

NONVISUAL TECHNIQUES: AN ASSET FOR PEOPLE WITH LOW VISION

By Jim Deremeik

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From The Editor: Jim Deremeik is a low vision specialist who is the education and rehabilitation program manager for the Johns Hopkins Lions Low Vision Rehabilitation Program. This is a transcript of the speech he gave at our 2004 state convention. We begin with Sharon's introduction.

Sharon: Newly blind children and adults frequently come to Jim Deremeik when they start to look for ways to cope. As America's population ages and the incidence of blindness increases, Jim Deremeik and his professional colleagues will have greater demands placed on them in the field of work with the blind. Their convictions about the usefulness of nonvisual techniques will have an important bearing on the future success of newly blind persons. Jim Deremeik has learned that there is not much point to waiting for the miracle of restored vision and that we should get on with the business of adjustment. Despite blindness we should live life to the fullest. Let's welcome Jim Deremeik to the convention!

Jim: Thank you Mrs. Maneki. I must say it's a pleasure to come to your annual conference and I'm embarrassed to say that this is the first one I've actually got to attend in person. And thank you.

I'd like to give you a little bit of experience in what we encounter day to day at Johns Hopkins at the low vision program. The problem with this program is that we're still striving to broaden the horizon on what low vision is and what it is not. Let me give you a baseline. We take anyone having functional difficulties in their daily performance. The way we get them is related to their vision because this is Hopkins. I say that because it's difficult. People come to Johns Hopkins not for rehabilitation, not for low vision, they come to Hopkins for one reason and one reason only - to get fixed. And the reality is - as good we are, we're not perfect. Unfortunately, when the perfection doesn't work they send them down to Low Vision as a way of trying to get them out the door. And that's not negative. It's a good sign that they're doing it. Until recently the journal phrase was: "send them down to Low Vision; they'll get you a magnifier and they'll fix you up." Well, if you can't see when you begin with a blind spot, a magnifier is just going to make that blind spot that much bigger. Kind of a tough way to go.

I want to talk about some of the nonvisual techniques from a low vision perspective. The nonvisual techniques should be part of a low vision evaluation. Why should we look at it this way? Unfortunately, or fortunately we get people based on acuity not on function. If you stop and think, everyone determines service by a certain visual acuity. And that is quite interesting depending on how you want to interpret the acuity. Our laws are that way, good or bad, we live with them. But acuity and function are very different creatures, and we tie them to low vision and

blindness in our definition. There are other things that we don't address, but need to go with acuity in terms of vision or lack thereof. There's a term called 'contrast sensitivity' and I'm going to give you an example of why this is so important when we think of low vision and some nonvisual techniques. Our quickest growing part of the population in need of low vision services is the older population. Those having central vision loss – particularly Macular Degeneration. We don't have to look far. You have someone in your family, somebody has called you. These are folks that can't see faces or details, they can't read print anymore, they're trying to hang on to their vision. They may have 20/40 or 20/50 vision, but have the problems that I'm talking about. That is going to continue to be a concern in terms of service providers having to meet that challenge. It is not something that is going to be fixed by magnifiers alone. We've got to expand the horizon on how we provide low vision rehabilitation services.

Diabetic Retinopathy is our second leading group of folks needing visual attention. By attention I'm talking about some type of intervention. Unfortunately, at Hopkins, by the time we get them the damage is long done. The issue of trying to work with vision in terms of reading print is not our concern. We're more worried about their personal safety, getting from point A to point B, maintaining their medications, and not hurting themselves.

Another area right now in terms of diagnoses and why we need to look past magnifiers is Uveitis, folks that we're seeing more and more with HIV symptoms coming in. They have uncontrolled flare ups, where during the day they can sit and read the newsprint fine and twenty minutes later with a flare up they couldn't get out of the room because their vision has changed so quickly, so fast. Again, if their primary modality in terms of getting through life is a magnifier – it's not going to work.

RP and Glaucoma – I don't need to say much. Two weeks ago a lot of these folks were getting along fine. All of a sudden they had problems. People working with these vision impaired people said, "Why, my gosh, they were doing just fine!" It's a little thing called Daylight Savings Time. Amazing, when you take an hour of daylight away, all of a sudden somebody seems incapacitated. It's a reality and if you're going to try to use a monocular, it's not going to work. The basic concept we all need to see when we work with vision is that we need light and magnification. Magnification puts an image on a particular part of the eye – that's why everybody has glasses. The problem is, if you're putting the image on the part of the eye where you don't see out of, it's not going to work no matter what you do, or it's not going to work very well.

The other part – the light - we're a little better there. We can control some of that, but what we can't control is another issue. You need the light, but you don't need the glare. I'll give you an example. Let's take someone 20/30, 20/40, 20/50, you read that eye report and you say, "No problem, everything's fine." Contrast point-four-five. Now, that doesn't mean much to most people here because you really don't see that very often. To put it in perspective, a normal contrast is one-point-six-five. That's normal. But point-four-five, you don't have to be a mathematician – it's not good.

We had a gentleman come in, his main concern was driving. We were doing a driving evaluation with him. I got in the car with him and sat in the backseat. What happened was that he could see lights, but he couldn't tell which color they were. While he was driving, he saw construction workers, but they weren't construction workers, they were the road cones which are the same color as the jackets road construction workers wear. This gentleman had 20/40, 20/50 vision. I said to him, "how do you get along driving?" He said, "I avoid the beltway." He lived in Edgewood and he worked in Aberdeen Proving Grounds so he controlled his life by going with the parallel traffic. When the cars stopped, so did he. After we took him on a road evaluation with the driving instructor on the other side, he did decide at the end of the day that he probably should not be driving.

I think one of the problems low vision has had is in the desire and the zeal to use vision. We've probably erred to the point of going over too far to the extremes. I think low vision has an appropriate place, but we need a continuum of tools. It's not the be all and end all. I think we need to keep it in perspective of when do you use it and when do you switch, when do you use combinations, when it's a secondary learning modality. You need to keep a lot of options open.

Why nonvisual techniques when we're talking about low vision? The most obvious answer is that you just can't see. It is as basic and as simple as that. The medical doctors can tell you that they're going to help you out. Your vision's dying, your vision's going to come back; come back and see me in six months. But you're sitting in my chair in our room and the problem is you can't find your clothes, you can't pour a liquid, you can't get from point A to point B. We need to do something. If you're going to try and do it visually, it's just not going to work so we need to look at some other techniques to help out while that's going on.

Also, the vision's going to fluctuate. Let's take Uveitis. I'll tell you as a clinician when we see this diagnosis, we cringe, especially with children. Those of you that work with children know the problem. Should this child be in print, should this child be in Braille, should this child be auditory? And my answer is probably all of them. We have had folks that come in with Uveitis and they're 20/30 and by the end of the two hours they may be 20/600 - not uncommon. The treatment sometimes is a topical ointment. If you are going to primarily address the problem through vision, you're not going to solve it. You're going to frustrate the individual and make them further dependent upon other services.

The area that I'd really like to spend a lot more time on, a term we've learned from the healthcare community, is energy conservation. At what effort and what expense do we try to use vision at the cost of performing our daily tasks? One of my goals, and I've talked to Dr. Zaborowski about this, is to somehow figure a way to measure body fatigue from some of these people that come in and want to read a newspaper. I don't have the answer, but one of the greatest ways – the fastest ways – is to learn how to use the Newsline®.

Energy conservation goes across the board on everything we do. The person who was working eight hours a day cannot put in eight productive hours if he's primarily trying to work through everything visually. What I'm suggesting and what I'm saying is that we need to look at a spectrum of ways to do things. Those of you in education have heard the term "primary learning modality." Unfortunately, within low vision we're probably trying to program to the least effective primary learning modality because that's what the patient wants, because we're working at where they're coming from.

What are the concerns? Number one is safety – that's our primary concern, but not necessarily the patient's - very rarely the patient's. I'll give you an example of when we're talking about safety. A patient fills out a questionnaire before he comes in. He wants a pair of glasses to fix his vision so he can fix one of his ADL tasks - pouring a liquid. He can't pour a cup of coffee by himself. I ask him, can you do it? He says, "sure, I have no problem at all." I look at his fingers – they're burnt. I say, "well, what happened to your finger?"

"Oh, I burnt it when I was trying to judge how hot the cup was."

I said, "did you ever think of doing it with some other nonvisual technique?"

"Well, thought about it, but I couldn't see with the vision – the pouring into a dark cup."

Anybody with central vision loss and low contrast is going to have this problem. The answer typically goes – I pour it over a sink. That's fine if you can get to the sink and you're mobile. What happens when you get up in the middle of the night and you've got to take your medicine, you're pouring a glass of water? Same problem. Again, you're trying to rely on vision. It's not going to be appropriate in terms of the low vision arsenal. We can't get glasses to fix everything. In most cases we can't get glasses to fix anything that the patient wants. I say that in sincerity because one of the problems we have is that one-third of the people we see, we can change their glasses. Of the one-third we can change, we're probably only going to meet 10% of the expectations. Because the expectations are going back to where they were before. By changing the prescription we can make the glasses stronger for reading where you pull it up real close, but that's not proficient in the sense that fatigue comes in again and energy conservation comes back. These are the things that we need to look at and figure other ways of doing things.

Locating items – we're back to safety – is another big concern. The two biggest problems that patients have when they come into Low Vision Clinic with central vision loss are, first, going into churches and restaurants and when they go there, locating the restroom. Again, they're trying to do it visually and they can't see with the light. The other is spilling drinks. Again, it's a simple task of teaching patients nonvisual techniques. They need to learn there are times when vision is just not going to solve the problem.

Our greatest concern right now is travel. The use of the sighted guide technique to get from point A to point B or the use of a cane is going to be far faster than trying to work with using vision that may not be primary.

I'll give you an example. Let's go back to patients with 20/40, 20/50 vision. It's typical at Hopkins because we get people very early in the process, that are just identified with macular degeneration. They want to get the vision eye treatment which is basically burning off ruptures that they have, trying to seal off future hemorrhages. If they're out in the lobby and they were trying to navigate the staircase, they'd find the first step and then fall down the next three. I don't say that negatively because the contrast isn't there. Everything blends together. The only way they're going to do it visually is if they could see the baseboards in contrasting colors.

Our challenge (and I'm not going to make it sound like it's a cakewalk) is trying to get people to realize they have this problem. Like I said from the beginning, part of the problem I have is where I work. The name "Hopkins" carries an albatross with it. Again, it's the fact that we're number one and they're coming to us to give them back what they had. So, we get people to come out and realize they've got some basic functional problems. We're doing a lot to make them realize that they've got to look at nonvisual alternatives.

So, how do we go about some of these things? Probably, we just go back to these folks and wear them down. And I say that in all sincerity. I'll give you an example. Folks that are trying to hang on to vision are coming in for glasses and magnifiers because they don't want their friends to know. Meanwhile, someone drove them here and I said, "Well, why do you think they drove you? Just give me the facts." That's what we're dealing with when we start. Over time, things have changed and these folks now need closed circuit TVs which reverse the print. Instead, black on white becomes white on black, much sharper and easier to read. And that's the way we like to start now with low contrast central vision loss. Go right to the closed circuit TV, begin there, and learn how to use Newsline®. When the fatigue comes in, which if it was after ten minutes before, we may get you to after 40 minutes now, and you complete the task of reading the paper in a day where before you couldn't do it in a week. So, it should be a combination thereof.

Very, very few if any of our patients leave without being told of Newsline® and given information on how to register. One of the greatest services that ever came out. It is a fantastic program that people should use.

People in the low vision field need to be exposed to other things and they are not quite ready for that. I think a lot of folks are hanging on to old theory. When I started doing this about 30 years ago, the theory was that if a person could see one-inch print, that was okay. But see and read are two different things. Now, we get patients who can see 20/50, but can't get out of their rooms. They can't read because it's a problem of fatigue, their primary learning modality, and what is going to be most efficient for them. This is a different way from what a lot of low vision folks are working with. A lot of folks doing low vision practice have happened into it over the years. They didn't have training programs per se to expose them to it.

One of the things that we do is to tell people about the NFB Technology Center. Many times you folks will get a call from us saying that we've got a person out of state – can we send them over? “When,” you ask. We say, “twenty minutes.” And no one has been denied. Thank you. You've saved our budget! We're Hopkins, but we can't afford the money identifier, the color identifier, and those are things that people have heard about, but really have not seen and they need to see more of this type of technology. We've got the lower end things. We're pretty good on that. We've got the scales and that's on purpose for the diabetics. We've got the talking glucometer. This is in addition to high plus magnification. Again, I'm trying to show that we're looking at different things here to expand the horizon of what people are doing.

We're in a society where we need to be able to communicate to get by. We basically need to be able to read and write. The way we choose to do that is open for debate and discussion. The typical low vision patient wants to read the newspaper. What they want to read in the newspaper is one of three things: obituaries, sports, and the stock quotes. That's a real easy job to do with low vision. For the obituaries, we can get you the magnification to see it, but by the time you probably find it, you may be part of the obituaries. The sports, again with Newsline®, and we have a lot of other programs to get it. The stock quotes, The Sundial is one of the services that could be activated that patients are not aware of. These are things that we need to make people aware of.

In terms of magnification – if you write something, you don't need anywhere near as much magnification if you see what you want to write as you do if you're going to read it. One of the big concerns that we have is that everyone who comes to the clinic should be able to sign their name. Our success rate is less than we'd like to admit because patients just choose not to do it. We have signature cards to show how you can do this nonvisually, how to work back within what you're doing with visual memory, and finding your guiding points. This works fairly well.

Here is the problem that we run into as more and more of our older folks are sitting in their own homes. They get a phone message to write down a number. They write it down just fine. I say, “can you read it back?”

“No.”

We try to show them how to use a tape recorder. I bring one in and I say, “Push this button. Say the number, and push this other button.” “Oh! I can hear it now.” Pretty quick way to get the message and the information and a lot more efficient. With voice indexing on the new digital recorders, it works pretty well. But again, a lot of low vision practices are not going to spend the time to do that. It's going to be far more efficient in terms of personal safety and the outcomes are going to be far more productive. This is something that, we're not doing in place of, but in addition to. Most folks we work with are pretty sharp people. If they find one easier than the other – you don't have to push. They can choose pretty quickly and they'll figure out what's going to work and they're going to accept it and use it.

The computer is our biggest challenge. The problem that we have is that most folks that want to work with computers have never worked a computer to begin with so they're computer illiterate. It's like trying to work with a patient who wants to cook. We ask, "when's the last time you cooked?" "Before I got married." And that was 50 years ago. What we're doing at the clinic, because it seems to work fairly well, is to use ZoomText because it combines vision and speech. Though the patient is looking at the visual cues from ZoomText, he is reading it auditory. I've worked with patients where I'll type something and say, "just want you to watch this." The number one thing that all the patients, the grandparents, want to do is email their grandchildren who are away in college. It's a great social cue because it forces them to look to something everyday. The reason I know that they're not reading it visually? I'll start it up with, "what magnification should it be?" Let's say six times. By the time we're done, I've got it down to normal setting. They don't know the difference. The point here is not that they don't know it, but they've read it. They've got the information they need to. Now, someone needs to teach them how to work the computer, but that's another story.

In terms of low vision, I mentioned earlier that when this drive began, we had low vision clinics and the push was for optical devices. Rehab wasn't really a part of it. It was a single clinician operation where you went to the doctor, they worked with high plus magnification and the theory was – let's get you down to one-inch print to be able to see it. It wasn't fluid and again it was just the time where things were. Things have changed now. What we're looking at now by the name of CERTS is rehabilitation. I'm not going to kid you. People have come in, and come out with an optical device. They may never use it but they'll go out with one. And that's fine. There's nothing wrong with that whatsoever. But, if they go out with an optical device and talking books, Newsline®, ZoomText - and they come back in three months, and they're beginning to meet their tasks – our job's accomplished. We've got them on the road to accepting a different way of doing things. Again, you're going to use vision when it's appropriate, but you're going to look at a lot of the nonvisual techniques.

The field of low vision got into a lot more discussion, debate, and controversy when it came to Braille and print. I was on that side. I was at the school for the blind. One of the best things that probably happened to the State and to the field was the Braille bills. It took a complete 180 from what the philosophy was and a lot of parents aren't aware of that. Now, you assume your child is going to receive Braille and prove that they should be taught visually. Well, it doesn't matter which way you want to prove and what you believe, but you should be doing what works. And what works usually is not going to be any one way.

If you take the low vision patients from three different clinics, you're probably going to come back with three different recommendations. Hopefully, the outcomes will be met, but the question is how quickly will they be met and how well will they be met. What has happened, which has forced a lot of these outcomes not to be met, where nonvisual ways can be, introduced or pushed, is that there really has been no overseeing authority to say that it works. Well, that's changing and here's what's changing. Two years ago Medicare allowed ODs to write

prescriptions for OTs to provide low vision services in home communities. I'm saying this as a compliment to standard rehab services because at the clinic at Hopkins, if you have vision and you go to state, the outcome is usually pretty good. But let's say you have vision loss – you have Parkinson's, some balance problems, or a slight case of dementia - you're probably not going to get the type of service that you really need. You know the vision may be addressed, but all the others need to be resolved probably in concert with it. We now have OTs doing it and in 30 days you have to address a plan to show this progress. That wasn't happening before the way the system was set up. The system would go out and provide under a voucher system where you had X amount of money and you would get services. Everybody might get the same services depending on what part of the country they lived in or they might not get any services depending on where they were. With the OTs getting in and healthcare coming into it, we're now having what with the older population we didn't have before – accountability. We're starting to have outcomes being listed to show what works. What we're doing is getting to the chase. You're not going to spend five to six hours doing a hand magnifier trying to read a newspaper when you get the same return in probably 20 minutes to a half hour of instruction in how to work some alternative technique – and again I use Newsline® as an example or talking books. We're going to see more of that over the next couple of years as the field keeps changing. And the field is changing. Don't kid yourself.

Back in the spring we proposed doing a meeting with the National Federation of the Blind and AER for low vision providers. Unfortunately, it didn't materialize because we ran into some conflicts and some scheduling problems. But the message is loud and clear: the way business is being done traditionally has got to change. The low vision repertoire is not just binoculars, closed circuit TVs, and six-six high plus lenses. It should also have in there talking books, you should have a recommendation for mobility, and in home ADL functional assessments. These things are going to happen more and more as part of this low vision intervention. I think you're going to see a much wider range in the interpretation of what low vision is and what the services should be.

Hopefully, these few minutes have given you a different view of what we think about when we think of low vision patients. The majority of our patients probably do not leave with equipment on the first visit. By equipment I'm talking about optical devices because everyone who comes wants a pair of glasses – they don't come to get magnifiers and to get fixed. But we try to put something in their hand so they feel like they got something. Thank you.