

Transcript of an informal chat with Dorothy Stiefel 2/20/99

(Edited for clarity and length.)

DAN: Dorothy Stiefel is executive director of the Texas Association of Retinitis Pigmentosa. She is also an author and motivational speaker on the subject of dealing with vision loss. Dorothy, before we open the floor for discussion, please tell us about yourself.

DOROTHY: Thank you, Dan. As soon as I learned I had RP and was told I'd be blind by the time I was 40, I set out to learn everything I could about this "thing" that threatened to take my hopes and dreams: my life! I was a frequent visitor to medical libraries. In time, still alone with RP, I became known as the "RP Lady." Doctors jokingly admitted that I knew more than they did. As early as the mid-70s I organized a support network to connect people with one another so they wouldn't feel alone and possibly succumb to depression. I made this more than my life's work: it became a crusade. Now that I am doing a lot of traveling overseas, I continue to help connect people with others for emotional support.

When I was not quite 25 years old and engaged to be married shortly, I went to an eye doctor for what I thought would be just a new prescription. I was a teletypesetter operator for a newspaper office and was having trouble reading baseball scores and other fine print.

Without warning, and in one curt statement, I was told I'd be blind by the time I was 40. I don't remember leaving the doctor's office. I telephoned a co-worker to come for me. I was afraid and panic-stricken. I didn't know what to do. All sorts of thoughts were racing through my head as I tried to sort out what the prognosis really meant. At one point I remember saying that I wished I were dead! These were the words of a desperate young woman.

When I sought answers from my mother, she exclaimed: "Where did you catch that!" I felt that the promise of marriage: love, children and a wonderful husband could never materialize. I knew I had to tell this man in my life that the wedding was off. In essence, I pulled a "pity party." But the man who was to be my husband, would not listen to any of this. He promised to stand by me and take care of me. Feeling vulnerable yet thankful for his supportive words, we were married as planned.

Both of us had children by a former marriage so with a ready-made family of four, I immediately immersed myself into mothering and child care. Thus, this became the escape--or the first line of my coping strategies. I was too busy being a housewife!

My second line of defense against this life-long intruder, was reading up on all the research papers I could find in a medical library. I needed to understand this "thing" that was threatening my sense of being a whole person in control of my life. I

entertained the thought that perhaps the doctor had made a mistake, because I didn't feel any different except I'd always known that I couldn't see at night or in a dimly lit environment. I knew in my heart that enough knowledge would set me free from the burdensome thoughts that would wash over me now and then.

Shortly afterward, I became pregnant and I was in for yet another shock. When I went for a checkup at a prestigious Baltimore clinic, a doctor told me that my unborn child would "more than likely be born blind!" This shattered, almost broke me. I went into seclusion: I wouldn't talk much and my husband feared for my sanity and safety. A trip to a psychologist was the best thing that ever happened to me.

Instead of pills, his prescription was for me to get away from it all: the children, responsibilities, and the area itself so I could sort things out. It worked.

After a week alone with my thoughts in the safety net of the home of my sister-in-law, I began to miss the children, felt that I had abandoned them, and wanted to go home. After the birth of my child (who was (and is) perfectly normal, I was determined to learn everything I could about RP. I continued to record my feelings in a journal (an exercise I highly recommend to people.) When you spill out your thoughts, you release yourself from them and they can no longer torment you. I regularly go back to look at the "terrible times" and it is as if I am reading about another person! You may notice this example in everyday life. When people experience a shocking event, they immediately call their best friend or neighbor to share in their pain or grief.

In 1975, I learned of the RP Foundation (now the Foundation Fighting Blindness). On the suggestion of a rehab teacher who also had RP, I contacted the Baltimore research group. However, I realized that there was a critical need for an emotional support group, and in 1979, the Texas Association of Retinitis Pigmentosa became a support organization. It continues to be a model for others around the world looking for a viable support system for their people.

After 28 years of "connecting" people, I hope that I can continue to be a source of information and emotional support to those who need it.

DAN:, you have stressed six steps for managing your life. Could you outline them for us before we open the floor to comments and questions?

DOROTHY: Here is my list of six "Steps for Managing Your Life:"

1. Give yourself space when you first learn of your diagnosis.
2. Align yourself with someone you trust and you know will give you the emotional support you need.
3. Get a second opinion, even a third if necessary.
4. Learn everything you can about RP/MD from a reliable source.
5. Don't give up on your future. There IS life after vision loss!
6. Last but not least, develop a sense of humor!

DAN: Dorothy, do you feel that doctors should spend more time after a diagnosis in explanation of a patient's condition?

DOROTHY: It would be nice if they could spend time for the patient, but unfortunately, this is not the case for two reasons: (1) they have a busy schedule, and allow a certain amount of time for each patient; and (2) most of the docs cannot handle the emotional outbursts or the crying...or the fact that he has given a diagnosis to this person, so it is better to have an assistant take care of that particular area.

Often, the doctor, when coming to that point in the patient's visit, will tell the patient that someone will come in and talk to him/her about the condition.

DAN: After your initial diagnosis, you said that you had some suicidal thoughts. What would you tell a person now who might be feeling that?

DOROTHY: The first thing is to get in touch with another person whom they trust. This allows for an exchange of feelings, sort of like a togetherness between the people that keeps them in touch with their feelings. And as they speak with one another, the person having the problem will suddenly realize that it is just the thought of losing all of their vision that is making them feel like they want to waste their life.

The most important thing is for a person to (1) be able to sort out the feelings without a whole lot of people trying to tell them what to do; and (2) be with that one other person for as long as it takes to get over the feeling that they want to get rid of their life.

What happened to me is that my husband sent me away from the children to his sister's so that i could sort out my feelings. I could not get back on track without having had that time to myself to figure out what I was going to do with the rest of my life.

DAN: Are there any comments from the floor at this point? Has anyone here ever felt this way or known someone who has felt this way?

DONNA: Yes.. He dropped off the list of many people, and emails me privately. He sounds on the verge of suicide many times, and he wants to let me off the hook. I forbid it, and then he relaxes and gets into a better state of mind.

DOROTHY: Has he been in touch with a doctor?

DONNA: Yes. His family life is bad. He is very depressed. I told him go to a doctor for medical help. He said depression medications didn't work. They do not recognize his need, because of his eyes. He has no support, and he has lost his job. He has a wife and kids to feed.

DOROTHY: He should be in the hospital for treatment of the depression, and get some help from the psychologists.

DONNA: Yes, he should, but because of lack of support, he feels it's all his fault and he won't do much about it.

DOROTHY: He needs to be in that setting so he can stabilize, and so they can find out the cause of the deep depression.

DONNA: I had hoped his med doc would tell him to go.

DOROTHY: I would say that you can lead a horse to water, but you can't make him drink.

DONNA: Yes, so I just keep the communication open, and pray.

DOROTHY: Absolutely. He has no one else. You might ask him to pray with you sometimes.

DONNA: No. He has a brother with MD who scoffs and calls him a failure etc. Also, his wife may leave him.

DOROTHY: Donna, please email me, and we can continue this discussion about the young man. My address is dstiefel@interconnect.net.

SHARON: I am wondering about how to deal with juvenile onset MD vs. adult onset MD I have the former and dealt with a lot of shame and fear of being different.

DOROTHY: Well, Sharon, this is out of my league as far as the particular disease which you have, but i would first ask, how have you always felt about yourself?

SHARON: I have cone/rod dystrophy, but was originally told that I had Stargardt's. I was 15 and was told that I would pass this along to my children, and not much more. I was scared and wanted to fit in very badly. I ended up hiding my disability for alot of years.

DOROTHY: First of all, this is normal. Secondly, give yourself the chance to continue to be the person that you always have been. I know that what you have found out is a shock and hard to deal with, but in time you will understand that you still are the same person, and you must go on in your life as you had before you found out that you had this, and that you might have the chance of passing it on.

SHARON: I have finally come to that conclusion but I am wondering how to deal with a child differently, given that they haven't formed their self completely. I wonder how to help young people to not take as long as I did to accept this disorder.

DOROTHY: A good beginning is to get the young person to talk. Establish a relationship so that they have someone to talk with. Usually, family members are not their first choice.

DAN: We know that retinal degeneration can be hereditary. What would you say to a woman who has the disease if she has concerns about bearing children?

DOROTHY: This is a personal matter between husband and wife, however they should both go to genetic counseling and find out all they can and then make up their minds what they want to do. Whatever they choose to do is fine, because they are in charge of their lives and whatever children they bring into the world. If they deprive themselves of having a child because of the thought of that child being affected, they may not be able to live with that deprivation for all of their lives.

Secondly, you cannot stop the course of genetics, no matter whether you do or don't have children. In other words, genetics are always going to be with us, so ultimately, it is still up to the couple and what they want to do. It is a very personal thing.

DAN: Comments or questions from anyone? Eventually, we will get into discussion of some hints for everyday living, but there are a few more points in this area which I think we would all like to discuss first. Edna, do you have a question?
EDNA: Not at this time. I'm so grateful for the information we are getting today. I'm still pondering my own situation.

DOROTHY: I am very happy to be of some assistance. This is very new to me, doing it slowly like this, but I am enjoying it and hope we can get together on email. Thank you for your kind words.

DAN: Dorothy, you appear to really have it together, considering the advanced stage of your disease (RP). What was the single most important thing that helped you gain acceptance of the disease?

DOROTHY: First, I want to make sure how we are using the word acceptance. I accept the fact that I have to live with this genetic disorder. (I choose to call it a disorder instead of a disease, because I am not ill from it, but I have to live with it). What I did was (because I couldn't get rid of it) I embraced it and made it part of me. Part of my choice in life was to help other people who have it. It's something that I'm almost proud of, because it created a challenge for me. Otherwise, I might not have done anything else with my life. Does that make sense?

DAN: Yes, it does, Dorothy.

DOROTHY: Every once in a while, I'll have a down day, but not necessarily because of poor vision. It's just that all of us at once time or another will feel down about everything about ourselves. It's ok to feel that way--to have a small depression.

There are two kinds of depression, the small ones, and then the deep ones for which one should get help. We must realize that, no matter what, we are basically the same person. The same person means that your attitude, your personality, your sense of humor--all makes you what you are. When something comes along to break that up, you should not let it devour you, but you should embrace it, and use

it as a tool for challenge.

SHARON: I was not able to use the word "accept" for a long time and had to change it to "cope," because to me, "accept" meant liking it.

DOROTHY: Either word is fine, but it should be a positive word.

JOAN: Relative to young people, I don't think acceptance is the only way to go. Lots of times kids get along fine just banging out their own solutions.

DOROTHY: Please allow me to define my concept of acceptance. Acceptance and more mature adjustment can often come later in life - with maturity. Your concept is fine, but what I meant was accepting that there is a problem out there that can be sorted out in various ways. Not to accept the disease, but to accept the facts.

JOAN: Yes, I understand. I don't think Sharon needs to beat herself up over what she may not have done when she was younger. Kids can have lots of problems they don't want displayed, because they make them feel different.

SHARON: I don't anymore, but I would like to keep someone else from wasting so much time.

DOROTHY: Yes, I understand that.

JOAN: Sharon, I don't see it as wasted time, I see it as the process of maturing.

DOROTHY: Good, Joan.

SHARON I think if I had support earlier--and information--it would have helped so much.

JOAN: Sharon, I wish you had had support. And I think we ought to extend it to younger people.

DOROTHY: That is exactly what I am trying to do, because I had not one person in the whole world until I found the Foundation Fighting Blindness, and met some people with RP.

JOAN: I also notice that lots of times they hear but don't act. Saving it for later.

DOROTHY: Absolutely, Joan, I agree. But only if they want it. You just don't know unless you extend the offer.

SHARON: It helps to know someone who really understands.

JOAN: You bet, Sharon. Let me tell you more about my children. First, we

had his, mine, and ours. Four to begin with when married in '57, then we had three together. Now, the children that were my husband's from a former marriage didn't have a problem with my RP, but my children did. That is probably not unusual. Has anyone else been in such a situation?

EDNA: Just wanted to say that after having MD for 10 years, this is the first time I have known anyone to talk with about it, other than my niece, Mindi. I can't say how much I appreciate this. Thank you so very much.

DOROTHY: You're welcome, Edna.

JOAN: Regarding offspring, I encouraged my daughter to leave, to go away to school to get away from this for a while. She has dealt with a mother who is "different" for most of her life. As much as I could use her help, I **really** want her to have her own life without this controlling her dreams and her decisions. Everybody thinks I'm wrong to do that.

DOROTHY: Was your daughter having to deal physically with your problem or things going on in the home?

JOAN: I have other physical limitations. It was just the two of us. I thought she had too much responsibility that had nothing to do with her, or with her developing into a person in her own right.

DOROTHY: Did she want to stay or leave?

JOAN: She wanted to do both.

DOROTHY: That's typical, but yes, I suppose she needed a breath of fresh air. Now she is happier out on her own. She is getting to know herself better. Test herself. But if she is away too long, she will begin to feel guilty, and want to return. That's good.

JOAN: I'd like to see her get over the guilt stuff. It isn't a big problem right now. I would rather give the future a geneticist than a housekeeper/mother's helper.

DOROTHY: Is she feeling guilt about going away? Even though it was best for her?

JOAN: She's better about it this year, but she wonders how I survive on my own.

DOROTHY: Very commendable. My daughter did the same thing. She is a nurse.

JOAN: Good for her. Different kids have different needs. I couldn't see crippling this one just so it would be more convenient for me.

DOROTHY: Does she realize that we have little tricks that help us get along on our own?

JOAN: Yes, but she thinks her mother is old, and clumsy, and forgetful (smile).

DOROTHY: haha

DOROTHY: Let me list some helpful tips for getting along in the home. Here are what I call "Common Sense Tips For Every Day Living:" Outdoors...

1. First and foremost SLOW down!
2. Wear a hat with a bill, a pair of wrap-around sun visors and a pair of sensible shoes whenever you are outside alone. And remember, cloudy days still contain harmful ultra-violet rays. The best time for walking is midday when the sun doesn't cast shadows.
3. If you take walks in your neighborhood, scout ahead for overhanging branches so that when you are closer, you will know enough to duck your head.

Are there other suggestions from you folks?

DONNA: Wear sunglasses if riding in a car at night..it takes care of the headlight halos and glare.

DOROTHY: Not the driver, though, right?

DONNA: Right

DOROTHY: Good, because I wouldn't want to ride in your car otherwise (smile).

DONNA: LOL

EDNA: There are night driving sunglasses which are also good when watching TV. They cut down the glare, which relieves eye strain.

DOROTHY: I'd like to know where to get those, Edna.

EDNA: Walmart.

DOROTHY: Now why didn't I already know that? (grin) What CAN'T you buy at Walmart?

PAM: I can still drive, but night is worse. I wear yellow lenses, but it is still not easy. Any advice? Got mine at a garage (gas station?). I'm English.

DOROTHY: You may not want to listen to what I would have to say about that. Quit driving at night.

PAM: I don't, unless it can't be avoided.

DOROTHY: Of course, I don't know the state of your vision, so that may be overkill.

JOAN: Here I go again. The gold anti-reflective coating I have on my driving glasses cuts down on the headlight glare. It has given me years more time to drive at night.

DOROTHY: Please give us all the information about those. My husband could use them. I, of course, do not drive anymore.

JOAN: Any aging person could benefit. Zeiss makes the coating. Gold seems to be better than the other colors for reducing glare without reducing available light. Expensive. \$50.00/pair of glasses.

PAM: With my vision at present, the worst thing is recognizing faces. How do I avoid people thinking I'm being rude, not speaking?

DOROTHY: Just speak up, and tell them that you do not recognize them. Be above board. Let them know, because they want to do the right thing. I used to hold back. Then I learned to hold out my hand first. Don't hold back. Let them know of your problem.

PAM: But walking along a busy street, I might pass someone I know among crowds. If someone carries a white cane it tells others the problem. I don't need it yet.

DOROTHY: Explain to that person later, so the next time, they may make it a point to greet you first. A cane would help to identify your problem. I didn't use one for a long time, and I knew I needed it.

SHARON: I have often considered wearing a sign (smile).

DOROTHY: A sign? Maybe a low-vision button? I have five of them that I will sell for 50 cents each.

DAN: I have over 900 logo pins.

PAM: People don't see them or know what they are YET.

SHARON I have found that people keep forgetting that I have a disability. They think I am rude without ever telling me that they saw me.

JOAN: I have to use a cane sometimes for getting around - especially on uneven ground or for walking long distances. It's real useful as an identifier, as well as for support. It is NOT a shameful thing. Works as a weapon for tripping mean people, too. (wink)

DOROTHY: You have it together, Joan. Good for you!

PAM: No way, Joan.

JOAN: I been at it a loooong time. I always take the cane on trips.

DOROTHY: I agree with Joan, Pam.

RUTH: I think a cane is a great idea, whether we have vision problems or not.

DOROTHY: I have a ball on the end of mine to whack people with.

RUTH: haha

JOAN: A ball and cane? (wink) Cool!

DOROTHY: LOL

JOAN: That cane was sooo useful when I went to NYC alone.

DOROTHY: Oh, yes.

JOAN: THAT was the ID card I needed to get help. People can't see my vision loss.

DOROTHY: Do you hold it, tap it, or slide it?

JOAN: It's not a white cane. I need it for balance and support.

DOROTHY: I see.

JOAN: I plunk it down in front of cabs.(smile)

DOROTHY: hehehe. I understand that!

SHARON: I am wondering about tips for before you need a cane. I find landmarks and count steps sometimes.

JOAN: There's a difference (mentally) between **NEEDING** a cane and deciding to get one and make use of it.

DOROTHY: You are right, but some people need to get used to it by using it in the house first. If a person is hesitant about public use, practice in the house first. Give it a name so it is your buddy, then go for it. It works.

JOAN: My kids named mine long ago.(smile) Mort. Mortimer Ichabod Cane.

DOROTHY: That name is cool!

SHARON: I seem to do okay once I am familiar with the area, for instance a new building.

RUTH: I think a cane can be a jaunty part of one's attire. Remember when "gentlemen" used to carry a cane for its elegance? I think women should have the same privilege.

DOROTHY: Absolutely, Ruth.

RUTH: Make that elegance!

DOROTHY: You are clever. I love this bunch of people!

JOAN: This is just the girls, Dorothy. You should meet the boys, too.(wink)

DONNA: How about some tips for INDOORS now?

DAN: I would like to get tips from everyone, and we will start with Dorothy's final list. Dorothy, please go on, and then we will open it up to the floor.

DOROTHY: In the home...

1. Whenever/wherever you have to bend over to look for something, especially in dim areas, crook your arm to shield your face and eyes.
2. Doorways never seem to be wide enough, so when approaching them, use the back of your hand to guide yourself through it.
3. Use warm white fluorescent lighting through the house if possible. It is cheaper than incandescent light and does not cause glare.
4. Use dimmer switches to control lighting for TV, reading, or conversing with another person.
5. Use light colors on dark upholstery in living room or den as markers.
6. I use a special halogen kitchen bulb for my stove overhead.
7. When fixing a recipe, place all items on a tray to compile the ingredients before preparation.
8. Purchase tables with rounded corners.
9. Keep all cabinets closed; chairs pushed in.
10. Avoid scatter rugs; they often cause tripping.

And now let's hear some new ones from everyone else.

SHARON: Pick specific places for items and train family members to put them back. Be organized.

DONNA: I found that, whenever I would want to change rooms or chairs, I would have to make a million trips. I now use a strong Easter Basket with my magnifying lite, my flashlight etc. Being an easter basket takes only one hand. When the hall is dark, I have a free hand to shield and find the doorway etc.

SHARON: Use needles that can be threaded from the top for mending.

JOAN: Put lighting on the task, not elsewhere in the room.

SHARON Purchase useable items like talking clocks, Braille watches etc.

RUTH: Keep the rooms free of clutter. But I would like to have some tips on how to do that!!! (smile)

JOAN: I need a clock that nags.(smile)

DONNA: When cooking, Stay in one place with the mess. In other words, if you need room, take care of it now. The rest of the kitchen will stay clean, and you won't have to look all over for a missing item.

SHARON: Mark items in the home, such as the washer, dryer, stove, microwave--being independant is so important.

DOROTHY: The commission for the blind will come out and do all the marking for you.

DAN: Any further suggestions for our list?

DONNA: Drag your dirty clothes in a garbage bag to the washing machine. It's easier.

SHARON: Buy clothes that are color-coordinated, but mix and match.

JOAN: Find another woman to tell you if/when you have stains on your clothes.

SHARON: Buy white socks that can be matched easily.

DOROTHY: I mark my colors on my clothing.

JOAN: I only buy black socks that I can tell apart by feel.

SHARON: I wash around my eyes after putting mascara on, whether I need to or not.

SHARON: Have a simple, but stylish, hair style.

DOROTHY: I have one of those. (smile)

DONNA: Put powder on your mirrors so you don't look terrible and feel bad when you look.

DOROTHY: hehehe. Love that one!

JOAN: Paint the mirrors black! (smile)

DOROTHY: LOL

SHARON: Become computer literate. (grin)

DOROTHY: I want to join your list! You guys are great!

JOAN: You are certainly welcome, Dorothy.

DOROTHY: Thank you, thank you, Joan.

DONNA: Cut your hair by feel while watching TV. It works. Use the rat tail end to measure a clump, then set it with roller. Then take another clump and measure from head out to end of rat tail. And repeat til done.

SHARON: Get measuring cups that are individual.

JOAN: Do your nails by dipping them in jelly and licking it off the soft parts. (smile)

DONNA: Hold a flashlight in your mouth when installing hardware in your computers.

SHARON: You have to have a big mouth don't you. I guess I could do it then.

DONNA: Or get a miner's head. Oops-- hat.

JOAN: Gee, a miner's head might be better company, Donna. Seriously, learn to use your hands and fingers to feel things you used to do by sight. It's amazing how well that can work.

DOROTHY: Use the back of your hand when going thru doorways. Otherwise, you might hurt your fingers.

RUTH: We have several flashlights in every room of our house. Mostly because of power outages. But good idea to look in dark corners that hide everything! (smile)

DONNA: Use only paper plates, cups etc.. No more breaking....and...compare price

of dishwasher running, and the cost for paper is less.

SHARON: I have all of my hair ties and barretts color separate and labeled. Use Correlle Ware.

PAM: HOW do you mark coloured clothing, like black and navy? I wore one shoe of each once, same style.

RUTH: I did that once, and only my husband noticed.

SHARON: Me too. I was told to mark the bottom of the shoes with dots (raised).

DAN: Pam, Chris says there is a paint for fabric called "puff paint." It is raised, and you can design certain symbols for certain colors. It comes in a small squeeze tube, and it's washable.

SHARON: Correlle Ware is a china that is virtually unbreakable and very pretty.

JOAN: The little telescopes are good for finding things other people have moved, and they are great for picking things out of backgrounds outdoors.

PAM: Joan what was that about nails and jelly?

JOAN: Biodegradeable nail varnish, Pam.(smile) I was KIDDING.

DAN: I'm sorry, but we're going to have to bring this session to a close. We have talked for more than two hours, and my phone bill is probably over a million dollars.

JOAN: Eeek! Can you pay them with pins, Dan?

PAM: Thanks so much, Dan and Dorothy:.

JOAN: Yes, thank you both. Dorothy, come play with us again!

DOROTHY: I want to say what a wonderful bunch of people you are. I just MUST get on the MDList. I'll see you all there!

DAN: Thank you for being our guest today, Dorothy. This session has been totally different than any in the past, and I would like to do it again some time.

DOROTHY: I would love to take you up on that, Dan. I have had a wonderful time, and thank you for inviting me.