic existence. Our illness gives us the opportunity to face the most basic of all questions: "What's life and what do I live for?"

This is a question that according to existential psychotherapists is the most basic and the most important. All people have to answer it, if they are to live a meaningful life. The challenge for us is always there and it is very big because it is really difficult to find a worthy cause for our existence. Our existence is more painful and difficult than the existence of other people who have no chronic illness and in addition we have always been told, directly or indirectly, that this existence we have is handicapped. Having all this in mind I believe that doctors should ask and wonder: Why are they still complying with treatment? What is it in our life that gives us the strength to keep on living and fighting every day of the year for our existence?

I am not of course going to answer this question because I am still trying to figure it out for myself and I believe that each one will have to answer it for himself. There are no readymade answers. This is why life is difficult not only for us but for everybody. I see it in my every day work with people. We all want readymade answers. We do not want to struggle to find our own answers. People very often go to psychologists just so that they can have their questions, dilemmas and conflicts answered and solved. They get very disappointed when I tell them that I am there for them in order to find their own answers and that I do not have the answers ready for them. However, this is another of the ugly truths of life. No one can live our life for us and no one can decide **for** us. We have to do it by ourselves.

Existential psychotherapist Irvin Yalom, who teaches at Stanford University School of Medicine, believes that there are four "ultimate concerns" in life that are at the root of our conflicts and our anxiety. **Death, freedom, existential isolation and meaninglessness.** People usually do not want to think about them and be aware of their implications because they frighten them. Thus they try to push them away from their consciousness.

However, these concerns do not disappear, since they are very important and they relate to our human nature, but they appear in disguised symbolic ways. They appear in the form of phobias or other symptoms both physical and emotional. These symptoms are what we call mental illness, psychopathology or maladjustment. According to existential psychotherapists the only way to deal with these psychological problems is to become aware of the above mentioned concerns and incorporate them in our life instead of pushing them out of our awareness.

Since these concerns are so important for our psychological well being lets pay a little bit of attention to them, although they may be scary and raise all sorts of resistances and defenses in us.

## **Death**

Death is one of our most important concerns and fears. What will happen to me? Will it be painful? I will have to leave everything I have created behind. How will others react? Thousands of questions and more important of all: What will I be? Nothing? Fear of death is shared by all people because no one can escape from it no matter how rich, famous, or successful s/he is. We are all humbled in front of death. We also, however, have the opportunity to see life as it is. Small things in life take a great importance. A sunny day, a long walk, a nice talk with a friend become important. These are the small things in life that we can start to appreciate when confronted with the reality of death. This is why existentialists believe that life and death co-exist and are the two sides of the

same coin.

Lots of people who either had near death experiences, like in accidents or suicide attempts, a life threatening illnesses, like cancer or AIDS share that their life changed significantly after the experience. They started to really live for the first time. In his book "Existential Psychotherapy" (1980) Irvin Yalom quotes Senator Richard Neuberger who shortly before his death from cancer wrote:

..."A change came over me which I believe is irreversible. Questions of prestige, of political success, of financial status, became all at once unimportant. In those first hours when I realized I had cancer, I never thought of my seat in the Senate, of my bank account, or of the destiny of the free world ... My wife and I have not had a quarrel since my illness was diagnosed. I used to scold her about squeezing the toothpaste from the top instead of the bottom, about not caring sufficiently to my fussy appetite, about making up guest lists without consulting me, about spending too much on clothes. Now I am either unaware of such matters or they seem irrelevant ... Instead has come a new appreciation of things that I once took for granted -eating lunch with a friend, scratching Muffet's ears and listening for his purrs, the company of my wife, reading a book or magazine in the quiet of my bed lamp at night, raiding the refrigerator for a glass of orange juice or slice of coffee cake. For the first time I think I actually am savoring life. I realize, finally, that I am not immortal. I shudder when I remember all the occasions that I spoiled for myself-even when I was in the best of health by false pride, synthetic values, and fancied slights"...

Individuals like us who have a chronic illness, as I said in the beginning, have the difficulty of not being able to deny so well as other people the ever present threat of death. In this respect however we are also given the opportunity to learn from such realizations. It does not have to be that death knocks right on our door before we start to see the reality of our life. We can start from now. It does not have to be that we realize what we have only after we lose it, but unfortunately this is what we most often do.

## **Freedom**

Freedom is another important concern because when we realize that we are free, we are free to choose from a number of alternative roads our own unique path in life, we get scared by the burden of responsibility and will power that this realization entails. We very often want to escape from our freedom, as another psychologist, Erich Fromm so clearly demonstrated in his book "The Fear of Freedom" (1979). If we are free to write our own history then we are also responsible for the choices that we make and for what happens to us.

Although we may not be responsible for the fact that we were born with a chronic illness we are definitely responsible for the way we react to it and the attitude we have developed. Granted this attitude has been influenced, most often negatively, by our parents and society but now it is in our hands to decide what we think and how we feel about it. I am definitely not the person to tell you that this illness was God's verdict for a miserable existence or that I believe that because of its presence I am less than other people. Each one of us is **responsible** to decide in his/her own unique way and then to have the will power to carry out his / her decision. Of course if you decide that it was God's verdict for a miserable existence you abolish your freedom, your responsibility and your will power, which is the easy way out.

## **Existential isolation**

Existential Isolation is the deeper inner awareness that we are alone. We are born alone and we will die alone. We are the ones that have to go through this existence, we are the ones that will have to struggle hard with our decisions and the course our life will take. No one can live our life in our place and as I said in the beginning no one can keep us in this life no matter how much s/he loves us or cares for us. We have to care for ourselves, we have to do everything by ourselves and for ourselves. Of course help is always welcomed but cannot substitute for our efforts. Yes, your mother can prepare your pump for you or arrange appointments for transfusions but it is you that has to actually do it.

The awareness of this basic existential aloneness is something that scares all people and this is why we all try to avoid it by forming intimate relationships. It is important to be able to be close to others, to give and take, but we cannot expect that others will fulfill all of our needs or will fill the void that we feel in our life. We often try to fill the void with material possessions, with objects or ideas like success and power but we rarely are very satisfied, or for too long, with our efforts.

### **Meaninglessness**

Meaninglessness is the last but not the least of our concerns. Is there any meaning to this painful life we are living? What is the purpose of all that we are going through in order to be alive and live? The problem, as existentialists see it, is that there is no inherent meaning in life. Life is what we make it to be. This is our ultimate freedom and our ultimate fear. Are we able to stand up to this formidable task? As I said in the beginning I am also searching for an answer. If I do not find it I believe I will not be able to really enjoy life and fully live it. However, I am optimistic that we can all find our own answer.

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(Speech delivered in Nice on the 9th of November 1991)