

Through Our
 *Eyes*

Reflections and Humor
by the People of
Macular Degeneration Support

1994 - 2012

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Foreword

We in the Macular Degeneration Support Community are an eclectic mix of people who have come together for one reason. We have sought the company of others who are dealing with vision loss.

We come from all walks of life. We are teachers, students, artists, musicians, homemakers, business people, laborers, and service providers. We all began by traveling different roads, but we ended up taking the same turn that led us to this unexpected place. A place where we find comfort in joining with others who see the world through imperfect eyes.

The Internet made it possible. We can communicate daily from nearly anywhere on Earth, and since 1994 we have been storing our thoughts on the Web for others to read. This is a collection, in no particular order, of the most memorable of those messages, essays, and poems.

Some of our friends have passed on, but they are still with us through their writings. The entries in this book are meant to be shared freely and often. We hope not only that our contributions will encourage and inspire those who must follow our path, but that they will help the “normally-sighted” community understand the unique and challenging world in which we have found ourselves.

Good or bad, funny or sad, this is how we see things “Through Our Eyes”.

Dan Roberts
Founding Director
MD Support

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Poems

A decorative graphic featuring several small, stylized raindrops scattered around the title. The title itself is centered and reads "A DROP OF RAIN by Tabby".

A DROP OF RAIN by Tabby

From my warm chair, I watch it move.
I know it is cold and alone,

It slides slowly and then picks up speed;
And then it is gone from my box view into it's world.
While my traitorous vision won't confirm it,
I know it is another drop of rain.
I wish sometimes I could storm and thunder.
I want sad droplets to make their treks down my face,
Not my window.

But I know with an alarming certainty that it won't happen.
I turn my anger on my sorrow and build walls against the rain.

I hear, "You don't have to be strong," and I toughen my resolve.
I hear, "It's okay to cry," and I set my jaw against emotion.

I hear, "We care," and suddenly,
A wall that took all of my effort to build

Becomes a door.



I Was Given Something to Wear **by Christopher Statham**

I was given something to wear that I did not want.
How could having this, help me to be proud?
It was ugly, and dark, just something to taunt.
So I wore this gift as a shroud.

Enveloped in a dimness that I could not shake.
Unable to notice a bright sunny day.
Hoping it was a dream from which I would awake.
Knowing, in fact, that it was here to stay.
Looking for a reason as to why it happened to me.
Wondering "What's next?" to challenge life further.
Feeling so weary of the battles to be.
Knowing that I can't quit, no matter the future.

I ask myself, "How do I embrace this thing?
Make it part of myself, without it overwhelming?"
An answer to which I wish someone would bring;
So I wait with hope from that eternal spring.



We Sit and Wonder
by Barbara McVay

What did that bird look like sitting on the branch?
I must have seen him many times in the past.
Are there leaves on that tree?
Oh, if only I could see.

What's on the page of the book on my lap?
Things to make me cry or laugh?
How long has it lain there alone unattended
Now I can't see it, I want to attempt it.

Why do we wait to appreciate what we have?
Why must we lose it to know that it's gone?
Are memories of past experiences all we have left?
Can we adapt to what's still possible?

Is knowing enough to sustain us and carry?
Can remembering be comforting to maintain happiness?
Is it really necessary to "see" something to
appreciate it?

We sit here and wonder these things.



I See
by Dan Roberts

I see the sweet face of a child and her shyly-penned words of love.

I see stars that are bright in their patterns of gods in the gloaming
above.

I see the one whom I married sleeping in the first dim light of dawn,
And I find my way from the darkened room to put my slippers on.

I see the sepia photographs printing sun shadows on the wall,
And every red leaf of the maple announces its fluttering fall.

I see every note on the page of a Beethoven bagatelle,
And a smile from a sickroom sentinal assures that a friend is well.

I see strokes of a brush once held by the likes of Degas or Monet,
As they borrowed the colorful contours of a clear and crystalline day.

I see the well-rehearsed gestures of actors performing their scenes,
Then follow them unhesitatingly into the darkness between.

I see this world in its wholeness, with clarity set apart
From the inadequacies of troubled eyes.

I see with memory and my heart.



A Secret Place **by Sharon Chism**

I once could see the looks they gave
for people like me.
Some pity, confusion, and even shock
that someone couldn't see.
Like speaking with foreign words,
it's hard to understand
the uncommon particularities
of a partially sighted man.

I struggle with the secret
of what to tell and when.
To face the discomfort sooner
or to continue to pretend...

My vision has no destination,
no arrival point.
Yet, to make loss my focus
would only disappoint.

I've met those insidious thieves:
Fear, Doubt, and Pride.
Still, I find myself allowing
them to be my guide.

I thank you God for courage,
for others who remind
that spending time with thoughts that lie
is worse than wasting time.

For no matter how long we do it,
the same truth remains:
the one we'll find in that secret place
the body can't restrain.



Amidst Familiar Settings **(Contributed by Bobbie Russell Broumly)**

Suddenly I'm a stranger
in this world I call my home.
Amidst familiar settings
I sometimes feel alone.

My eye sight's growing dimmer
and the sounds of life grow faint.
I'm almost like the artist
who's misplaced his tube of paint.

My friends all tend to holler and
to grab my arm and shove,
To see I walk a straight line
and I know it's done with love.

The family doesn't understand
because I seem a little strange.
When I insist familiar's better
that it's hard to deal with change.

Folks always seem to question
when your eyesight's not so keen.
Sometimes they think you've snubbed them
when in fact they were not seen.

To tell the truth it's easier
to sit at home and mope,
But all the work is waiting
for me to learn to cope.

I still retain my talents
and with God's boundless grace,
I'll overcome life's challenges
and meet them face to face.

I'm oft' in need of guidance
and my foolish pride must start
to realize, with clouded eyes
I still see, with my heart.

When I tend to get discouraged
and feel I'm not quite whole,
I place myself in Heaven's Hands
and listen, with my soul.

(Author Unknown)



Broken Eyes by Ralph Nave

I live in a world without readable signs,
No faces with features, or even straight lines.
Things taken for granted, once seen clear as day,
Now shrouded forever in layers of gray.

As if once removed, life is now passing by,
Viewed as it is from the corner of my eye.
Like all that's around me has been re-arranged,
But it isn't the world, it's I who have changed.

The sun's magic remains, at dusk and at dawn,
But it's just not the same, with it's center gone.
Once transfixed by its colors, I'd sit and stare.
Now I look to the side, and just know it's there,

If I could be spared just one gift for a while,
I'd choose to be touched by the warmth of a smile.
To be given the chance to stand face to face,
And look into one's eyes, and not empty space.

With technology's tools, I will persevere,
And as time's gone by, I've overcome my fear.
But the detail of things, wherein beauty lies,
Still remains out of reach of these broken eyes.



My Blue Eyes
by Sandy Beaches

My blue eyes open now just as they always did,
But rather than pure sunlight, I see a cloud instead.
The sunlight still warms me and always lights my way,
But the cloud in the center turns faces gray.

The objects that I look at are becoming unclear,
And memories of sharp vision are becoming more dear.
I still see completely in my mind's eye,
But the cloud in the center blocks the blue of the sky.
All that I see are the edges and the sides.
The center of life's picture behind the gray cloud hides.
My sight is failing, but my faith in God and family remains.

I'll continue to find the sunlight,
Even through these closed blue window panes.



The Encounter **by Ralph Nave**

Standing alone, I sip my drink,
People around, I try to think,
No need for panic, some are friends,
But can I find them, that depends.

To find someone, I have to be,
Somewhere where someone can see me.
For otherwise I'll pass them by,
Their face escaping from my eye.

I wait and soon someone comes near,
Though where they're looking isn't clear.
It seems they're coming right at me,
I brace myself, who can it be?

Familiar carriage, shape, and gait,
but still unsure, I hesitate.
Too many times I've felt the sting,
that using the wrong name can bring.
I shift my gaze from side to side,
In hopes they'll be identified.
But features I should recognize,
Remain elusive from my eyes.

It's nothing new, I have no choice,
I wait until I hear the voice.
A welcome sound - still makes me sad,
He touches me, and says "Hi, Dad."

Just Hard

by Becky for husband, Joe

A person with retinitis pigmentosa:

Can know you are there but have no idea who you are.

Can watch a movie but miss all the full screen action, any dim scenes, and all the subtitles.

Can see the sky but not the stars.

Can read a book but can't find the book.

Can paint the entire house and the next night, not see the house, car, driveway, etc.

Can put up sheet rock and install fixtures but not see the tools at his feet.

Can craft an intricately detailed guitar and not be able to locate it in a room.

Is defined by the state as a "Catastrophic Disability".

Is defined by those who have it by the series of adjustments that make up life.

Is not sighted enough to be sighted.

Is sighted enough to get around in a restaurant, awkwardly hesitating, then bumping into people while finding the way to the table or the mensroom.

Is not blind enough to be blind.

Is blind enough to need a cane to avoid stumbling, yet able to look you right in the eyes while you speak.

Sometimes it's hard to know what's worse. Explaining how sighted you are to the sighted world or how blind you are to the blind world.

It's hard to justify your ability or explain your disability.

Hard, I know, for people to understand.

Hard, I know, to experience.

Just Hard.

Not Impossible.

Just Hard.



A Parable of Vision **by Dan Roberts**

And God created light,
So Mankind could view the colors of Earth.

Then Satan created ultraviolet rays,
And Mankind covered his eyes.

And God created a bounty of fruits and vegetables,
For the better sight of Mankind.

Then Satan created tobacco,
And Mankind inhaled.

And God created intelligence,
So Mankind could build machines for
seeing and learning.

Then Satan created ignorance,
And Mankind published manuals in
small fonts and large words.

And God created language,
So Mankind could freely share knowledge.

Then Satan created greed,
And Mankind invented subscription fees.

And God created empathy,
So Mankind might help itself to heal.

Then Satan created insurance,
And Mankind invented HMOs.

And God spoke to Satan, saying,
"I have given to Mankind many wondrous things,
That he might see with the eyes of an eagle,
And you have thwarted me at every turn.
Don't you have anything better to do?"

Then Satan sneered and created hopelessness,
And Mankind began to drown in self-pity.

So God raised Mankind high above the earth, saying,
"Behold all that I have given you.
Why do you let the shadows in your eyes
Dim the light in your mind?"

Then God grabbed Satan by the horns,
And flung him into the realm of the visually-impaired,
Who then awoke in great numbers and
Set about giving the devil Hell.

And Satan cried, "I thought you people were blind!"
"We may be," they said,
"But together, we see you very clearly."

So the devil retreated in haste to his dark domain,
Where he rules over the sighted who choose not to see.

And there he remains, befuddled, for the rest of his days.





Thoughts For The Night **by Sharon Chism**

For every star left dim
a universe of courage has been lit.
For every knowing glance that's missed,
a heart of insight enjoyed.

Each temptation of independence thwarted
a freedom given, uncorrupted.
And for every tear that's shed,
a well of compassion filled.

The isolation of faceless crowds
calls the deep ache of unseen smiles.
Yet the outreached hand of kindness
breaks the silence with laughter's grin.

A thorn, to some it's called,
a true and worthy title.
But those who overcome the wound
marvel in the flower's glory.

Is the trade an even swap?
Could I know surrender's power without?
Acceptance, not the loser's consolation,
but the faithful crown of victory!



The Five Stages of MD Grief
A poem in cinquain form
by Irving Faust (1928-2004)

Denial
Fear, Loss
No! Never! Impossible!
This Cannot Be Happening
Help!

Anger
Rage, Fury
Screaming, Crying, Cringing
I Am So Frightened
Depression

Negotiation
Bargain, Plead
Begging, Dealing, Promising,
What Can I Do?
Compromise

Resignation Helpless, Hopeless
Acquiescing, Surrendering, Yielding
I Can Do Nothing
Submission

Acceptance
Confirmation, Approval
Acknowledging, Agreeing, Understanding
Life Continues after MD
Hopefulness

**YOU
DON'T
HAVE TO
SEE**

**by
Mary Brown**

You don't have to see to brush your teeth,
Or rinse that mouth you love to feed.

You don't have to see to kiss the head
Of the grandchild you hold 'til ready for bed.

You don't have to see to smell a rose
Or fee a dandelion tickle your nose.

You don't have to see to clean your ears,
And to hear the latest news both far and near.

You don't have to see to talk on the phone,
And gab with the girls, on and on.

You don't have to see to feel the warm sun
And the cool ocean breeze while at the beach having fun.

You don't have to see to taste the fragrant wine,
One glass is enough. . . it will do just fine.

You don't have to see to sit in your swing,
And listen to all the birds so sweetly sing.

You don't have to see to go out to lunch,
With kind friends to assist you a bunch and a bunch.

You don't have to see to stroke your dog's fur,
Or hear your kitty cat, purr and purr.

You don't have to see to hear good books on tape,
And listen to music...so beautiful and great.

You don't have to see if you know how to care,
And help others by spending much time in prayer.

You DO have to see to drive around town,
But I sure don't miss those traffic jams.

You DO have to see to read your grandkids a book,
But you can tell a tale curled up in a nook.

You DO have to see to go out and shop,
But now I don't have to shop 'til I drop!

You DO have to see to cook a good meal,
Now hubby helps out...oh, what a deal!

You DO have to see to walk around outside,
But to hold on to someone, well, I swallow some pride.

So all I can say to this saga of mine,
Is to be content with the passing of time.

And I'll always hope that someday divine,
We will all see clearer than we do at this time.

Lines
by Susan Morrison

Lines are everywhere.
The world is rife with them:
lines down the middle of the road,
louvres, blinds, tile floors, street signs,
roof lines, light poles, picture frames.
Angles are mitered, poles are plumbed.

But for me they are no longer straight.
They wave, undulate, snake and dip.
Words rollercoaster across the page.
My stomach lurches with each new assault,
as my eyes try to make sense of them,
as my vision unravels.

I turn from this man-made world to God's,
where lines are more forgiving,
made with curves and crags and bumps.
I rest my eyes on true things:
clouds, crooked coconut trees, the Koolau crests.
and still - for now - your sweet face.

Essays

Detours

by Dan Roberts

Isn't it amazing? You set out in life with a vision of a straight, smoothly-paved road along which you plan to travel unhindered into the future. But sometimes barriers block your way. You then have a choice to either stop and give up, or to shoulder your bag and take the detour.

And that's the amazing part. There will always be detours, which will take you in some very interesting directions. And every time you return to the main road from one of those adventures, your bag will be a little heavier with the stuff you have picked up: souvenirs, hitchhikers, treasures, even some trash. It's all in there, and good or bad, it is a unique collection.

You may be afraid right now; but, hopefully, your fear of the unknown will not stop you from taking the detours, because that's where you will find all of us. And when we all finally get to the end of the road, we'll throw down our stuff, give one another a big hug, and say, "Wow, that was some trip!"

New Beginnings

by Tom McDonald

This coming Thursday, April 16, I say good-bye to a career path that stretches back nearly two decades. It seems I can't keep the pace any longer. I'm dragging my team down when only a year ago I was propelling it forward. It's time to go.

You know, some things we choose, and some things just happen; but all in all, one's life can get to be like a cluttered closet. I can stand back from it all now and see what and why and how things happened, and choose again what I would do differently this next time around. I can clean out the closet and decide what to keep and what to toss, because it is as though nothing needs to necessarily carry forward except my love for special people and my most basic principles.

This time there will be no more clever strategies to keep myself on the same path, the way I did with earlier vision setbacks. This is the time to harvest the lessons and blessings of the past, immerse myself in some of that laid-back peace, and--through a mixture of discovery, recovery, and decision-making--build a fresh life organized in new ways and carried forward by new means.

I'm not losing everything by losing a career, or even all those strategic adjustments made to keep it afloat as my eyesight dimmed. I'm glad for every piece of it, but won't mourn its passing. Every 24 hours the world spins around, and a new day replaces the one before it--no matter what we have, what we do, what we lose, or what we choose. Sometimes what we do is a pain when we do it, but

later it is a memory, and all memories are resources if we choose to accept them as such.

I've chosen to simply harvest the bounty of the past, assess the lessons I've learned, and sow the seeds for a new future. If you have a thankfulness for what you've received and a faith that life always has possibilities, there is no reason to fear. Be my witnesses: I'll see less, but I'll do more, and give more, and receive more. To me there are only two choices: either you harvest the best from the past, learn from the mistakes, and keep yourself active so that life's possibilities can be found, or you sink into despair, wither and shrivel, and become a faded memory of whom you once were, and a shadow of whom you ought to be--and you can't see shadows anymore.

Grandma Is My Hero
A Dialogue From the Future
by Dan Roberts

Child: Who's in that photo, Mom?

Mom: That's my grandmother. Your *great*-grandmother.

Child: Can we go see her and get a present?

Mom: Not now, honey. She passed away before you born.

Child: Was she nice?

Mom: Very nice. She taught me how to play cards and knit and cook and all kinds of things.

Child: I wish I could see her.

Mom: You would think she was magic. I did.

Child: She was a magician?

Mom: Kind of. Grandma could tell when the bacon was done, she could tell me what I was wearing, and she could tell if I was happy or sad. All kinds of things.

Child: That's not magic. Anybody can do that stuff.

Mom: Without looking?

Child: Oh.

Mom: Remember how the doctor fixed your eyes when they got sick?

Child: Yeah, I got a shot.

Mom: Don't sound so grumpy. Grandma' eyes were sick, too, but her doctor didn't know how to fix her like your doctor did.

Child: She couldn't see?

Mom: Not very well.

Child: That's sad.

Mom: It could have been, but Grandma decided to help the doctors by letting them study her and try out new medicines.

Child: She got shots, too?

Mom: Sometimes. And the most magical thing was that Grandma was always happy.

Child: With all those shots? Why?

Mom: Because whenever she started to feel sad or scared, she would think of you.

Child: Mom, I wasn't here yet.

Mom: No, you weren't. But she knew you were coming someday; and she knew your eyes might get sick, too. Grandma helped the doctors so you wouldn't have to ever be sad or scared like that.

Child: Grandma is my hero. That was a good present.

Mom: Yes honey . . . That was a *very* good present.

A Beautiful Place to Be **by Tabby**

Among cherished hobbies and interests, I hold particularly dear my ability to make people's heads vanish. I intend this statement in the least metaphorical sense possible, because encroaching blindness has given me superpowers. With a simple redirection of my blind spots, a stained shirt is rendered clean; a dinner bill is reduced by factors of ten; and a distinguished professor is morphed into a headless body, arms flailing animatedly in an intriguing demonstration of his point. To be sure, blindness is never a dull companion.

I was diagnosed with Stargardt's Disease, a juvenile form of macular degeneration, at 17. While I've retained the mobility of a sighted person due to my peripheral eyesight, the fine vision necessary to read books, see street signs, or recognize friends is mostly gone. Though overcoming adversity is often touted as the greatest challenge of a disability, this has not been the case for me. Don't get me wrong-bypassing the various obstacles of deteriorating vision isn't easy. My life often requires more planning and a different approach. But challenge can be an irresistible temptress. Add blindness to any enterprise, and success will breed a precious and unique brand of confidence. Much harder than overcoming my limitations is admitting to them. Afraid the elusive line between letting go and giving up would fade with my vision, I spent my first two years of college "passing" for a fully-sighted person. I refused to use magnifiers in class, pretended to see things I couldn't, and labored to keep my disability a secret.

Al showed me the peace and strength born of acceptance. Each plain, white door at the local hospice is adorned with a dry board. His read: "Al: A Friendly Guy." I sat with Al every Sunday for the last four months of his life. One evening, his hand trembled so violently he was unable to hold a fork. I offered to help, and Al accepted. Afterward, he declared: "That was the best dinner I've ever had." Al made this claim after every meal, but this time his words catapulted beyond endearment, and landed in the realm of the sublime. I fought tears as my irrational construction of disability as weakness came blissfully crashing to the ground. Al had lost the ability to feed

himself, but as he sat back, Lincoln-like in his tall armchair, I had never seen a person look more dignified.

Inspired by Al's courage, I resolved to change the way I handled my own impairment. In perfect personal-statement splendor, the defining moment of my experience as a blind person occurred on top of a mountain. My junior year of college, I decided to try blind skiing. The sport involves verbal cues from a sighted guide and orange safety vests. For me, the scariest part of blind skiing was not barreling down a mountain without usable vision; it was putting on the bright orange vest that said: "Blind Skier." Fiercely independent, I had long feared the day when I would not only have to acknowledge my limitations, but inform those around me of them as well.

As I stood at the top of my first ski run, my hands shook and my large, red mittens refused to cooperate with the vest's small fastening hooks. My guide offered his help, and I accepted. It was the first time I was easily identifiable as a blind person, and to my great surprise, the earth did not crumble. The sky did not fall. To the contrary, a previously uncharted world of convenience and understanding unfolded before me: the chair lift slowed, other skiers kept courteous distance, and life was easier than it had been in a long time.

I returned to college with the wisdom that acknowledging limitations creates new possibilities. That spring, I co-hosted a fundraiser for The Foundation Fighting Blindness and gave several speeches, including one to the College Council. More importantly, I began sharing my experience with my friends, whose unwavering support reinforces my faith in this life every day. Marvin Bell writes of losing vision: "Autumnal light/gave to ordinary things the turning/beauty of leaves, rich with their losing." Blindness is indeed a beautiful and enriching loss-the gems of wisdom my shattered vision reveals remain my most treasured life lessons. So, when the daily grind of low vision wears me thin, I imagine the day when I'll go soaring down that mountain once more: I throw my poles behind me, crouch firm against the wind, and shoot a smile to the headless skier next to me. It's a beautiful place to be.

Blessings On My Path **by Beverly Castellini**

Macular degeneration is something I had heard about all my life because my mother's family had experienced it before it was popular. Macular degeneration was genetically imposed on me in middle age. I was surprised because I felt too young to walk down a blind path.

For a year or two, waking up each morning was painful. I would open my eyes and think, "Oh, no! I don't want to be blind!" Now, even though my sight is still deteriorating, I cheerfully say, "Good morning!" I smile as I swing my legs over the side of the bed. I scramble round for two slippers. I find one of them, and my other foot is searching round when I hit my dog's soft muzzle. Jade doesn't complain but stands and stretches before following me as I go to the kitchen.

Now, I face the first challenge of the day- making my morning pot of coffee. I reach and find the coffee canister. I pick up some coffee with the scoop in my right hand. First, I put my left index finger into the scoop. Is the scoop full? If it is, this is my first big success. With my thumb as my guide, I fill the coffee pot.

While the coffee is brewing, I go to the bathroom and wash my hands and face. Brushing my teeth is more tricky than brushing my hair. I've learned to squirt the toothpaste onto my finger and to check the toothbrush to make sure that the bristles are pointed at my teeth and not pointed at my upper lip nor at my nose. This may seem absurd, but the backside of the toothbrush won't do too much to make my teeth sparkle.

The coffee is brewed. I pour myself a cup. Before pouring, I pause for a second to make sure the cup is right side up.

The coffee was good. Now, I have enough energy to walk down my blind garden path, but, first, I need to hitch Jade. Now, I can give all my attention to the beauty ahead. I trip over a rock on the way. And I do stumble! This hurts so badly- so much- that I can't do anything except wish to cry. However, I can't walk down the path

with tears in my eyes, for I will, probably, stumble more. But I will keep walking slowly so that I won't trip too many times.

I do fall on the green grass, which is comforting. It is soft and sweet. I will sit here and enjoy my sense world. I breathe in the smell of the sweet clover, and I rub a stone and feel its smoothness. Above my head, I hear a robin scolding me, asking me to move away from her nest high up in the branches. My left foot stubs a persistent stone and disturbs it, bringing worms to light. I move on quietly. I don't want to alarm that robin nor her babies. I reach the foot of the path. I stand, looking out across the meadow. I hear in the distance the water from the small stream trickling down from the pine forest. I see the fields dotted with daisies and black-eyed susans. I feel the eyes of the daisies and of the black-eyed susans, and they stare back at me. I am slightly jealous of their seeing eyes.

There was a shower in the night, so it causes the brook to trickle a little more loudly. That water and the early morning dew make my sneakers squish. I almost enjoy the sound. I watch my footsteps as I move around the wild buttercups. A small grey toad hops across my path and moves away. I take two steps and move homeward. On my left, the toad inspects the bleeding hearts. They politely bow to him. The coral bells sway in the gentle breeze. I can't hear them, but I do hear my dog, Jade, calling me home.

I step through the wooden gate and say goodbye to the flowers, the toad, and the robins. Back in my kitchen, I pour myself another cup of coffee and count my blessings.

Fear

by Sharon Noseworthy

This essay was written by Sharon soon after her diagnosis of macular degeneration. It is representative of the initial stage of grief which many people enter upon hearing that they are losing their vision, and it is published here with her permission so that others may realize that such emotions are not uncommon.

The important thing to remember is that, with the right kind of information and support, even depression this serious can be alleviated, allowing the person to deal with their condition on a much more positive level.

Today, as one of the most valuable leaders in the MD Support Community, Sharon says, "I searched the web and found these wonderful people who provide support and information, and they took away my fears."

I lie in bed, listening. I hear nothing except the rapid pounding of my heart. I am too afraid to close my eyes and too afraid to get out of bed. It is not only the night and the quiet it brings that disturbs me, it is also the day. The day brings with it my ongoing struggle with my enemy. The day exposes me to the realities of living in a world that is foreign to me. No longer do I live in the old world, the carefree and happy world of yesterday. I live in a new world that is distorted and ugly. I don't know how to function in this hostile environment. My days are full of fear.

How can I explain my fear in terms that others will understand? The fear I want to describe is not the simple adrenaline burst that comes with a perceived threat. That type of fear is powerful, but momentary. It is a required, natural fear, which puts our senses on alert and protects us. The fear of which I speak is not the normal fear that comes and stays for the brief period when confronting a problem or a change. That fear is manageable. We know that time and resolve will overcome the trepidation and return us to stability.

The fear I want to describe is a fear to be dreaded. It is powerful and omnipresent. This fear puts our senses in the panic mode and leaves them there. This fear takes us from the safe place

we have come to know to a place that terrorizes us. This fear is so intense that it takes over and permeates every fiber of our being. This fear grips us with such power we feel the very breath of us being squeezed out. Eventually our body goes limp with the overwhelming impact of this burden it bears. Gone is the ability to think or feel anything but the weight of this fear. We move from our safe place to a place of emptiness, nothingness.

How comforting it would be to believe in a spirit that would rescue me from my peril. I call upon my inner spirit for strength. However, I am so overwhelmed by the enormity of this terror that I don't even know where to look for my spirit. I ask, "How can I find my spirit when I don't even know where I am?"

I am lost, somewhere, in a deep, dark hole. How did I get here? I can't think of one reason why I should be here. I am cold and lonely. Fear has put me here, and I cannot imagine that I will never find my way out.

In order to fight this fear I need to fight the enemy that is the cause of the horror. How do I oppose this enemy that attacked me with such force when I was least expecting? How could I have ever been naive enough to think that I was exempt from encountering such a formidable foe?

I should have been better prepared. But how can I prepare for something that I do not expect? I wish I knew the answers.

I am so angry. Why has this enemy chosen to thwart its vengeance upon me? How can I get someone to understand what this evil is inflicting upon me?

Don't tell me you understand what I am going through. There is no way you can identify with my fear when you have never had this experience. No one can tell me they understand unless they are fighting this exact same battle. You are not.

If only I could rid myself of some concerns. Some fears are mere anxiety. Fear of the unknown would be relatively easy to exclude if I had the necessary knowledge. I need a means to equip myself, a way to gain control of my destiny. I need specific details in

order to build my suit of armor. I need to know how to fight this enemy. Information would assist me to escape from this black hole. Those who should know my enemy say they have no advice for me. They offer no known way to confront this adversary. This news compounds the unrelenting threat and escalates my fear. I am afraid that I will never get the information I must have.

I need to be comforted. Like a small, lost, child separated from her mother. I am scared. I want so desperately to hear "those words." I hear words but none of them are the words I am yearning to hear.

Don't tell me you are sorry. These are not the words I want to hear from you. You are the one person who should have all the answers to my questions. How dare you say you are sorry! Isn't it your responsibility to fix this, to drive out this enemy? How dare you, of all people, say you are sorry. I need your help. I want to scream out to the world, and at the same time I want to hide from all of you.

I want to feel "that special touch," but none of your touches are the touch I am craving. Don't hug me! You have no right to hug me just because it makes you feel better. I am the one who is dealing with this fear, not you.

Don't ask me to provide you with love and understanding. I am the one who is in need of love. I need to be loved but I can't feel any love right now. I barely have the strength to get through this day. I can not help you now, please go away.

I am so very lonely. Please stay with me awhile. Would you please put your arms around me and hold me? Yes, I know I am being selfish and this brings me pain and worry and adds to my fears.

I look at your faces, and all I see are sympathy and concern. I don't want you to worry. It is my responsibility to protect you from the evil forces in this world. When I see you I must put on a smile and tell you everything is being taken care of. I must distance you from my pain. I am alone.

Please, won't you listen for awhile? I am trying to tell you about how I am feeling. You are polite, it seems to me, but you are not listening. I can sense you want to change the subject. I need to tell you more about this appalling fear. I desperately need to share this burden. It is too heavy for me to carry all by myself.

I try to explain. I will stop trying to explain, as I can see your discomfort. You clearly have no answers for me.

I think, "Please go away. I am too sad for company." I say, "Would you care for more tea?"

Perhaps, if I could find a way to face this fear, it would disappear like a mirage. I wish this was a mirage.

I don't know how to get out of this black hole, and yet, most of the people I meet don't even know that I speak to them from here. They see me in front of them. They see me laugh and work and play. This, truly, is the mirage because I am actually not there. I am here in this abysmal black pit of hell. Fear put me here and fear won't let me out.

No one can help me. Perhaps I have the strength to help myself. I try to rationalize my fear in order to make it more manageable. "Get control." How can I gain control? This is not a belief that can be rationalized. This is reality. I have this enemy, and this fear, and I have lost dominion of my being.

"Remember how special you are." How can I feel special when I am but the shell from which the special being has escaped? The self-assured, independent, in charge, special person I once knew is no longer here.

Stop being a victim." I would if I could. The reality is that I am a victim, a prisoner of my enemy. I am tethered by this fear, wrapped in darkness and too scared to scream.

Fear is called the "fight or flight" syndrome. If I found the strength, I would run forever, but this enemy would follow, and hence the fear. I would stand and fight but I have no equipment. To fight the enemy you need to know all about the enemy, and

determine a tactic to confront the enemy. I am here, living in this fear, because I have no plan.

"Take responsibility for yourself." I do. The enemy is simply too monstrous for one to handle all by myself.

I am told "You need to accept the enemy as part of your new world. This is what you need to do to get rid of the fear." Stop! Don't tell me to accept this enemy. That word accept means to embrace, to welcome. What a foolish thing to say. Are you actually suggesting that I must learn to accept, rather than fight, this enemy?

I cannot breathe. I feel dizzy. My whole remaining being rallies, and from somewhere deep within, I hear a cry. I cannot live in that world, that abstract world my enemy sent me to. That is the deep, dank, hole I want to leave. My fear is now a terror.

In anger I protest, "Don't tell me to learn to live with this enemy. This only serves to make the fear more intense." How can I live with just the shell of myself? How can I live without my spirit? What you meant to say was not "live," but "exist." I do not know how to exist, and I do not wish to learn. What a horrible prospect. I contemplate, and then feel, the effect this terror is wielding on my body.

I am asked, "What is the enemy that causes your fear?" It is not the cause I fear as much as the fear itself. No one understands the enormity of it.

What does my tomorrow bring? I dare not think too long on this, because the real fear, that overwhelming terrifying fear, comes in and pushes me ever further into the black abyss.

These are too many thoughts. Too much pain. I am tired. I need to sleep but fear is here, with me, in my bed.

Growing Up With Vision Loss **by Sharon Chism**

I am the oldest of four children, three of which have what we now know as cone/rod dystrophy. I received my first pair of glasses at age five in kindergarten and would continue to achieve adequate correction until the sixth grade. By that time I figured out that the new glasses I was getting were not meeting my needs.

My brother and sister already were experiencing much more serious vision loss, and I must have made an inner choice to avoid the recognition of my own problem. I constantly lost my glasses (on purpose), especially on vision testing day. This way, I could blame my inability to see the chart well, on their absence and not on my diminishing vision. I got by on my wits and chose to sit up front in class. With good lighting, I was able to read regular print, but was noticing that others seemed to be able to see things that I couldn't.

To belong to the "group" was the most important thing to me! I watched how my parents and others reacted to my siblings' vision loss, and it made me want to run and hide. As the teen years approached, I noticed more difficulties. Seeing well in the dark was increasingly problematic, and more light was required to see details. By the second half of ninth grade, I was no longer able to see the board well from the front row. My grades began to slip.

One of my teachers confronted me about my grades. When she asked me if I had a boyfriend, I was relieved to tell her yes! Again, a "normal" excuse for slipping grades. I had developed such elaborate denial tactics that I was able to avoid my parents' detection, as well. They were quite involved with my siblings, and I was happy to leave it that way.

In the beginning of tenth grade, I found that the summer had taken its toll on my vision. I could no longer read normally. I needed to hold the book up very close and in very intense light. My grades continued to suffer and, God help me, I even took Driver's Education! I remember praying that the lights were green and hoped that if they weren't, the instructor would put on the brakes for me.

I experienced the pain of others looking over their shoulders and the strange looks I received as a result. Knowing that I was missing the nonverbal cues essential to communication, I found myself becoming more and more introverted and watched my personality change. I avoided eye contact whenever possible, and, when necessary, I would look at someone's nose to give the appearance of looking into their eyes. I need to remind you that this was in the late 60's and early 70's. The kind of help we have today was not available then. I watched with fear as my brother was sent to a blind school. I was willing to be considered dumb, ditzy, or even rude before I would allow myself to be called BLIND! Already I had been witness to the comments of pity and ridicule that some offered to my siblings and others, and I was unwilling to be subjected to the same.

When my vision loss was finally discovered by my parents, I was immediately tested and given the diagnosis of Stargardt's disease. I was a junior in high school and had somehow managed to pass with a C average despite my undisclosed disability. The sad fact is that I insisted on it remaining that way, and my school never knew about my problem. That was a grievous mistake.

By that time, I had developed some very negative coping skills and beliefs about myself, both of which were based on lies. I graduated from high school believing that I was unintelligent and somehow less than I should be. I was living with a highly involved system of denial. Those erroneous beliefs left me with a self concept that was much more detrimental than blindness, and it took me much of my adult life to overcome.

I realized after many, many years of faking it, that I was becoming just that--a fake. I came to see that any relationships I gained were based on a lie, with secrets and falsehoods, never knowing when people would find out the truth.

Appearing "normal" was all-important to me. I would open my books to the wrong pages. Imagine how much more foolish I looked to those who noticed. I would say "yes" to the question, "Did you see that?", sometimes looking the wrong direction. I was nervous when asked out to dinner and would call ahead to a restaurant in order to know what was on the menu, all to avoid facing the truth.

Over time I came to terms with my depression and grief. I had been expressing these emotions through anger and denial. I was to begin a long difficult process of accepting the truth about myself: the truth that I was legally blind and not stupid. I needed not to be ashamed, and not to hide any longer. I found that honesty about my vision, while initially very uncomfortable, left me free to be myself. I discovered that most people eventually would forget about my disability and would usually take their cues from me. If I was comfortable with myself, they were much more likely to be comfortable, as well. I have developed new ways of doing what is necessary to remain independent and found that I can do much more than I previously thought. I can now ask for help when I need it without feeling like I am helpless or inadequate. I have learned to "see" with my heart and have found there all of the important things of life: love, relationship, kindness, courage, and joy.

It is my desire that each young person newly diagnosed with retinal degeneration will be able to avoid the pitfalls of self degradation and the unfruitful patterns of denial in his or her life. There is a huge world out there just waiting for the amazing contributions of those of us who have grown up overcoming the difficulties of vision loss. Those experiences need not destroy us, nor do we need to lament who we could have been. Instead, they can make us who we are: strong and ready to successfully handle the challenges of life.

Now almost totally blind, **Sharon Chism** remains positive and very active. She and her husband travel regularly and ride tandem bikes on mountain trails.

Sharon's strong faith not only sustains her, but it is contagious, as she continues to be a source of inspiration and comfort for all of us in the MD Support community.

Living With the Threat of MD: A Spouse's Story

by Sandra Semple

My husband was diagnosed with wet AMD in one eye some 3 years ago. As is often in these cases, there was a long delay in actually getting a diagnosis. Much of this delay was with the (privately paid for) specialist who was totally reluctant to tell us what the diagnosis was, even though he had scheduled a laser treatment for it. (At that time PDT was not routinely available in the United Kingdom). The laser treatment failed, and all the central vision in my husband's left eye was destroyed at once. Whereas initially he had the "wavy lines," he then had an extremely large blind spot.

At first my husband thought he had a brain tumor and thought this for some time. However, I did some research on the Internet (thank Heaven for the Internet!) and realized he had wet AMD and all the consequences that entailed.

My husband crumpled after the failed treatment. He expected his right eye to go the same way almost immediately and began to grieve for his lost sight even before it actually happened. I didn't go to pieces immediately, but over the course of the next few months I coped less and less well with the idea of having a "blind" spouse. Even though I read about all the reading aids, etc. I could see how difficult our life was going to be, and for a long time could concentrate only on the down side.

Eventually, I was coping so badly that a friend of mine suggested I ask for counseling at the university where I worked. This was a confidential service which she spoke highly of, having used it herself when she suffered a bereavement. What I was going through was also a bereavement of sorts: the loss of a secure future (well, who has one of those anyway), thoughts about how bad our situation would be, a sense of many losses, etc.

The counseling came through quite quickly, and I slipped away from my office desk for an hour. I sat down with my counselor (a woman in her 50s) and poured my heart out about how low I felt, how bad our situation was, etc. I shed many tears and, as one might expect, she passed me the tissue box. We agreed that we would meet up for six sessions to talk things over.

At the start of the second session, my counselor said that she had something she needed to tell me. It was not usual to share confidences with the person being counseled, but she had thought long and hard about what she needed to tell me. I was rather mystified about this.

She told me that she had had Stargardt's disease since her early 20s. She had no central vision and relied on specialist binoculars to travel to work. However, once at work she got around nicely, thank you. She had studied for her counselling diploma with everyone else, but had had her text books transcribed on to audio tapes by the Royal National Institute for the Blind. She had married and had three children and some grandchildren. She and her husband had just come back from a holiday in Europe, which they had thoroughly enjoyed.

Wake up call! I had gotten no idea from the first session that there was anything unusual about her at all. I realized this was not a death sentence and not about living in dark rooms and doing nothing with your life. It was about making the most of things, being glad you were alive, and getting on with it.

I can't say I have fully managed to take all this on board, and I am sure my husband still has his bad days. At the time of this writing, my husband has been doing all the right things (AREDS, leafy green vegetables, lutein, orange vegetables, losing weight, taking statins--you name it he does it, mostly thanks to things we have read and subsequently researched here. We are currently totally remodeling our apartment, and we have built in as many AMD-friendly changes as we could. Lots of contrast where needed, good and appropriate lighting.

We do expect that one day those wavy lines will appear in the right eye. But this time we have a load more things to try: PDT, Macugen, and anything else that comes up. And when the time comes, we will give them our best shot.

In the meantime, we both took early retirement and live for today. And my counselor still works at the university.

Loss of Confidence by Dan Roberts

I have experienced a symptom of vision loss, and I wonder if anyone else can relate to it. It is not physical, and it is not emotional. I have experienced and identified most of those during the years, but this I find to be a much more subtle psychological symptom which seems to lurk in the background and affect nearly everything I do.

My wife, Chris, has been trying to get me to fix our refrigerator's ice maker for months. This would normally have been a welcome challenge to me, but after a feeble attempt which took much too long, I gave up.

Our porch light developed an electrical short. A project which used to take me only a few minutes used up nearly an hour, and my half-hearted repair will probably not last.

I am frequently invited to do acting workshops for schools and businesses--something at which I have always been successful. But a session which I did two weeks ago kept me awake all of the previous night wondering if I was going to ruin a hard-earned reputation.

I have been rationalizing this new personality of mine with thoughts like "I don't have the time," "I don't need to prove myself," and "I'm semi-retired, so I don't have to work so hard." Then, last Monday, I began to admit the real truth: that I am starting to give in to my slowly-decreasing vision. I am losing my self-confidence.

It started when I went to the computer store with Chris. I had not been in that store in quite a while, and it all looked slightly different to me. Everything was more askew and unfocused than the last time, and I had trouble reading the displays on my favorite software racks. I displaced my frustration with surliness, and Chris (bless her heart) decided to not take it personally.

When we left, and I got into the driver's seat (I still have one eye which allows me to do that), I was feeling a little shaky. Of course, I didn't tell Chris, because she already worries about

whether or not I am fully capable of driving safely; and if I were to admit my nervousness, that would only concern her further. Anyway, I had already lost some Brownie points with her earlier by narrowly missing a concrete divider in the parking lot.

I needed to go to a computer store on the other side of town, and Chris had other things to do, so I dropped her off at home. She offered to go with me, but I told her it was not necessary and set out on my own. This was the first time in a long while that I had driven any real distance without her, and I felt a twinge of loneliness as I pulled out. Loneliness? What a strange thing to feel, I thought.

Twenty minutes later, I pulled into the parking space at the store. As I got out, I berated myself for parking over the line and too close to the vehicle on my right. I have never understood people who do that, and I considered correcting it before going inside. Deciding, however, that I would probably not do any better the second time, I left the scene of the crime.

The store, of course, did not have the computer hard drive I needed, and the salesman recommended another place west of there. He gave some vague directions, and I headed out. As I drove away, I was immediately disoriented. This made no sense, because I knew the area. So I drove carefully and paid extra-close attention to my surroundings--a totally foreign way of thinking for me.

As I headed west, I avoided the highway. I had driven that stretch a week earlier with only my nine-year-old granddaughter and me in the car. It was dark and raining then, and I worked hard to see through both the distortions on the windshield and the distortions in my eyes. Driving slowly in the right lane, I got us home just fine, but the fear I had experienced then was now flashing back at me, so I took the city street instead.

After a while, I began to wonder if I was going the right direction, so I decided to pull into a convenience store for a phone book. I turned left at the next intersection, into the wrong side of the median, and ended up facing oncoming traffic. They stared at me as if I were some senile old man while I inched my way along; and

thanks to one gracious driver, I was eventually allowed to turn across the lanes into a parking lot.

I phoned the store and was put on hold for ten minutes. Trading my 35 cents for my pride, I finally hung up and decided to push on to the west.

By now, the overcast day had turned into a very bright, cloudless one. I had not brought my sunglasses, and the afternoon sun was shining right through the windshield. I knew that I was going to have to read every street sign along the route, but I also had to drive in the left lane to be ready for my turn. How was I supposed to see those signs? And even worse, how was I supposed to look out for the traffic in that busier lane while I was doing all of that squinting and blinking?

I felt helpless. I considered stopping and calling Chris-- something I always promised I would do. But it's not time for that yet. She would never feel safe with me again, and she would worry even more than usual whenever I go off alone. I still have one pretty good eye, and I'm not ready to give up yet.

Finally, I found the store I was looking for. I followed my nose instead of my eyes, and I was pretty proud of myself. I had set out to buy a hard drive, and that was one of the hardest drives of my life. Pretty funny, huh? Anyway, by the time I had paid for it, I thought, "How am I ever going to install this thing?" Ten years ago, that thought would never have crossed my mind. But something had happened to me, and it was made worse by the past hour. I hated that.

Just to see if I could do it, I took the highway all the way home. I made it. Then I wrote to a friend on the Internet and--thinking that my computer would probably go up in flames and I she would never hear from me again--I said "I'm going to install a hard drive. Good bye." Well, it took me three hours, but I did it.

Yesterday, Chris asked me if I could replace the posts on our granddaughter's canopy bed. She was very kind, saying, "But you don't have to get to it right away." (She remembered the ice maker

and the light switch.) Okay, I got my tools, and those posts are not only in place, but they are almost vertical, by gosh.

On Monday my confidence was gone. By Wednesday, I had it back. That's all I know. I still haven't figured out what happened, because I'm still riding the roller coaster. I just want someone else to know that this is happening so that--if it is happening to you, too--we will both know that we have company.

I have learned one thing this past week: there is something in me that will try to give up when things get tough. But there is also something in me that gives me strength to do what has to be done. It looks as if I am going to have to keep that in mind from now on.

Now I'm going to go give that ice maker another shot.

Red Sea

by Joel Deutsch

On a bright, warm Los Angeles September afternoon, I was strolling down Fairfax Avenue past CBS Television City and Farmers Market, headed for the neighborhood supermarket, my purposeful stride belying the fact that my eyesight was more than three-fourths obliterated by Retinitis Pigmentosa. But so it was.

Despite advancing research on gene therapy, retinal transplantation, and even the development of an electronic intraocular prosthesis, there as yet exists no treatment or cure for this predominantly inherited condition that afflicts something like 100,000 Americans. And so my irreplaceable photoreceptor cells, which in most people last a lifetime, keep wiping themselves out by a kind of bio-suicide called apoptosis, with nothing to be done about it.

The world looks like a hazy, unfinished painting. After a few nasty mishaps when the deterioration first became severe. I learned to scan ahead radar-like as I walked to catch at least a glimpse of approaching hazards. I owned a long, white cane, but I didn't have it with me. Isn't a cane, I thought, for when life feels constantly like coming awake in a strange house in the middle of the night? Doesn't "blind," after all, simply and unequivocally, mean sightless?

I'd considered carrying a cane if only as a signal, to forestall incidents like the time I stumbled into the side mirror of a bus while hurrying clumsily to board, and the driver, climbing out of his seat to readjust it, inquired sarcastically if I was blind or something. To simplify the process of asking strangers for help, as from time to time I must.

But I wasn't about to do it. No way. For one thing, I had this spooky foreboding that to take up the cane would be a dangerous capitulation, would bring on total blindness even faster. Magical thinking, I knew. Primitive. A child's metaphysics of causality. But I couldn't help it. Besides, I'd be marking myself disabled, for all to see, destroying whatever vestige of masculine appeal I'd managed to preserve into middle age. I'd become just another blind guy, groping his expressionless way along on some pathetic errand of the terminal, aging bachelor. So the cane, as always, was hanging by its elastic handle loop from a hook inside my living room closet, gathering dust.

Now I was passing beneath the protruding eaves of one of the Farmers Market buildings, grateful to be shielded from the sun's dazzle by more than just the brim of my baseball cap. A few feet away, the midday traffic rushed by in a din of car engines, horn blasts, diesel rattle, and the concussive thump of mega-watt, bi-amplified hip-hop bass.

Suddenly, something charged past me, tugging at my T-shirt sleeve. Through my remaining islands of vision, like a bird darting across a slit in a castle turret, flashed the profile of a small face, a boyish body hunched forward over handlebars, a flurry of legs churning.

"Damn," I yelled, edging over more toward my side. I probably looked, I knew, as if I might be playing a crazy, private game of chicken, had meant to surrender those few extra inches of clearance at the last second, but had simply miscalculated. When the truth, of course, was that I had no warning at all. Anything moving faster than walking speed can slip from blind spot to blind spot, completely undetected. Skateboards betray themselves by their clatter, but not so bicycles, with their rubber-tired stealth. I took a deep breath and resolved silently to be yet more vigilant, in the future.

And then something slammed into my shoulder, the same shoulder. Another flashing image of a small boy, pedaling. But this time, I was flung from my feet. I felt my skull collide against asphalt. I had a dim but troubling realization that my body was laid out full length across the northbound curb lane of Fairfax and that I could, in a heartbeat, be crushed and dismembered. Fueled by a burst of adrenaline, I made a mad scramble back to safety.

At the point where I had left the sidewalk stood a short, elderly woman, trailing a two-wheeled wire shopping basket behind her. "Crazy," she clucked empathetically. "Crazy. They almost killed me, too." She spoke with the old-time Yiddish accent that is rapidly giving way to Russian as the Fairfax District and neighboring West Hollywood become the Southern California version of Brooklyn's Little Odessa.

"I'm fine," I assured her, and as she continued on her way. I brushed myself off, gingerly checking for damage. My head was bruised and bleeding, my shoulder ached, the forearm I tried to break my fall with was a mass of lacerations, and my cap was

missing, probably pulverized into blue cotton oblivion. Dazed, but nonetheless still in need of groceries, I proceeded with my shopping and trudged home to a stinging shower and some bed rest.

The next time I left my apartment, there was a nylon day pack slung jauntily from one shoulder, the kind students carry their books in. And in my right hand, I held the long white cane. Not tapping it in an exploratory arc. Not yet. But bearing it before me like a protective talisman, a Mosaic staff. And feeling relief mixed with horror at the sight of people making way for the blind man I was still in the process of becoming.

The Day I Quit Driving

by Joel Deutsch

The phone on the night stand rang, shattering my last dream of the morning.

"Hullo," I mumbled. It was the woman from the Substitute Unit of the L.A. Unified School District. I was to fill in for an English teacher at a middle school halfway downtown.

I didn't know how much more substitute teaching I could take. By this time, my eyesight was severely compromised. And this trip would be straight into the sun. Another harrowing commute. I had the Beverly Boulevard route to the school pretty much hammered from long experience. Whether I could see the traffic lights at first glance or not, I knew which cross streets had them, and I'd become pretty good at telling the color of a light by watching traffic.

I made it through all the major intersections, talking myself down the road. Finally, I took a left into the street and began to peer along the curb for a parking space. I couldn't have been going 10 mph.

Suddenly, I heard the sickening thud of my front bumper hitting flesh and bone. My right foot slammed the brake pedal. The car stopped just short of an airborne boy, maybe 12 or 13, levitating a few inches above the pavement as his unzipped nylon school bag launched itself from his shoulder and spewed notebooks, pencils and personal effects all over the street.

The kid lay sprawled in a heap on the pavement. A car door slammed somewhere off to my left, and his mother was kneeling beside him, crooning and fussing, her face a mask of incredulous fury completely at odds with her tender ministrations. And then sirens came speeding toward us up the avenue.

As the mother stood behind the ambulance watching them shove the gurney inside, I finally got up the nerve to approach her. She was talking in Spanish with a man who had come over from the auto body shop across from the school.

"Lo siento, señora" I said. *"Lo siento mucho.* I'm very sorry. She wouldn't even look at me. The man from the body shop wasn't so reticent. "I seen it, man," he snarled. "You seen him and you just keep going." And I thought, yes, that's exactly what it must have looked like.

"I just didn't see him," I admitted, which was true. The officer didn't ask me anything about that, or even issue me a ticket. He simply said the kid shouldn't have jaywalked in front of my car, which was also true.

The next few weeks, I spent a lot of time in my apartment, only leaving home for errands I could accomplish on foot. I tried taking the car out one more time to the neighborhood laundromat. But even that short trip unnerved me. So, finally facing facts, I put the car up for sale and surrendered my driver's license for a California ID card.

No one ever contacted me about the accident. I felt justified in assuming, thankfully, that the boy wasn't hurt too badly.

But still, every time I think about it, my hands remember the weird, rubber shock of the impact through the steering wheel, and I see the whole thing all over again. I especially remember the look on the mother's face. Some things, some of us learn only the hard way.

Lo siento, señora. Lo siento mucho.

Joel Deutsch was a prolific writer and a good friend who loved to learn. His biggest frustration was his gradual loss of vision from retinitis pigmentosa. But his greatest fear of becoming totally blind never came to pass. Joel died of cancer in 2011 at the age of 67.

Former Driver, Retired With Honor
by Dan Roberts

Dear Driver's License Inspector,

Yesterday you granted me the privilege of driving for another six years. Since I could read the largest line of numbers with my one remaining eye under perfect lighting conditions, you determined that my vision was good enough to allow me behind the wheel.

But do you know I have a chronic retinal disease which could take away my remaining functional vision before you test me again? Do you know I have poor night vision, serious problems with glare, and low contrast sensitivity? Do you know that I have backed full speed into a tree I didn't see, almost pulled into the path of a truck that appeared out of "nowhere", and driven the wrong way down a one-way street? You didn't ask me. Instead, you have allowed me to negotiate the highways with drunks, druggies, neurotics, and sleep-deprived drivers all speeding less than ten feet apart on the way to places they just have to be, no matter what the cost. Do you really want to add me to the mix?

In case you are now having second thoughts, I want you to know that I have decided to be one less driver for you and your family to worry about. Like a certificate for over a half century of distinguished service, my shiny new license, and its mug shot of an old guy I just met, will remain safely tucked away behind my Medicare and AARP membership cards. It was a tough decision, but *someone* had to make it.

Thank you for your trust in me, but now the only way I am going to meet your family on the road is as that guy smiling at you proudly from the passenger window.

Sincerely yours,

A Former Driver
Retired with Honor

The Gray-Haired Bearded Lady: My Experience with Charles Bonnet Syndrome by Marge Louer

I am 93 years old and was diagnosed with macular degeneration several years ago. About one year ago, I began having hallucinations that puzzled and confused me. The most regular one was a miniature of a woman's round and placid face, surrounded by bushy gray hair that extended onto her chin. She appeared as a bearded lady.

Sometimes three or four images of my bearded lady would appear at the same time. These hallucinations would come and go. Other images were of varying patterns and colors of textile designs and of a subway map. But when these hallucinations began to appear constantly, I felt so distressed that I went to the emergency room at the New York Presbyterian Hospital/Cornell Medical Center in New York City. I spent the whole night there and was put through a series of brain scans and many questions. At that time, I informed the doctors of my diagnosis of macular degeneration. However, the next morning I left with no more understanding of the hallucinations. I was also assured that there was nothing wrong with my brain, and that was a big relief.

Nevertheless I wanted to know more about why I continued to hallucinate with no regularity, but often enough to distract and puzzle me. I asked my daughter to research this condition on the Internet. Without much difficulty, she soon found that this phenomenon is well known in England. People with macular degeneration are commonly informed that hallucinations often accompany this disease. I was very surprised that the doctors I met did not seem to know this medical fact.

In 1769, Charles Bonnet described this condition. "Sufferers who are mentally healthy people with significant visual loss have vivid, complex, and recurrent visual hallucinations." The retina is badly damaged by macular degeneration and sends strange messages to the brain, which gets confused and tries to interpret these jumbled messages which results in hallucinations. Quite simply, it is a damaged retina, not a damaged brain. This knowledge

informs and consoles the individual who may experience hallucinations with macular degeneration.

Shortly after I wrote this article, I met my neighbor, who asked me, "What's happening?" I told him about my experience with hallucinations and my concern to share what I had learned. When I finished, he thanked me and then told me that for several years, he had been seeing visions of green or ashen forests.

He had never told anyone for fear they might think he was crazy. He told me he has retinal disease and thanked me for sharing this information with him. He promised to speak to his ophthalmologist about this.

I want all individuals with macular degeneration, retinal disease or severe visual loss, and all doctors who serve them, to be aware of the occurrence of hallucinations that might accompany their disease.

See and hear Marge's presentation about Charles Bonnet Syndrome on the MD Support web site at:

www.mdsupport.org/nsg/cbs/index.html

Writing to Live **by Charles Champlin**

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In something more than half a century as a reporter, writer and critic, I wrote more millions of words than I can count. When I was the film critic of the paper, I saw 250 movies a year and reviewed half of them. As a critic at large, I saw and wrote about plays, lectures, panel discussions (spare me, please), appearances, places, happenings and personalities. I wrote about visits to film festivals in England, Spain, France. I went, I saw, I wrote.

My eyes, not less than my ears and my fingers, were my livelihood.

Then, a year and a half ago, those visual excursions came to a kind of squinting halt. Something called macular degeneration invaded my "good" right eye. The left had actually been hit by AMD, as it's called, for age-related macular degeneration, a decade ago, leaving me with only peripheral vision in that eye. But the right eye soldiered on for a decade.

I was reading a book in the back yard in bright sunlight. There never seemed to be quite enough light indoors. As it was, I needed a little help from a magnifying glass. There suddenly seemed to be pieces of ash falling on the pages. My first thought was there must be a fire a canyon or two away and I looked for the telltale column of smoke. There was none. I was burning holes in the pages with the glass.

I called my ophthalmologist for an early appointment and after I did my best with the eye charts, he said, "My friend, you are legally blind."

The AMD closed in fast, and within days it was no longer safe for me to drive a car and I couldn't read a book, a newspaper or a letter. As I also soon discovered, I could see television or movies only in sidelong glances, looking left or right of the screen and

piecing together what I could with my peripheral vision. It was, of course, a stunning, staggering deflection from the way I had lived my life--and earned my bread--for all my years.

And yet the story of this last year and a half has not been a hopeless surrender to limitations, but learning how to cope and get on with life and my passion to write. (One of my earliest pieces for The Times was an essay on being a compulsive writer.) I am not blind-blind. I see the larger world as through a theatrical scrim, with some loss of detail and a slight fading of colors.

There are problems closer up. I can't make out my fingernails, for example, and I shave by touch. Parting my hair is such sweet sorrow, also done by touch. I have a little trouble making out faces, and I had lapel pins made that say "Vision Impaired. Please say your name." You can't make out the pin unless you are close enough to kiss me. But the design is intriguing and sometimes people are inspired to ask what lodge I belong to.

Not driving does raise hob with the life that once you led. For all my half-century in journalism and even now in retirement, lunch was a social ritual that was also a battery charge for renewal of news, information, gossip and the nurturing of often long-established friendships.

In my working days as a magazine and newspaper writer, I had lunch "out" as many as five days a week. I never kept count of the interview lunches I conducted at the grand old Brown Derby on Vine Street, at Musso & Frank over on Hollywood Boulevard, at the smoke-filled Redwood Restaurant a few doors from The Times, or, depending on the grandeur of the interviewee, in the Polo Lounge or on the terrace at the Beverly Hills Hotel.

All that, of course, has come to a shuddering halt. My wife, Peg, drives me to lunch or I take cabs; occasionally friends pick me up and deliver me home. But those grand lunches have dwindled to one or two a week. The old lament of wives that "I married you for better or for worse but not for lunch" is relevant here, although Peg has not complained.

It requires more than an assault by macular degeneration to demolish a lifetime's affection for the arts in all their infinite variety. It is no use kidding yourself that the perceiving of art is undiminished. Only the pleasures of music remain unaffected. I have found fresh delight in the fairly large collection of LPs and CDs we have accumulated over the years. Enjoying the other arts post-AMD requires a certain amount of adjustment.

As with movies and television, I have to look sideways at paintings and sculptures, and while in my peripheral vision I can glimpse the whole painting or carving, the image is blurry and, although the color is present, a great deal of detail is lost. Seurat and other pointillists seem to have lost the point and are using flat paint only. Sculpture appears curiously rubbery.

The greatest casualty is the foreign film, which I have loved obsessively ever since my first viewing of "Children of Paradise" and "Open City." The subtitles, however, are now an indecipherable garble at the bottom of the screen.

It is true, indeed, that memory is newly important to me in many ways, as in identifying friends by their voices, but in a real if subtler sense memory is more than ever a key to the arts. The pleasures of culture are very often remembered pleasures, pleasures recalled in sound and impaired but evocative images. Painfully, it is the new cultural experiences--new TV, new paintings, new plays, new films, that are diminished by one's damaged vision.

My great boon and blessing is that I took typing in high school. The commercial teacher was the prettiest in the school. By such accidents are lives shaped. Touch-typing has served me wonderfully from college through a long career. Now I can type at the computer even though I can't make out the screen. What I do need is proof-reading, and occasionally I hit the all-caps key and find I've been shouting for a paragraph or two. More alarmingly, I get off the so-called home keys and type what looks like a cryptogram. Peg has even learned to translate this gibberish if there's not too much of it.

I early on acquired a large magnifying machine, a video camera aimed downward on a platen on which you place material to be

scrutinized. The camera can enlarge what it sees up to 55 times and transmit the results to a monitor above the camera.

The machine doesn't work with books because of the difficulties of focus. Reading newspapers is a nuisance because of the folding and refolding required. It's as bad as trying to read the New York Times standing in a crowded subway. But the machine is a godsend for mail and documents.

I have found that I can dictate letters and indeed editorial copy. My wife and also a part-time secretary can type the dictation straight into the computer. I find that editing is trickier now--trying to keep two or three alternate versions straight in my head.

Yet I keep remembering what James Thurber said when he lost his sight completely (he lost an eye as a child when his brother hit him with an arrow). He did not mind being unable to draw his lumpy dogs, strange men and women, he said, but if he could not write he would suffocate. I had the same anxiety when the AMD recurred. But Thurber kept writing and so, at a very different level, am I.

The other boon is the number and variety of recorded books available. The Braille Institute on Vermont Avenue in Los Angeles maintains a library of 70,000 volumes, recorded by and for the Library of Congress, available postage-free and rent-free for as long as you need them. Not long ago, I listened to a magnificent reading of Dostoevsky's "Crime and Punishment," read by the fine radio actor Alexander Scourby and recorded in the late '50s. Not all the readings are as thrilling as Scourby's, but all are competent at a minimum. There are also the commercially available audio versions, unabridged from Books on Tape and the other major rental concerns, and there are as well the abridged versions of current bestsellers. John le Carre is his own best reader, with an actor's gift for accents and voice changes. His reading of "The Constant Gardener" is a superb condensation.

A counselor at the Center for the Partially Sighted in West L.A., which I visited soon after the onset of the latest run-in with AMD, questioned me about the problems of discouragement and dismay. I assured her I could cope, but it was actually an apt warning. I live in a house full of books, shelves in virtually every room, and they are a

continuing frustration. Even now I occasionally pick a volume off the shelf, only to realize freshly that I can't read it.

Daily chores present lesser frustrations. To take a really minor example, it's almost impossible to see butter (or margarine) on a china plate. I surrender to having my bread and rolls and toast buttered for me. It took a while to discover that it was easier to put some toothpaste on my index finger and spread it on my teeth rather than try to negotiate the paste onto the brush. Yet what the loss of a certain quantity of vision has done above all is to create an immense new appreciation for those who have no sight, or virtually none, and yet who manage to live full and independent lives and cope with challenges of mobility and street-crossing that are troubling to me in my limited darkness.

I am lucky naturally, that these troubles commenced after I had retired from daily journalism. And whatever the frustrations of legal blindness are, I remind myself many times a day that I am very lucky, a writer's need for expression by no means silenced yet.

Getting My Mail by Susan

I was pacing slowly down the sidewalk, so I wouldn't trip over that crack like I did the day before. With the mail in one hand, I shaded my eyes with the other. My sunglasses were the recommended kind, but I realized I should have worn my big hat to keep the sun from glaring off of them.

I heard the clack-clack of skateboard wheels coming at me head-on. A few years ago, I would have stepped aside, I didn't know which way to step. So I just froze in place, hoping the pilot of that conveyance would have good maneuvering skills.

He didn't. He collided with my left hip, and his ride escaped into the street. He ran after it, and I screamed at the sound of a blaring horn and tires scraping on loose gravel.

The boy returned unharmed and slammed his skateboard back onto the concrete walk. He stood in silence for a few seconds. Probably scowling at me. Then, with a push of a toe, he was off again, leaving me standing there wondering how I would get my mail from then on.

A Blouse For Church by Edna

All I wanted to do was press my blouse for church. So I found the board and my old steam iron with no difficulty (because I have learned to be very organized) and set them up in the kitchen. After plugging in the iron by feeling for the socket and somehow not electrocuting myself, I discovered that the reservoir was empty. As the iron heated up, I filled a measuring cup at the sink and returned to perform what used to be a simple procedure.

I never thought pouring water could be such a challenge. That was a tiny little hole, and I had to hit it directly with no central vision. It would have been easy if I had a funnel, but who owns a funnel anymore? I guess I could have made one out of paper, but that would have meant finding paper, scissors, and tape. This shouldn't be so difficult, and I don't have the time!

I tried making a funnel out of my fingers and only made a mess. That's when I decided to just wear the blouse wrinkled. Who would care, anyway? "I'm an old blind lady, for Pete's sake," I said aloud. "What do they expect?"

I started to cry. And that made me mad. And the madder I got, the harder I cried. Then a big tear dropped onto the blouse, and I flashed back to my mother sprinkling water on my pinafore with her fingers.

"How stupid of me!" I thought, and within an hour, I was at church with a freshly-ironed blouse done the old-fashioned way.

What's so *Funny* about *Low Vision*?

by Dan Roberts

Nothing is really funny about low vision, but some humor can come from living with it. You know, those gaffes and missteps which may not be funny to anyone who hasn't lived with visual impairment, but which can make us grin when we realize we're not the only ones who commit them.

Lord Byron wrote, "Always laugh when you can. It's cheap medicine." And recent research has shown that it actually does make you healthier. This presentation, therefore, is dedicated to humor, featuring contributions from the people in our Internet community who understand visual impairment first hand. It won't cure what ails us, but it might be one of the best treatments we'll ever get.

I'd like to start with a short poem by Marion. She calls it "Macular Mayhem".

I feel my life is all a blur:
I cannot tell a him from her.
I once approached a garbage pail,
And thought it an attractive male.

And since I am a friendly soul,
I wave and smile at every pole.
And this is just the normal state
Of a macular degenerate.

Thanks, Marian. It's good to know that I'm not the only one who talks to inanimate objects.

Faux pas like that abound in this strange world of ours. Like this one from Sharon, who wrote:

"We were listening to a guest speaker at church, and the topic was 'Are you desperate enough for God?' It was a powerful message and I was quite moved. "As we entered into the greeting area, I went

up to a friend of mine and gave him a hug, then leaned in and whispered in his ear, 'Are you desperate enough?'

"When I pulled back and realized that this was not my friend, but some elderly gentleman I had never met, I blushed and moved right along. I can only imagine how well this story got around at the senior men's breakfast.

A somewhat similar story was contributed by Mary:

"My husband deliberately wore a bright yellow shirt when we went shopping. That made it easier for me to find him in a crowd. Well, I found a perfect purchase, but realized I didn't bring enough cash. So I approached the yellow shirt and said, 'I don't have any money. Could I have your billfold?'

"A strange voice said, 'What?'

"'Oh,' I said, 'I'm sorry. I thought you were my husband'.

"The African American gentleman looked at my fair skinned Irish mate and said, 'No, I'm not your husband, but it looks like we have the same good taste in shirts'.

And speaking of shirts, Lorraine wrote about the time she was shopping for a blouse. She saw one on a mannequin and began fingering the material. She let go quickly, however, when what she just *thought* was a mannequin pushed her hand away and said, "Ma'am, I'm not for sale."

Shari's faux pax was even more embarrassing. She wrote:

"George and I were invited out to dinner by his new boss and his boss's wife. The restaurant was dark, but everything went well...until we prepared to leave. That's when I reached for George's hand so he could help guide me through the maze of chairs and tables. Only it wasn't George. It was his boss. And it wasn't his hand I grabbed. Oops.

"George explained my situation, but the wife didn't seem to be as amused as her husband. She said to me, 'You don't *look* blind.'

“To which I wanted to respond, ‘And you don't *sound* like an *idiot*.’ But I resisted, because George needed to keep his job.

And then there are those times when we simply don't see things the way they really are. Like when Irving confused hemorrhoid cream for toothpaste and then worried all day that his teeth were going to shrink.

Or like when Jenny thought something terrible was happening to her recently-treated right eye. She keeps her reading glasses attached to a chain around her neck, and while preparing the evening meal, she put them on to see better.

Jenny began to panic when she noticed that her vision was much worse, and her eye was beginning to sting and water. She described it to her husband as calmly as possible, but real tears were also starting to flow. Her husband smiled and gently removed her glasses to show her a big thin slice of onion nestled in the bottom curve of the lens.

Vera wrote about the night she rolled over in bed to see what time it was. Her clock was always brightly lit, but that night she couldn't see it at all. She panicked and woke her husband by yelling, "I can't see!" He sat straight up in bed, then started to laugh.

Now she was screaming: "Didn't you hear what I said? I can't see!"

Calmly, he said, "Neither can I, sweetheart. The electricity is off."

And another time, Vera wrote:



"I was taking my daily walk to the bank from my office. The big clock on the bank sign was always my point of reference as I got closer. But that day, when I got to where I could usually see it, I couldn't! When I drew closer, I still couldn't! My heart started racing. I was scared silly.

"When I got to the entrance, I saw that the clock wasn't even there. It had been removed for repairs."

Considering Vera's luck with clocks, maybe she should just buy a talking watch.

We all have trouble locating our keys, finding our cell phones, and trying to change TV channels on our stomachs because we're holding the remote backward. But I'll bet every one of us can, the first time, every time, from three feet away, hit the snooze button on our alarms. Why is that?

Shirley keeps calling her son-in-law to come over and get rid of snakes in her yard. One of them turned out to be a long scarf that blew out of someone's car window. Another snake was some black tubing left by the landscaper. She says she's afraid no one will believe her now if a snake really *does* show up.

Pam decided to make a stir-fry. She threw pieces of chicken and other ingredients into a white bowl, mixed them together, and heated it all up for dinner. Turns out the bowl she used was half full of sugar, so dinner was provided by McDonald's that night.

Dina thought she was going blind when the lens fell out of one side of her glasses.

James thought his vision in *both* eyes had gone overnight until he realized his bedroom window had frosted over.

Carol thought her bag of almonds had gone bad until she realized she had popped a handful into her mouth along with her multivitamin capsules.

And then there's Maxine. She reported that she came in all wet from watering the garden one evening. So she took off her clothes, and placed her wet socks and tennis shoes on the porch to dry overnight. Next morning, she opened the door to get her mail and found that what she thought were her socks was her brassiere. She said she wasn't sure if her old mailman noticed. She said Ernie never actually mentioned it, but he seemed a lot friendlier after that.

It's not so bad when we don't recognize *things*. But when we don't recognize *people*, that can be a social nightmare.

One Monday morning, while waiting my turn in the post office, I saw Sheila, a fellow teacher, at the counter. It has been over twenty-five years since my retirement, but that was Sheila, all right. I couldn't quite make out her face, but she was talking a blue streak, as usual, to the postal clerk about something or other; and I would know that voice anywhere.

By way of greeting her, I very loudly joked, "You know, if some people weren't so gabby, the rest of us might get faster service here!" To which I expected good old Sheila to bite back with something like, "And if you weren't so crotchety, you could have gotten here *before* me!" Then everyone in line would have had a healthy laugh at our antics, and this particular Monday morning would have become a little brighter.

But she wasn't Sheila. I don't know who she was. She just gathered her purse, whispered, "I'm sorry, sir," and slipped quietly away.

All I know is that my mumbled apology meant zip to her and everyone else in line, and I'll never be able to show my face in the post office again.

So I decided to become a social hermit. Yep, if I couldn't be trusted in public, I would just stay home and communicate by telephone. Then, at least, I would have an excuse to say, "To whom am I speaking?"

Speaking of telephones, a few years ago, I heard about a great service offered by our local company: free directory assistance for the visually impaired. This is a wonderful concept offered by most states, whereby a vision-impaired person can simply pick up his receiver, dial 1-411, and ask the operator to connect him at no cost.

So I called the phone company to sign up. After several attempts at hacking my way through a jungle of automated phone prompts and dead ends signified by some confused human whose final reply was "hmmm", I came up with thirty easy steps to acquiring free directory assistance. I'll list them for you to save you the time and trouble.



1. Make sure you're calling the right phone company. The company you *think* you belong to may have been bought out, merged, taken over, or split up anytime during the past billing period.

2. Call the billing department. Don't call customer service, or you'll be sorry. Also, don't call 1-816-474-0516. That was obviously only one digit away from being the billing department of my phone company, and the person who answers will tell you so in no uncertain terms.

3. If you get this far, you'll be connected, and you will listen to a 90-second commercial message. That is exactly how long you'll remain on hold. It's always 90 seconds. Never more, never less. Exactly the length of that commercial message. Curious.

4. When prompted by an automated voice, say your 10-digit telephone number.

5. When the voice prompts you to do so, say any number for which you hear the word "billing" in the recorded message. It was number four for me, but they later told me it might change at any time, so don't count on it.

6. Say any number for which you hear the phrase "arrange billing payments" in the automatic voice prompt. I didn't write down that number, because I knew I couldn't count on it.

7. When prompted, say the last four digits of your account number from the upper left corner of your phone bill, which is neatly filed away somewhere upstairs.

8. Look for your hand-held lighted magnifier, and make your way upstairs. Locate the shoebox of last month's receipts under the bed, find the one you are looking for (the one on the bottom of the pile), and make your way back downstairs to the phone.

9. Repeat steps 1-7, because you have been disconnected for taking too long.

10. Say the last four digits of your account number. The number will be in size 7 font, so you'll need your magnifier.

11. Realizing you left your magnifier in the shoebox, climb the stairs again.

12. Find it, hurry back downstairs, and say the numbers.

13. Repeat the numbers several times slowly, because you are so out of breath that the automated voice keeps saying things like "I do not understand wheezing. Please try again."

14. After several more tries, during which time you have become someone your mother would not even take to church, the voice says, "Please hold while I transfer you to a human who understands that kind of language."

15. Check your pulse while listening to the entire second movement of a lovely string quartet by Mozart.

16. A human will eventually answer and ask you for your 10-digit telephone number.

17. Don't bother to explain that you already did that back in step number four, because they don't want to hear you whine.

18. Just give the human your phone number.

19. The human will ask for your name as it appears on your phone bill.

20. If you don't know which page of the receipt that is on, don't bother crawling upstairs again, because you mailed it with your payment.

21. Say any name, and hope the human doesn't become miffed if you are wrong.

22. Miffed, the human will ask how it can help you anyway.

23. Say, "I would like to receive a request form for directory assistance exemption."

24. If the human says "hmmm," immediately ask to speak with a manager. That's the secret. Don't try to explain it to the human, because it will only get more confused and start transferring you to places unknown.

25. Listen to the third movement of that lovely string quartet. Then have a little lunch. Maybe take a course in Braille, which you've been meaning to do for a long time.

26. The manager will eventually come on the line.

27. Repeat, "I would like to receive a request form for directory assistance exemption."

28. If the manager doesn't say "hmmm," you have succeeded!

29. You will receive the form in the mail in a few days.

30. Sign it, have your eye care specialist verify it, and mail it back to the address shown. That's all there is to it.

And what do you do if the manager doesn't know how to help you?

Hmmm . . .

So things like this happen a lot. We either don't see it, can't find it, run into it, or fall over it. And even when we think we have everything under control, we somehow still seem to find ways to draw unwelcome attention to ourselves.

Take Sharon for example. This is another Sharon--not the one who propositions elderly men in church. This lady bought one of those new voice recognition phones and was anxious to make her first call without operator assistance. Here's what she wrote about her experience as she tried calling her house from the store.

"Home,' I said into the microphone. Nothing happened. Then I realized maybe I wasn't using the right tone. So I stood there just

outside the entrance to the store repeating 'Home' in high, low, sweet and, eventually, not so sweet tones. Still nothing, but I wasn't giving up.

"Before long, several people had gathered around with offers of transportation. Hey, maybe next time I won't even turn the phone on. I'll just yell "Home!" and choose my ride."

Gideon knew how to use the voice feature on his iPhone, but he had another problem. Once, while trying to see the tiny screen, he accidentally made a long distance call by hitting "redial" with his nose.

Hannah, one of our more progressive seniors, purchased that new phone that can carry on a conversation with you. It's called Siri. She says the best part of Siri is that it will actually answer when you request to be beamed up by Scottie. Other than that, Hannah says she finds it to be pretty useless.

For example, she asked Siri to call Panera Bread in Charleston. It kept saying there was no listing for Hanera. So she broke it down phonetically: "Pa-ne-ra", to which Siri announced, "Sorry, we have no listings for dating services".

Hannah said she and her husband were in the car at the time. It's a good thing the windows were closed, she said, or he might have had to stop and help her look for Siri by the side of the road.

We *can* get pretty frustrated at times. But I think it's forgivable, as long as we don't let it get the best of us.

After her six-month eye exam, Olive's ophthalmologist told her there was nothing he could do for her. "God did this to your eyes," he said, "Now please leave, as I have other people waiting." So Olive pinched his nose and told him God made her do that.

8-year-old Brittany got her first long white cane. It not only helps her navigate through the halls at school, but she says it also comes in really handy for "whopping" the boys who tease her. A little more training may be necessary for Brittany.

And then, funny things just seem to happen *because* of us. And when they do, it's usually best that we keep our sense of humor.

Patty sometimes has to close one eye to look at something close up. One day, her dentist numbed her for some work on a bad tooth. As he waited for the novocaine to take effect, he saw her closed eye and exclaimed, "Oh, no! I put your eye to sleep, too!" Patty thinks he seriously thought so, too, until she stopped laughing long enough to explain.

In my music teaching days, I took my children's group to perform at a local choir festival. As usual, I brought along a portable light to help me see the score. As we entered the performance hall, the light dropped out of my folder and crashed to the floor, spilling its batteries across the carpet.

As my kids scurried around to pick them up, the harried festival monitor said, "Never mind those. We must remain on schedule." To which one of my little sopranos scolded her with, "Mr. Roberts can't see without his *batteries!*" Not only did the monitor wait patiently, but my young wonders took first place at the festival.

If nothing else, having poor vision provides us with plenty of excuses for bumbling through life, whether it's really due to our eyesight or not. To wrap things up, here are a few great excuses offered by our low vision community:

- When you go out with friends, you never have to be the designated driver.
- When getting engaged, you can encourage your fiancée to get you a diamond big enough to see.
- You can get seated on the front row of the airplane so you can "see the movie. (You know you really just want the extra leg space.)
- You can pass right by someone you don't like and pretend you didn't see them.

- You can get your spouse to cook the dinner because you can't read the cooking instructions.
- You can be forgiven for introducing yourself to a tree.
- You never have to worry about cobwebs around the ceiling, dirty shoes, or dust on the top shelves. Out of sight, out of mind.
- You never have to be the map reader on trips, so you are blameless when your husband finds himself hopelessly lost.
- You can pretend not to notice that your children's faces are covered in chocolate ice-cream so someone else will wash them.
- You still look the same in the mirror as you did ten years ago.
- You can't read your calendar, so you have an excuse for forgetting birthdays and anniversaries.

You know, Mark Twain said that “nothing can stand against the assault of laughter”, and that includes vision loss. Which is why I hope our stories have made you chuckle.

And remember to smile often. It not only helps you feel better, but it causes everyone around you to wonder what you've been up to.



There is Life After Macular Degeneration

A personal history of the road to vision loss

by Dave Pearce

Introduction

What do you do when everything in your life evolves around what you can see, and somebody tells you that you have a condition that is not only going to take your central vision from you, but is also untreatable? I know what I did. I immediately felt like I was going to be sick to my stomach for the rest of my life. My world seemed to be caving in on me; and yes, the "poor me" syndrome really started to take hold. My world, as I knew it, was falling apart, and I could not control what was happening.

Life In A Gray And Fuzzy World

In the early stages of the onset of the disease the changes are usually very subtle. In my case, I first noticed a small area in my right eye at about the five o'clock location that appeared to be a water spot on everything that I looked at. While I knew that it was there, it really was more of a nuisance than anything else. Once you are aware of this, it is rather easy to work around this area of your vision.

As the dry form of MD progresses, the water spot areas may enlarge, or there may be additional spots occurring in the field of vision. This form of MD usually will progress at a slow rate to the point where your central vision is blurred and cloudy. The fine details of objects that you are trying to view (words, facial features, and shapes of objects) become distorted to the point of being unrecognizable. Straight lines appear to be wavy or squiggles in your vision. You can see the form of a person across the room, but you can't see his face. This level of visual distortion normally will lead to high levels of frustration for the affected person and many times will result in the person not wanting to leave their familiar home environment.

Many victims of the dry form of MD will isolate themselves from the potential discomfort of not recognizing people and bumping into a person or object that is in this blurred area of vision. If this

isolation from the rest of the world is allowed to continue, the person will begin to develop fears of crossing streets, maneuvering in traffic, and encountering many of the normal obstacles that life puts in his path.

The most effective way to combat this problem is to obtain the services of a low vision specialist who will train the MD person in the adaptation and mobility techniques that allow him to perform the tasks he is used to. Some of the more common techniques are the use of other senses to compensate for loss of vision. The use of touch and hearing can compensate for the lack of vision in many of the normal daily tasks that are encountered. Another effect of this disease is distortion of colors. As my own condition progressed, I became aware that I was unable to distinguish the difference in colors such as gray, blue, and brown.

A major complaint of many MD people is that the glare of bright sunlight and the glare of lights at night leaves them virtually unable to see anything. When I am in bright sunlight, it is easy to add a pair of clip-on sunglasses to combat the glare; but in the evening it is difficult to reduce the glare without eliminating all objects from my field of vision. I needed to find that fine balance between adequate lighting and non-glare lighting. I have learned to place the lighting that I require between me and the object that I am trying to view. This eliminates the glare of the lighting in my eyes.

Most people who are afflicted with MD try to regain the vision they had before being diagnosed. This is an impossible task. The key to adjusting to this new world of gray and fuzzy objects in your central vision area is to learn to utilize the healthy peripheral vision you still have. The most effective tool for accomplishing this is you.

The art of using the healthy peripheral vision is known as eccentric viewing. It is accomplished by concentrating your point of focus off center of whatever you are trying to view. If you are trying to see a face on the TV, it is necessary to look off to either side or above or below the face, so you are capturing the person's face in your peripheral vision. While eccentric viewing requires extensive practice, the rewards are very gratifying. As an MD person develops this ability, the area of vision being captured in the peripheral vision expands. I have been able to develop my own peripheral vision to

the point where I now am able to see approximately 50% more in my peripheral vision than when I was first tested.

Many people with MD also experience the appearance of a colored area in their field of vision. I have seen a rust-colored area approximately the size of a quarter each morning for the past year when I first awake. It will normally gradually fade to the light gray blur that I live with each day. The duration of the appearance of the colored spot varies from fifteen minutes to as much as an hour and a half; however, the most annoying effect of this disease is when I close my eyes at night to try to go to sleep. The blind spot in my left eye becomes a brilliant green spot that flashes with tracers running around the perimeter. While this is going on in my left eye, the right eye displays a faint red image of the blurred vision area in that eye. It is like having a laser light show going on when I am trying to go to sleep. Our vision is constantly going through a myriad of changes never experienced by people with normal vision. Our world is changing every day for those of us battling this "life in the gray and fuzzy world."

When Did It Begin?

In the fall of 1985, at the age of forty-five, I went in for my annual eye examination with my optometrist, not having any major complaints other than that my prescription glasses did not seem to be doing the job for me after a year. This was nothing new for me, as for the last few years I had to have a new prescription almost every twelve months. Once I had to cross that bridge into the world of bifocals, it seemed to be another part of entering middle age.

During the examination my optometrist noticed I was having difficulty detecting numbers in a colored grid. I must admit I really didn't pick up on this during the examination. Rather than alarm me during the examination, the optometrist conducted additional tests in such a manner as to not cause me any concern. There also seemed to be more questions than normal.

Once the exam was completed, the optometrist advised me that there had been a slight change in my eyes that would warrant a change in my lenses. Since I have always worked in engineering requiring extensive close detail work with drawings and

specifications, this seemed to be par for the course for me. I usually had to have my lenses changed at least every other year, and now it was becoming every year.

Then came the devastating news. My optometrist said he had found evidence of a condition that was known as "Senile MD." My first reaction to this was focused on the word "senile." There I was, a relatively young, active professional being told I had a condition that was a condition that should be coming into my life at least twenty years down the road.

The doctor went on to explain that this was a deterioration of the sight cone cells that make up the the macula. He very calmly showed me pictures of a healthy retina and macula along with a very explicit set of pictures that had been taken of an eye with MD. He went on to give me a detailed explanation of how MD would eventually impair my close central vision as it progressed, but it would not destroy my peripheral vision. Most of what he said seemed to go in one ear and out the other. I suppose I was in denial.

He then took a series of photographs for a baseline record of the condition of my retinas. The good news, he said, was that I would not lose all of my vision. His explanations sounded like pure Greek to me at the time. Remembering that now has helped me to understand how other people and their families must feel when they are diagnosed with this "untreatable" condition. A major case of depression, confusion and helplessness all rolled into one major crisis, and being explained in a foreign tongue to boot! What had I done to cause this? Why was this happening to me?

As I left the doctor's office, I was trying to figure out how I was going to explain this to my family. How do you prepare your family for a bomb like this? Even though I lived less than five miles from the doctor's office, it took me a while to get home. To this day, I am not absolutely sure where I drove, but I know it took me almost an hour. When I finally did arrive, I had decided to explain the situation to my wife and children in a way that would capitalize on the positive aspects emphasized by the optometrist.

First, I tried to assure them that I would not be totally blind. I told them it was my understanding that most cases of MD have been

found in people who are later in years. I told them that doctors were now able to detect this condition earlier than before, and we should, therefore, see this as a warning, allowing me to maintain an active normal life while checking my vision on a regular basis. Hopefully, by the time my condition would affect my vision, there would be major progress in the treatment of MD.

My Initial Feelings Of Despair

While I was trying to be positive for my family on the surface, I was scared to death inside. What could have possibly caused this condition? What could I have done differently in my life that would have prevented this from happening? Why was this happening to me? What was in the future for me? How much longer could I look forward to working? How long would I be able to drive a car? How was I going to go through my life without being able to see? As I looked at each member of my family, I was thinking how terrible it would be to never see them again as I was able to at that minute. What kind of a life would I have without being able to see? Was I in store for a life as a blind man, like my paternal great grandfather? The stories of his dependence on other people kept running through my mind. I could feel the "negatives" taking control of my every thought. I had to find some way to stop thinking like this. It would surely wind up destroying me if I didn't get out of the doldrums.

Being an eternal optimist and an engineer by trade, my mind kept searching for some logical explanation. Surely, there had to be some treatment that would correct it, and everything would go back to normal. During the next few weeks, I tried to research every piece of information I could get my hands on. I went to the encyclopedia. I checked every medical book that we had in the house and checked with my pharmacist and optometrist for any additional information they could give me. Each piece of information I read contained the same basic fact: there is no known treatment for this condition. This really wasn't giving me a chance to be optimistic.

At that time, there really wasn't a wealth of information about MD like there is today. If only the Web had been available to me then, I am sure it would have made a major difference in my mental and emotional outlook. In my frustration with all of the negative information and thoughts, I contacted my optometrist to make

arrangements for an appointment with a retina specialist whom he had recommended during my examination.

Time For A Second Opinion

Neither the retina specialist nor my optometrist prepared me for what was to come during this examination. I assumed that the doctor would just take another set of pictures like before; but that was my first experience with fluorescein angiography. What an experience that was!

The light flashes in my dilated eyes were brighter than anything I had ever seen. Why would somebody be exposing my eyes to something like that? I was convinced this procedure was either illegal, immoral, or possibly some satanic ritual. The temporary loss of vision that followed was frightening at best. Was this the way I would see the world for the rest of my life? What was in store for me? This couldn't possibly be the way I would spend the rest of my life.

Much to my chagrin, the specialist confirmed the diagnosis. He was extremely optimistic though, and he tried to assure me that, since they had discovered this condition at such an early age, there was hope that the medical community may find some way of treating it during my lifetime. Then he shared a recent article with me that reported mega doses of selenium, vitamin C, and zinc had been successful in retarding the progress of MD.

For the next two months, I faithfully took the vitamins. Although I saw no appreciable change in my condition, I assumed that this would take a considerable time before there would be any noticeable change. The reasoning engineer again felt that he was retaking control.

The First Setback

I took the vitamins for about two and a half months. About that time, I was attending a four-day business meeting for my job at my company's main office outside of Boston. Although I had advised my immediate supervisor of my diagnosis, I was not ready to let

everybody know about it. How could I possibly explain something like this to others, when I really didn't understand it myself?

The evening of the third day, I attended a dinner meeting with my supervisor and about five of my coworkers from other regions of the country. About half way through the dinner, my vision in both eyes became blurred. Within a few minutes, I could not see anything in the top two thirds of my visual field. Panic set in immediately! This couldn't be happening to me now! My doctors had told me this was a slowly progressing condition that would not take all of my vision. My stomach started to do flip flops, and I thought I was having a heart attack.

With the help of my supervisor, I called an ophthalmologist at a major Boston hospital. The doctor said this may be a temporary condition that would clear up in an hour or two. He told me to get back to the hotel and to try to relax and not allow the panic to control me. He suggested that I take some Tylenol and get some sleep, allowing that if the condition did not improve by morning, I should contact him again.

Needless to say, sleep did not come easy that night. I didn't want to call my wife, because she would hear the panic in my voice. After an hour or two, I did drift off to sleep. Come morning, I was seeing better, and I knew I had to call her, as she would need to take me to Akron to see the retina specialist when I got back to town.

When I arrived home, my wife was ready and waiting for me with open arms. She could not hide her concern, fear, and worry. Recently, she had let me know of the total frustration she felt. There she was, standing on the sideline, watching her husband lose his sight and not being able to do a thing. Only now can I truly begin to understand how she felt. I was so consumed with my own concerns, that I really didn't consider completely how this was affecting her.

The retina specialist in Akron gave me a thorough examination and advised me that a small blood clot may have passed through behind my eyes, causing this temporary condition. The cause might have been the vitamins, so he suggested I stop taking them and continue with a multiple vitamin that included a lower dosage of antioxidants.

Coincidentally, two or three weeks later there was an article in our daily newspaper about this very same side effect of taking mega doses of vitamins. What a way to find out about the side effects of a medical treatment or procedure! That was my first realization that there is a multitude of information available to the average lay person through many sources outside of the normal medical profession. Little did I realize that this was the first of several unusual experiences I would be subjected to in my coming battles with MD.

Remission. Life Returns To Normal

The next ten years proved to be quite uneventful, as far as the progression of my MD. Being a parent to nine children, there has never been a time when I could really say that my life has been uneventful. I continued with my multiple vitamins on a daily basis, my annual eye examinations, and my daily check of my vision on the Amsler Grid. It appeared that the situation was under control and that my fears of losing my vision would not materialize for a considerable time.

Although my vision appeared to be stable, I always kept one ear open for any news or new developments about MD. The more time passed without any further developments, the more I convinced myself that this would not affect me in the near future. I was back to my optimistic, invincible self again. "Senile MD" was not going to get me yet.

The Onset Of Wet MD

In June of 1994, I was requested to go to Saudi Arabia on a business trip. During my ten-day stay in Saudi, I came down with what I thought was an attack of food poisoning, but after a couple of days I seemed to be back to normal. In November, however, I went for a check-up and discovered that I had not had food poisoning, but had a heart attack, which had left a small area of permanent damage to the lower portion of my heart.

One of the tests they gave me required taking a blood-thinning agent both before and after the procedure. For some reason, this concerned me, and I even discussed it with the cardiologist,

emphasizing my MD. I suspect that my original episode with the blood clot behind my eye in 1985 stuck in my mind. My cardiologist, a very direct person, advised me that if I didn't take the medication, the risk of an additional heart attack was too great to ignore. He asked me what good it would be to worry about my vision if I were to die. Good point! I agreed to take the blood thinners.

In February of 1995, I was watching television late at night and noticed that the picture was curving inward on both sides of the screen. Within a few minutes, the center of the picture was becoming distorted and blurred. I had never seen anything like this before. Fortunately, my optometrist had given me a colored brochure that included very explicit detail drawings of how the effects of MD would distort the normal vision in both the wet and dry states. I dug out a copy of the brochure and very quickly realized this sudden change in my vision might be the onset of wet MD. It took me a while, however, to realize that this was being caused by my left eye, not the eye that had shown signs of my MD.

The next day, my ophthalmologist found hemorrhaging in the left eye that should be treated immediately. He explained the condition to me and advised me that it was crucial to get it taken care of immediately. Within approximately thirty minutes, an appointment was made with Retina Associates of Cleveland for that afternoon with their top retina specialist who treated MD.

Wet MD Diagnosis

The only procedure that could be performed at that time was laser surgery to stop the blood vessel from leaking, which, if allowed to continue, would lead to total loss of vision in that eye. The one negative aspect of the laser surgery was that it could possibly leave a permanent blind spot in my eye.

It was now approximately 5:30 in the afternoon. My wife had been fighting a migraine headache for the last three or four hours. The look on her face was enough to make me realize that she was truly scared. The tears welled up in her eyes, and she came across the room and hugged me. It was impossible for either of us to say anything at first. Finally, we both mustered up the courage and

strength to talk about it. We both knew that I really didn't have a choice in this decision. It had to be done.

The morning after the laser surgery, I did have a blind spot, but I was able to be as mobile as I had been prior to the procedure. Things had turned out better than I had expected. But two months later, the doctor discovered further leakage. This required a second of what would be four additional laser surgeries on that eye. It turned out that each time I went back for a check up through August of 1995, I had another leaking vessel. The final result after five laser surgical procedures left me with the loss of most of my central vision in the left eye.

This was not what my optometrist or I had expected as a "slowly progressing condition". During that time, in July of 1995, I also had a cardiac stent implanted in my heart that I am sure contributed to the continued leakage in the left eye. As in the original cardiac catheterization, I had to take blood thinners, which I believe contributed to my eye changing from dry to wet MD..

Learning To Use My Peripheral Vision

The loss of all central vision in my left eye proved to be quite a challenge to my normal daily activities. Initially, I learned how to compensate for this loss with the central vision in my right eye. Along with turning my head slightly to the left, my central vision in my right eye seemed to be taking over so that I really did not notice much influence of the left eye after a couple of months. This started to be a real inconvenience when I was driving. By turning my head to view the side mirror on the car, I was moving my center of vision away from the road in front of me. There had to be a better way to do this.

Since I drove quite a bit each week, between 500 and 1,000 miles, I had a lot of time on the highway by myself. I had read in several sources that when your vision becomes impaired, your brain is capable of using other areas and enhancing other functions that were secondary functions prior to the disability. If this was true, I should be able to do something to improve or at least capitalize on the vision that I still had.

I decided to experiment with how much I was still able to see with my left eye, even though I had little to no central vision left. As I was trying to pick up objects in the peripheral vision, I noticed that by looking straight ahead in the same manner that I would with normal central vision, I could start to detect objects in my peripheral vision. As I practiced viewing objects with my left eye, I found that, if I moved my normal central viewing point up and down or left to right slowly, I was able to recognize objects almost as clearly as I used to with my central vision.

As a result of these exercises, the peripheral vision in my left eye had developed to an improved state that made it possible for me to see almost as much as I had before. I could even look in the side view mirror of the car without moving my head to view the mirror with my right eye. I found that I was now able to view objects in my peripheral vision in everything that I encountered in my normal daily activities.

Later, I was told that I was practicing eccentric viewing, a recommended way to maximize vision. Most people with whom I associated or worked were not even aware that I had no central vision in my left eye. It appeared on the surface that I would be able to work right up to my normal retirement age. I was convinced that this was the point I had been striving for. I had this MD under control--again!

MD Marches On

During the last week of June, the vision in my right eye was beginning to blur. That evening after dinner, my first reaction was that I had probably pushed myself too far beyond my limits at work. My wife drove me to the retina specialist's office for an examination. This examination included two different types of angiography tests to ensure that there was no hemorrhaging in my right eye. The tests proved to be negative, and the doctor felt that the problem was being caused by a build up of drusen. My eye appeared to still be in the dry state, which meant that I would not need to undergo laser surgery. Neither that, nor any other treatment, could correct this condition. This latest flare had impaired approximately one third of my central vision in my good eye.

Many of the fears and negative thoughts concerning MD were once again surfacing in my mind. Was this the beginning of the end of my career as a wage earner? What was I going to do now? What kind of changes were my wife and I facing? Would we be able to continue to live in our condo on the lake? As in the beginning of this adventure with MD, the questions came much faster than did the answers. When they did come, they were no different than before. There is still no cure for this condition. Keep checking the Amsler grid every day in order to detect any changes. And then what?

One morning approximately two weeks later, I noticed a change in my vision on the way to the office. For a change, it was an improvement. The spot that had covered almost a third of my central vision in the right eye was now about half the size it had been since the last week of June. I contacted my doctor that morning, and he said there had probably been a reduction in the swelling behind the retina. Most of the central vision in the upper left quadrant of my good eye was distorted now, but I could still see pretty well with the rest of my central vision in that eye. I was tickled to death that my worst fears had been proven to be false. It truly seemed that this was going to be a case in which the central vision in my right eye would be on a steady path of improvement, and I was going to be able to continue working.

Short-Lived Euphoria

By August, I was rolling along again in my standard mode of operation and feeling that my vision had arrived at a stable state. In spite of a small blurred vision area in my good eye, I was able to do almost everything I had been able to before the previous setback. My life was becoming normal again, and I felt generally quite optimistic. MD was not interfering with my ability to work, to boat, or to enjoy the many important things in my life.

With my personal life and my work life both appearing to be back to normal, the travel was also returning. By the middle of August, I was back in Minnesota for a weeklong project meeting with my customer and part of my project team. As normal, the work days were being stretched out to twelve- and fourteen-hour days at the job site, followed by at least two or three hours of meetings and paper work in the evening. We had traveled to Minnesota on Sunday

so that we could get started first thing Monday morning. Much to my surprise, Wednesday evening I noticed that the vision in my right eye was again getting blurry.

I made an appointment for the following morning. Since my wife was not expecting me until Friday evening, I knew that I would have to call her and once again give her the news that my good eye had acted up again. This was beginning to become a too familiar situation, and I hated to be putting her through this roller coaster ride. I guess the strain of the day was very evident when I walked into the house that night, because she threw her arms around my neck and just hugged me. Instantly I knew that we would get through this together.

The next morning, we repeated the same routine as six weeks earlier. This time, however, my normal doctor was not available, and his associate was going to see me. He appeared to be quite knowledgeable about MD, but his people skills left a whole lot to be desired. After examining my eyes and reviewing my file photographs, he advised me that the drusen had created this recent loss of vision and that there wasn't anything that he could do. As he started to leave the office, I asked what I should do now. In an almost inaudible tone he said, "Call Doctor Novak if it gets worse," and walked out of the office.

How could a well-educated professional be this uncaring and oblivious to another human being? When we checked out through the reception area, I found that he had not even scheduled me for a follow up visit. And he gave no advice or recommendations for anything that may help me in any way.

In hindsight, this doctor may have done me a favor in the long run. As I was stewing and venting to my wife, I realized that, with my central vision down to about 50% in my good eye now, the only way I could actually read was with the bifocal in my glasses. The light bulb flashed. Why not get a pair of glasses made the same as the bifocal strength that would be the normal size of a full lens? This was bound to give a larger viewing area that would utilize all of the central vision that I still had. Why hadn't that MD specialist thought of this?

We headed for the optician at our local mall. I picked up my new reading glasses the next afternoon and was able to read more than in the last two months. Unknowingly, I had come up with what low vision specialists now call computer glasses. I, the patient, had self-prescribed the best tool yet for me. This was a real boost to me. The glass was approaching the half full mark again: no longer half empty.

The Information Bank Opens

The thought crossed my mind that this now would be the time to start investigating what was available for people with impaired vision. I certainly qualified as visually impaired now, and there was no indication that this situation was going to improve or clear up of its own accord.

I went over to talk to our neighbor, who works for the Cleveland Sight Center. She told me about a litany of programs offered through the Sight Center and other agencies, and she would get me some literature about them. She told me that the State of Ohio has a Bureau of Services for the visually impaired that is a department within the Rehabilitation Commission. Their primary goal is to either get people back to work after a visual disability or to help the visually impaired continue working. I did not feel that I was really in either of those categories yet, but it seemed like a smart move to become informed about what services would be available when I reached that point in my deteriorating vision. Just hearing about the services was a tremendous lift, and my mental attitude began an upswing.

First, I phoned the State Department of Rehabilitation. Probably the most difficult part of making that call was admitting to myself that I was now going to be considered a disabled person. It seems that we all have a fear of admitting defeat and asking for help. I know I did, and have since found that it to be unwarranted.

I talked to a counselor, who asked me to gather my medical records and anything else pertaining to my job performance and work experience, and to meet him in two days at his office. At that meeting, he told me the first step was to have a low vision evaluation performed by an accredited vision center.

The Benefits Of Low Vision Specialists

The evaluation started with an extensive eye examination. The examination and review of my previous records took almost two hours. When it was over, the doctor informed me the vision in my right eye had deteriorated to the point of being legally blind. She felt, however, that with a new prescription and some low vision aids, she would be able to help to keep me working.

After looking at the reading glasses I had made in August, she recommended that I change to the half-lens style, which would allow me to use the prescription area for reading and my natural vision for distance. To this day I still use this style of glasses for reading and working on the computer. Since the computer was such a major portion of my job, the doctor prescribed the reading lenses so I could see the computer monitor and the keyboard.

The next two or more hours was dedicated to exposure to, and trial of, a multitude of low vision aids and equipment. This was a world totally foreign to me. The first aid to be discussed was proper lighting. By using strong, safe lighting, I was able to read print that I was having trouble with in the past. Of course, the new reading lenses also had a tremendously positive effect on this.

Next came a reading table that, along with the light, eliminated the glare and allowed me to view written materials at the most comfortable distance for me. Each piece of equipment was making the previously difficult tasks much easier for me. I was really getting excited. I could see light at the end of the tunnel, and it wasn't a freight train coming at me.

The magnification devices proved to be even more encouraging than the other low vision aids. I was seeing more types and styles of magnifiers than I ever thought possible. Trying those was a real challenge. Some of them helped, and some did nothing at all for me. It became a game to find which seemed to be the best for my individual needs. By the time we finished, I had selected five different types of magnifiers that would make it possible for me to continue working. Each style gave me a means to accomplish vision tasks that had been getting more difficult each day.

After lunch, I was given an opportunity to try out some of the computer software that would magnify any text or software that I had on the computer. This was extremely encouraging and gave me hope that I would be able to continue many of the tasks required in my job. I also had an opportunity to try several different types of closed-circuit television (CCTV) units. For those who are not familiar with this equipment, they are devices that project any text or material (a book, a magazine, a letter, a checkbook, etc.) onto a monitor with adjustable degrees of magnification. The devices also allowed me to write a letter or fill out a check on the slide tray under the monitor. We determined that, for the time being, this was more than I would require.

The doctor then summarized the recommendations we had come up with throughout the day, and she performed the final sizing and measurements for my new glasses. By the time we were finished, I had spent six and a half hours at the low vision center. I was bushed, but I was so excited about what was being recommended to the state as low vision aids for me. My life with impaired vision was going to be much better than I had thought.

About two weeks later, my state counselor arranged for an industrial low vision consultant to meet with me at my place of employment. When he arrived at my office, he surveyed the physical work area environment and the equipment (computer, printer, desk, telephone and lighting) that I used everyday. He subsequently recommended the furnishing of the Zoom Text computer magnification software, a computer monitor glare screen, speakers for the computer, a scanner and a work stand for my desk. He advised both me and my supervisor that the State of Ohio would furnish all of the equipment, and the only contribution required of my employer would be the services of someone to install the equipment. Naturally, my supervisor readily agreed.

By the week before Christmas, all of the equipment furnished by the State of Ohio through the Vision Center and the Industrial Consultant arrived at my home. It was just like having an early Christmas present. Since I was on vacation until the first of the year, I was able to inspect all of the equipment and start using the low vision devices at home.

I was anxious to try out some of the new low vision toys on my own computer. Between the glasses and the magnification software, I was able to see things on the computer screen that I had not been able to view before. I was really excited about how much better things would be at work when I returned after the holidays. I just knew that things were going to be better now. I would be able to see documents easier and would be able to get back to the speed that I used to be able to maintain.

The Bottom Falls Out

Early in the morning of January 2, I woke up to a severe pain in my good right eye. When I got out of bed, I noticed that it had a blind spot approximately the size of a half dollar. It was a gray spot that appeared to be made up of bubbles. What now? What could possibly have been causing this to happen to my good eye? It wasn't like the left eye when it went from dry to wet.

It was the day after New Year's Day, and I just knew that almost every doctor had taken a long weekend. I knew that I could not call anyone at three in the morning, so I took some Tylenol and went back to bed, with the hope that the pain would subside. By the time I awoke, the pain was gone, but the blind spot was still there. My heart was in my throat, and I just knew that the end of my central vision had come.

When I called the office of the retina specialist, they told me they could not possibly get me in today, even with an emergency. They did, however, make arrangements for me to see my doctor at a closer office the following morning, Saturday.

After the examination, the doctor said there was a major buildup of fluid behind the retina in my right eye and there was nothing that could be done to evacuate it. The swelling caused by the buildup of fluid had created the blind spot, and there was no way of predicting what the permanent effect would be on my vision. He said that the eye was still dry and would not require any additional laser surgery. He could not explain why it had happened, and he did not know if it would dissipate. If it were to do so, he was unsure of how long it would take for that to happen. Not a very comforting prognosis.

As we were ready to leave the examining room, I asked the doctor what I should do next. He said to plan on coming back to see him in six months. I left the office in a state of total frustration, coupled with a major case of devastation.

The next couple of days were not among the best of my life. Not only was my central vision just about totally gone, but also my insight into life was not very clear right then either. I had to face the reality that my driving was definitely curtailed for the time being. If I could not drive, how was I ever going to get back and forth to the office? The trip was forty-five miles and I knew that there was no way for me to accomplish this on a daily basis. What was I going to do to earn a living now? I found myself on a major downer. My excitement about using the new low vision aids on the job had been replaced with total despair, and I was experiencing every negative feeling that I could possibly imagine. I was vacillating between, fear, pity, anger, inadequacy, failure, and downright disgust with this whole battle to overcome MD. I had lost the battle and felt like I had also lost the war. There was no light at the end of the tunnel, and I was sure that I could hear that freight train coming at my back.

I did not know where to turn. I could not even find a way to discuss this with my wife this time. In the past, I had always been able to sit down with her, and we could both freely discuss anything that either one of us was facing. But this time was different. I had lost, and I did not know how to push my ego aside and talk about it. This was the first time I had ever felt so abandoned by all hope, and the first time I had felt alone in a world that appeared to me to be filled with darkness.

When I went to bed that Saturday evening, I could only think of one source to turn to. I prayed to God for the understanding and guidance to get through this, and I asked for his love and protection. The only answer that kept running through my mind was the one line of the Serenity Prayer that says, "accept the things that you cannot change." By morning, I awoke with a feeling that God was telling me to get back on track with my positive attitude and that He would guide me down that path--no matter how dark it was going to be.

Later that day, I was able to start talking to my wife about how I felt and what we were looking at in the future. We were both able to

let our thoughts and feelings out and assure each other that we would overcome this. Together, we have faced some major crises in our twenty years of marriage, and we both knew that this could also be handled. This has turned out to be another test for our strong relationship that began as a friendship and has grown to be an example to our children of what a truly loving marriage should be. Being best friends as well as lovers makes it possible for you to turn to each other in any situation. You always know that your best friend will be there for you. This time, we were there for each other.

The Second Shoe Falls

A week later, I received a telephone call from the personnel department at our main office advising me that the paperwork had been started for my short term disability leave effective immediately.

On the first of March, I received a call from my supervisor advising me that they had hired two engineers to replace me. They asked me to come into the office and empty out my office, as they were short on space. It was quite demeaning to think that fifteen years of work as a major contributor to a company I had admired could be reduced to three boxes of miscellaneous papers. Not even a thank you from the management or a farewell luncheon. That probably hurt me more than anything else. When I walked out the door that last day, I made up my mind that this was the closing of that chapter. My life would go on.

Adjusting To Vision Impairment

While I was going through the rejection by my employer, I was working with the Ohio State Bureau of Services for the Visually Impaired to make sure they were apprised of what was happening, both with my vision and my employment status. They were most cooperative, and they worked with me to get an appointment with the low vision specialist so I could be reevaluated based upon my change in vision impairment.

They determined that I was now qualified for some additional low vision tools that were not appropriate when I was first evaluated. I was examined and fitted for telescopic glasses that appeared to be a solution for me to be able to drive again. This gave me some

encouragement that I may be able to return to work on a part-time basis someplace in the future. There did appear to be hope arising in my outlook on life again.

By the end of March, I had been informed that I was approved for long-term disability under the insurance policy that I had carried for years at my place of employment. This was a lift to my morale, as I then knew that the coverage would carry through until my normal retirement age of 65. Although the benefits awarded would be a reduction in net earnings of about 25%, the benefits were not taxable. Thanks to that, we would not be hurt too severely and could maintain our present life style--a concern of mine that I had not even mentioned to my wife. Being the only wage earner and the bread winner of the family, it was disconcerting to not know what our income would be at the end of the thirteen week full-salary short-term disability benefit period. Put the "For Sale" signs away, and don't worry about standing in the food stamp line. We're going to be okay.

As part of the long-term disability benefit, it was my responsibility to apply for Social Security Disability Benefits within thirty days of being advised of my insurance award. As I prepared to submit my application, I was hearing horror stories of people not being approved for up to two years after their application and following numerous appeals to Social Security. By the time I was set for my interview, I had gathered all of the requested information, plus any other piece of supporting information that I could find. The interviewer advised me that the normal time for processing a request for disability benefits was at least six months, and that I should not be surprised if I had to go through at least one appeal. Much to my surprise, my approval notification arrived three months to the day from my initial interview. This reinforced my belief that if you tell the truth and furnish the information requested, you will receive whatever is due to you.

By the middle of March, I was working with other people on the Internet who were victims of MD. Before I knew it, I was spending from four to five hours a day on the Internet sharing information with others and trying to give them some level of hope. Much to my surprise, this became a tremendous healing agent for me. The more I worked with others who were battling this disease, the better I was

adjusting to the life of a visually impaired person. It dawned on me one day that I had finally accepted the fact that I was visually impaired and that I was never going to have the same level of vision that I had before. All of the low vision tools I could get would never bring my vision back to normal again. I was learning how to use the vision I still had, and I was not doing too badly. I even had the prospect of driving my car again.

With the acceptance of my own visual condition came a desire to share this with others who were battling the same monster I had just conquered. As I pursued this through the Internet, I found that I was feeling better about my current life and myself. This really wasn't a bad hand I had been dealt. Now, I was able to help others start their healing process, and they were feeling better about themselves, too.

Boy, this thing was getting contagious, and I liked the feelings that I was experiencing. I had found a level of self-satisfaction that I had never experienced in thirty-four years of working in engineering. Could this be what God had in store for me when I asked for His help? If it wasn't, someone sure was pulling my chain. I now could see a purpose and a challenge for me to help others resume their lives. When I started to type a message to a stranger who was going through the denial of becoming visually impaired, the words seemed to be coming from an unknown source. Someone or some force I had never experienced before was helping me. I had found a purpose for my own life.

A New Challenge And Opportunity

During the summer months, I continued on the path of helping others through the Internet and had expanded my efforts to a site that was dedicated to support for people with MD. My time on the Internet kept increasing, and before I knew it, I was talking to people all over the world who were battling MD. I was sharing experiences and learning more about this disease everyday.

By the end of July, I had received my telescopic glasses and found that I could see objects and people I had not seen in the last year or so. I was elated that these glasses could make it possible to use my peripheral vision to replace my lost central vision. The day I received them, my vision tested better than my low vision specialist

ever anticipated. The corrected acuity in my good eye had improved from 20/125 to 20/15 with the telescopic lens, and I could drive a car without having to get a special license in the Bioptic Driving program.

I now knew I was legally able to drive with the telescopic glasses, but I also knew I would never be able to drive at night again. With oncoming headlights appearing to be three feet in diameter, I knew I was not a safe driver at night. I could live with that, because I was the one who stopped driving in January when I knew that I could not see other cars on the road and did not want to cause an injury to some innocent driver. But now I could see the real possibility of me being able to work part time. This would be a real boost to my ego and my feeling of self worth.

In October, I was offered a position with the Ohio State rehabilitation agency. I would be responsible for setting up a separate group that deals strictly with the visually impaired. I accepted the offer and started working twenty hours a week in that capacity. I don't honestly know when I have ever been so excited about a new job. I found myself planning things I would like to include in the effort to find employment for the visually impaired and preparing interviewing guides for employers and clients. This opportunity to get people back into the work force gave me a chance to help the more than 80% unemployed visually impaired people feel good about themselves again.

A Short Lived New Career

Unfortunately, the job was not quite what I had anticipated. Ironically, all of the forms required by the state and the federal government agencies were in very small print that was impossible for me to read. The first two weeks I worked were spent revising the forms to a larger font that was easier to read and obtaining approval of the modifications from the agencies and the management of the private job placement company that had employed me. This also meant that any private or agency documents that would be distributed to visually impaired clients would require the same type of modifications.

I finally had an opportunity to work with some real people that were defined as visually impaired. Much to my surprise, however, the agency's definition was far different from mine. Any client who wore glasses was considered visually impaired. People whom I was assigned to assist had some type of mental or learning disability as their primary affliction. This became a very difficult situation for me, as I had zero training in dealing with these types of impairment. I learned that the job development program had been created through the MRDD (Mental Retardation Development Disabilities) through the federal and state governments. There were very few truly visually impaired clients who fell within the true definition of visual impairment.

Additionally, I was required to drive to the clients' homes and potential employers place of business at their convenience. This often meant I would wind up driving in the evening hours that put me in an unsafe situation with my own visual impairment. When I requested assistance from the agency owner, I was told it was my responsibility to take care of this and make any necessary arrangements.

The final blow came late one afternoon in a client's home. I was conducting an interview to determine what basic skills he possessed, when he suddenly went off the deep end. Before I knew it, he was physically threatening me, and it was all that I could do to get out of the house without being injured.

I immediately contacted the president/owner of the agency to advise her of the situation. She instructed me to write a report that would be forwarded to the state MRDD agency. Two days later I was handed a copy of the report and noticed that most of the information had been changed and did not represent the actual incident. In fact, the revised report essentially inferred that the situation was the result of actions I had initiated. Needless to say, this did not sit well with me, and I could see that this was not a situation where I could possibly meet the expectations of the agency or the governmental overseer agencies. My resignation was gratefully accepted, and I anxiously went forward with finding a new endeavor that would utilize my experience and talents.

Back To My Old Familiar Field

Shortly after my departure from my brief career as a job developer, the president of the owners' association at the condominium development contacted me where we live inquiring as to my willingness to assist with a problem at the condominium complex. There were a series of problems with construction work that had been contracted through a local contractor. It would require an in depth investigation and inspection of work that was being invoiced that did not appear to have been completed. The association wanted to know if I would head up a committee to oversee this effort and conduct the inspections and evaluation. This appeared to be a stroke of luck, since it would permit me to work out of my home and utilize my thirty-five years of construction and engineering experience.

After approximately six months of successfully completing the volunteer work on this task, I was asked to take a position on the association Board of Directors. Even though I had previously held positions as either a director or as president of the Board during the past years, I agreed to do it again. I am either a slow learner or a glutton for punishment.

Two years later, the condominium owners (the association members) offered me a part time position as resident manager of the complex that would include overseeing operations, maintenance and contracted services. Between being an "A" type personality and not being able to say "no", this part time job became a 50 to 60 hour per week job. Although the job was quite time consuming, I felt good about myself and was proud of what I was able to accomplish for the overall good of our condominium complex, even though I was visually impaired. My days flew by, and I felt as though I was truly a contributor again.

I was shocked as to how easy it became for me to request help from others when my visual impairment prevented me from seeing something. I had always had a problem with asking for help, even before I became visually impaired. To this day, I am not sure whether this came about as result of true acceptance of my macular degeneration or just plain "getting old". Whatever the reason, it has surely helped me, and I am not going to question the "what, where or why" of this change.

Eventually, after about three years, the long hours and the telephone calls in the middle of the night got to be more than what I could tolerate without some sort of a break. I gave the association notice that I would be terminating my position as resident manager at the end of 2003. Volunteers are now performing my job tasks, and I even find myself pitching in to assist when it is convenient for me.

Is There Life After Macular Degeneration?

Yes, there is a wonderful life after you have been diagnosed with macular degeneration. First, you must accept the fact that you are now one of the almost two million people in the U.S. alone who are affected by this disease. Then, you must make up your mind that you are going to learn how the vision that you still have can be utilized to remain independent and a productive member of our society. Don't give up and wait for some miracle to come your way. Life does not work that way.

If you have access to a computer, get on it, and search for information. One source of computer access many of us overlook is the public library. Also, if you have a friend or family member who has a computer, ask them to help you look up information on this disease that is about to change your life. Visit every site you can find, and don't rest until you have found the answers you are searching for.

If you have not visited a low vision specialist yet, by all means, find a qualified one that will take an interest in you and will help you to make a life for yourself. If you don't feel comfortable with the first person you encounter, get a second opinion. Some of the best low vision specialists are right in your own area. They are the local optometrists who have already worked with people who have macular degeneration.

Don't stop searching for the medical help that will address your own individual vision problems. Each of us is unique, with a different set of visual effects and symptoms. Many doctors truly dedicate their lives to help those afflicted with this disease. It is up to you to find the one who can meet your individual needs and desires.

After you have found all of the information that you can, and you have found a good low vision specialist and followed his or her recommendations, you have one more job to do. Work harder than you have ever worked in your life to apply everything that you have learned and heard. Give this job more effort than you have ever put into anything. It is the most important task that you have to accomplish in your life. It will mean your life as you want it to be.

Yes, there were many times during my own battle that I was down in the dumps and ready to give up. Every time I felt that way, I would give myself a kick in the butt and get on with my own battle to not let this disease get the best of me. I also tried to be aware of how others were dealing with it. Invariably, I would find that others with whom I came in contact had it a lot worse than I did. This would bring me back to reality and make me realize that, if someone else could deal with his or her problems, I could certainly handle my own. That usually pulled me out of the pity party.

Another excellent source of help was my Internet group, MD Support, which is now affiliated with numerous international groups. My wife and I have an excellent relationship that always allowed us to share our feelings with each other, but it is difficult to explain your visual experiences with someone that does not have MD. This is where my "cyber family" has been a constant source of comfort and understanding.

It does help to share your experiences with others who are going through the same thing or have gone through it already. You wind up realizing that you are not all alone in this battle. I have learned that having a support network of family and friends is the secret to overcoming the obstacles.. As the owner of our web site says, use these obstacles as stepping stones to a better life. Try it. It works!

Finally, I truly hope this tale of my battle with MD will help at least one more person to find that yes, there is life after macular degeneration. Whether it is you or a loved one who is battling this disease, you are not alone in the war. Above all, always try to keep a positive "can do" attitude. You will succeed and you, too, will learn to enjoy *your* life after macular degeneration.

Conquering Low Vision

How low vision rehabilitation gave Patrick Gonzales his life and family back

Extracted with permission from "Occupational Therapy Interventions for Adults With Low Vision" (ed. Mary Warren, PhD, MS, OTR/L, SCLV, FAOTA, American Occupational Therapy Association, 2010)

Patrick Gonzales is a retired man in his mid-70s who lives in a rural suburb of Minneapolis. He is married, with grown children and grandchildren. He is of Irish-Mexican descent. His father emigrated from Mexico in his early 20s and married an Irish immigrant, Shelia O'Leary. They ran a popular Irish-Mexican restaurant in the Twin Cities for 30 years.

Patrick's Wife, Juanita, emigrated from Mexico as a child and is a legalized citizen. She is fluent in English, but has retained much of her cultural heritage, particularly the delineation between male and female roles within the family. Patrick and Juanita have three adult children, two daughters and a son. Their oldest daughter, Maria, lives in California. The other two children live in an adjacent community 15 minutes away. Their youngest child, Kevin, has two young children and owns a contracting business that allows little time to assist Patrick and Juanita. Their second daughter, Anna, is divorced and works full-time to support her teenaged son, Michael. She is also a primary caregiver for her parents.

Patrick retired at age 64 after 40 years of working in an automobile parts distribution plant where he stocked and shipped parts. Later, he served as the plant union representative. He receives Social Security benefits and a pension from the plant. Because Juanita never worked, the two rely heavily on this income. The couple resides in a paid-for two-story home on two acres an hour's drive from Minneapolis. The backyard borders a field, beyond which is a river where Patrick has a private dock for fishing. A large, insulated pole barn, where Patrick has some power tools for woodworking, is located twenty feet from the house down a dirt path. This has been their home for for over thirty years.

Patrick fishes daily since his retirement, weather permitting,. Sometimes his son and grandkids join him, but he mostly fishes alone. He also dabbles in woodworking. Grandson Michael visits

every few weeks, and together they create small projects like bird houses and garden benches. Patrick takes great pride in teaching and working with Michael.

Patrick enjoys reading books and articles about fishing and woodworking, as well as detective novels. He reads mostly in the winter when it is too cold to fish. He avidly works the crossword puzzle and Sudoku in the local paper each day. He spends fall and winter weekends enjoying his favorite football teams on television. Son Kevin introduced him to an Internet fantasy football league, and Patrick is proud that he beat him in the championship game the first season he joined the league.

Patrick also loves to cook. On Sundays the family comes over, and he makes his father's secret recipe for tamales. Patrick has always been the head of the household, working full-time while his wife stayed home with their children. Juanita manages the home and kitchen, often serving traditional Mexican food. Her family considers her one of the best cooks in the country.

Patrick has been responsible for all the financial management, home maintenance, and yard work, using a riding tractor to mow in the summer and to plow the snow from the driveway in the winter. He has always been the primary driver in the family. Juanita has a license but has not been behind the wheel in fifteen years, openly admitting her aversion to driving.

Patrick is an independent and traditional man. His perspective has always been that Juanita's caregiver personality has been fine for their children and grandchildren, but not for him. He has had his own interests and daily duties, and she has had hers.

Like many Americans, Patrick lives with chronic diseases, including stage-2 diabetes, hypertension, and osteoarthritis. He was a 3-pack-a-day smoker for fifty years and recently managed to cut down to 1-1/2 packs a day. Despite these comorbidities, he has always looked forward to a productive retirement and a high quality of life.

Then, at age 70, Patrick was diagnosed with macular degeneration.

Three years later, his left eye developed the wet form, which destroyed significant vision. But, because it was in his nondominant eye, he had little trouble completing his daily activities and continuing to drive. He kept a standing appointment with his retinal specialist every three months. Then he gradually became aware that he was not seeing as well as usual. He had difficulty seeing his crossword puzzles, even with his prescription eyeglasses. He told Juanita he needed stronger glasses, but, when she tried to push ahead the appointment with his retinal specialist, he said, "No, let's just wait until my regular exam".

A few days later, while fishing, Patrick's fishing rod looked crooked. Thinking his "crooked vision" might be due to not sleeping well the night before, he returned home and took a nap. When he awoke, he looked to see what time it was and could not see all of the numbers or hands on the clock. He reached for the light and could not locate the switch. He called Juanita, who called their daughter. Anna left work and immediately drove them to the retinal specialist.

Patrick tells the rest of this story as it is best told, in his own words.

Patrick's Story
by
Dan Roberts

We pulled up to the professional building around 10:00 in the morning. Anna dropped us off and drove on to the mall to do some shopping. Juanita and I took the elevator to the eye clinic on the third floor. She had to push the button, because I couldn't find the darned thing; I will admit, that made me mad. Juanita said don't worry about it, but I couldn't stand it if I had to live the rest of my life not being able to push my own elevator buttons.

The waiting room was already full of people, and the receptionist said we would have to wait about an hour. I told her I couldn't believe how much more crowded it was than last time I was there. She said a lot of people were coming to the clinic these days for a new drug injection that could actually save their sight. That was pretty interesting, but her phone rang, and she didn't have time to

tell me anything more. She handed me a clipboard, and I sat down with Juanita to fill out the forms.

Finally, another young lady opened the door and called my name. We followed her down the hall to an examination room, where she dilated my pupils. Then we waited about twenty minutes for the doctor to come in. I hoped all of this was just a waste of time, because whatever was wrong with me was probably something that would go away on its own. Or my crooked eyes were just part of growing old, and, like last time, the doctor wouldn't be able to do anything about it.

Doc came in sooner than I expected to discuss the test results. He showed me on the pictures where my retinal layers were being pushed apart by blood leaking between them. That was distorting the vision in my good eye, which was why I thought my fishing rod was bent. What I hadn't realized was that my bad eye had gradually lost almost all of its central vision over the years. My good eye had been making up for it, so I never noticed how bad it had gotten. But my good eye had been going, too, which is why I kept needing stronger reading glasses and lighting. Now blood vessels were leaking in the back, so the central vision in both of my eyes was damaged.

I asked Doc about the new treatment I heard about in the waiting room. I thought maybe I could get a shot of that, and I'd be able to see everything like before. My peepers hadn't been perfect for a long time, but I always did okay with the one good one. Doc said too much bleeding had occurred, so it wouldn't help. There was too much scarring, but I would always be able to see the world with my peripheral field.

He said there was no reason why I couldn't learn new skills to help make up for the vision I was losing. All I needed was to be referred to a low vision rehabilitation program. He said they would work with me to be sure I could still do all of the things I wanted to, like reading my Field and Stream, paying my bills, and fishing. When I asked if that included driving, Doc said they would look at that, too, but I was not to drive until they evaluated me and told me I could. Juanita paid close attention to that and gave me a look that said I'd better not cheat and take the truck for a drive before then.

After we left the office, I felt like a Mack truck couldn't have hit me as hard. Doc was trying to make me feel better by referring me to a low vision rehabilitation program, but all I could think about was not being able to read Field and Stream anymore, not being able to drive my truck or work in my wood shop, not being able to mow my yard, and not being able to see the eyes of my pretty Juanita.

Doc said the low vision doctor would examine me to find out exactly what I could and could not see. Then an occupational therapist would evaluate me to identify my needs and goals. After that, I could go into a low vision rehabilitation program right there in the city. I know he said all this, because Juanita took good notes, and she read them to me in the back seat of Anna's sedan on the way home.

All I really heard was I was going to be a blind man dependant on his family for everything. No amount of rehabilitation was going to change that. They could give me a cane, an accordion, and a tin cup for all I cared, and it wouldn't make my life worth living. Just the thought of groping and stumbling around the house and having Juanita feed and dress me was more than I could bear. And what if I outlived her? I couldn't ask my kids to take care of me, so I pictured myself sitting in the corner of a nursing home somewhere, waiting, and wanting to die.

Juanita was still chirping on, now reading from the pamphlets Doc gave her. "First thing in the morning," she said, "we're going to call this rehabilitation center and get you in their program." I felt like a criminal being prepared to re-enter society.

"They even have a support group," she said, "where you can meet other people going through the same thing." No, sir! I would not sit in a circle with a bunch of old blind people whining about how miserable they are. Or even worse, trying to cheer me up with stories about how terrific they were doing.

Juanita told me I was just being an old *pesimista*. She said we had a whole team of people ready to help us get through this, and I was going to be just fine. I didn't understand why she was taking this so lightly. It was like we each heard different things from Doc. How could she not be worried to death about how I was ever going to be

able to take care of her, or even more important, if *she* would be able to take care of *me*?

It was all too much. I started to cry. I didn't even do that when I buried my older brother three years ago. But as bad as that was, this was worse than Roberto dying. He was an old man, and his time had come. I was still healthy and necessary to my family. I was always able to take care of anything Man or God threw at me, but this invisible monster was attacking me from my insides. I couldn't see it or feel it, and I couldn't stop it.

So I cried, like when I was little and had to go to bed before the sun set. Or like when I had to stay at the dinner table until I had eaten all my broccoli. The rest of the night, buckets full of anger and helplessness spilled out of me. By dawn, I was finally empty enough to agree to let Juanita call the number in the pamphlet.

The low vision exam wasn't what I expected. The best part was, everybody treated me with respect. They didn't hand me a cane right off, pat me on the head, and tell me to buck up. They told me they would work with me to build solid skills and they even taught me some neat tricks for making my life almost normal before we even finished the tests. They really listened to me and made me feel like what I had to say was important, and that gave me some control. When a guy is used to being in charge of his own life, that's a pretty smart approach. I gave them a lot of credit for that.

Doc had said they couldn't make glasses that could give me back the vision I lost. Even though I understood in my head what he told me, I just didn't want to believe it in my gut. Believing him would have meant there was nothing anyone could do for me, and I'm not the kind of guy who lets a door slam in his face like that. I hoped he was wrong and that my new low vision doctor could just give me stronger glasses and make everything all right again so I could read and drive.

Well, the low vision doctor said glasses had done all they could for my eyes, but it wasn't the end of the dance by a long shot. I was close to saying something real clever like, "I'm an old dog who doesn't want to learn any new tricks," but he was talking real emphatic like Juanita does when she knows she's right. So I did the

two things that have kept me happily married for 53 years. I shut up and listened.

The doctor took time with me and asked me what I wanted to be able to see to do. There are a *lot* of things I want to do again, but he said it was important for me to concentrate on one goal first. I decided it should be reading.

He eventually figured out that the best magnifier for me was one I held in my hand like I remembered Mama using. I didn't like the idea, but had to admit I could actually see words in the Field and Stream I brought with me. Still, it was hard, and I wasn't sure I would have the patience to work so hard to see. The doctor said that was where therapy came in. The occupational therapist (OT) would work with me to learn to use the magnifier, and in no time I would be using it to see all kinds of things. That sounded good to me.

If anyone was to ask me ten years ago what my favorite pastime was, reading would have been way down on the list. Sure, I'd look through my magazine and skim through the Sunday sports section, but I never was the type to read a whole book cover to cover. I was what I called a reasonable reader. If I had a good reason, I'd read. But the funny thing was, when my eyes went bad, reading was one of the things I missed the most. See, I never realized how important reading was to me until I couldn't read through the Sunday sports section. And reading medicine bottle labels was impossible! What would I have done if Juanita wasn't there to help me? I was like a little kid again, asking Mom to read me a story. Only now it wasn't fun. It was downright humiliating.

I didn't believe my occupational therapist that I could see better by looking sideways to see words, but I eventually understood how that might work. And when the doc said I needed to read with a magnifier, I thought I'd be walking around like Sherlock Holmes with one of those giant magnifying glasses, but the magnifier I learned to use wasn't so bad. When I used it at the lodge the other day to read the events calendar, Charlie wanted to know where I got it so he could get one!

"Bigger, brighter, and bolder," was what the therapist said I needed in all things, and that's my motto these days. I'm even

thinking of getting Juanita a bright yellow dress so I can find her in a crowd. Of course, I'll never be back to where I was, and I know I might have to find other ways, like talking books, to read for recreation. But at least I can do it myself, and that's pretty darned important. I was getting pretty good at my reading skills, but there were still some things I couldn't do with the magnifier that the low vision doctor prescribed.

The occupational therapist said I should try one of those electronic magnifiers and some modifications to my computer. But what if I spend a million dollars on fixing up my computer, then hit a wrong button and blow the dangd thing up? And how would I look with my nose plastered to a giant screen reading one letter at a time like a kindergartner? All that stuff was probably more than I would ever need, which was good, because I couldn't afford it anyway. And how would I even start to look for such things or know which was best for me? It was all real overwhelming.

So I got my electronic magnifier after all, and now I can do the crossword puzzles again and even design woodworking projects. Plus, we figured out how I could start banking on line and sometimes do a little shopping. That eased the tension between Juanita and me and made my little *senorita* much happier. And I got back into the fantasy football league, which allowed me to do things with my always busy son, Kevin. Best of all, I got to spend time with Michael, as we practiced with the computer. One day, he called me a computer geek, and I took that as a compliment.

My OT said if I had to get macular degeneration, I picked a good time to do it. The technology had never been greater for helping me see better and live a better life. With all that going for me, and with my low vision rehab team behind me, I started feeling a lot more positive.

I used to be the captain of my own ship. But as time went on, I found myself letting Juanita take over the helm. In the beginning, I didn't like the idea of her helping me, but I gradually started depending on her to do the simplest things, like laying out my clothes to wear each day. It was easier that way, because I didn't have to take the responsibility for my personal success or failure.

But at the same time, I felt like a little boy, not a husband, and certainly not a grown man and grandfather.

The worst part was letting Juanita pay the bills. After all, I was the breadwinner. She had never done it before, and it made her anxious and nervous. I worried that she would make a mistake, so I made her read every single thing to me and check all her figures twice. That only made it worse. The day she threw the checkbook in the trash and locked herself in the bathroom for an hour made me realize that something had to change.

I had to quit making excuses for not taking care of myself and my family. I had to go back to doing what I enjoyed, even though I needed to keep finding other ways to tie flies, read, and work with wood. And I needed to let Michael visit more often, even though he might have to help me more than before.

So I started taking more responsibility. I quit waiting for life to happen and started *making* it happen. That's when I quit being afraid. See, when I didn't have control, I was scared to try. I wouldn't pay the bills. I wouldn't get out my tools and work on a project. I wouldn't even try the new recipe for Papa's tamales. But when I started taking control again, I began to feel like my old self. Life with low vision still wasn't easy, but it was possible. I was back on track. We went back to having family tamale dinners again, too. The healthy kind. I knew Papa wouldn't mind. I was still the principal *cocinero*, and that felt good.

If there's anything good about macular degeneration, it's that it won't make a person totally blind. Even after my central field was gone, I could still see to get around. I counted on my memory and a lot of guessing to make up the difference for my lost detail vision, but sometimes that wasn't good enough. For instance, I never had a problem if my favorite footstool stayed in the same place. But one day, a yet-to-be-identified grandkid moved it a few feet to the left, and grandpa did a Dick Van Dyke right over it onto the floor. Nothing was hurt except my ego, but everyone made darned sure after that to keep things pretty much glued into place.

I had some problems outdoors, too, like walking to my mailbox. That's a couple of hundred feet from the house and across the main

road, so it was always a good way to get some exercise. But you would be surprised how many things can trip a guy up when he can't see well. It could be just a dip in the yard, or a mole hill, or a snow drift. Yep, I found every one of those things the hard way.

Things were even worse out in the real world. My last trip to town was to the foodmart. I swear, I couldn't see a thing in that place. I mean, the lights were on, and I could see like always, but I got real disoriented. Nothing looked familiar, and I couldn't make sense of what I was looking at. I got so confused, Juanita told me to sit outside on the bench while she bought the groceries.

As for my social life, I tried staying with the lodge, because I was past-president and everything, but that didn't work out either. The guys meant well, but they treated me like an invalid. They didn't understand how I could find chairs and doorways just fine, so someone was always grabbing my arm or pushing me around. If I told them I'd be better off on my own, they would laugh and say something like, "I thought you were blind. Have you been putting us on, old buddy?"

Eventually, I started skipping meetings, which I guess didn't matter, because no one ever called to ask about me. It wasn't long before I just quit going altogether. If I was going to see worse in unfamiliar territory, and if putting myself in those kinds of situations stressed me out, I would just stay in the house. Juanita didn't mind getting the mail, and the world was obviously doing fine without me, so I thought that was a reasonable solution.

When I gave up going to the lodge and into town with Juanita and started staying in more, the rehab team acted like I wanted to give up breathing! The doctor wrote a referral for a certified orientation and mobility specialist (COMS) to teach me some skills better suited to public places. My OT worked with Juanita and me to make the house, yard, and even my pole barn a safer place to be.

As for the real world, my team said I was opening myself up to depression by isolating myself. They kept reminding me our brains are made of plastic, or something like that, so I'd get used to new places in time. Then I learned how a white cane might come in handy in public, and the COMS gave me a little training in how to

use one. I appreciated that I didn't have to use it all the time, and I could unfold it for times when I needed it for safety or identification, and that made a lot of sense. I even wondered if I could afford one of those GPS phones.

I called Harry, the lodge president, to let him know I was still alive. He said he hadn't called me, because he heard I was getting ready to live with my daughter in California. Now where did that come from? Anyway, he said, because I was staying in town, it would be great to see me at lodge activities again. He asked if I'd like to give a speech about living with visual impairment. I wasn't so sure I could do that, but my OT said it would be a good opportunity to teach others about low vision. I never thought I could be a teacher, but you never know what life's going to throw your way. I told Harry I'd give it a shot, and Juanita started calling me "Professor." I might get tired of hearing that someday. Not real soon, though.

I wondered how I was going to get to the lodge meetings, though. Used to be, I would just climb into my truck and go, but now things are different, and that frustrated me. The worst thing about not driving wasn't the not-driving part. It was knowing I couldn't. I used to go a whole day sometimes without thinking about driving, but when they stopped letting me, not an hour went by that I didn't think I needed to go somewhere. I missed everything my truck stood for. It was my independence. It was part of everything I did, and I couldn't imagine how I was going to maintain a normal life without it. I could substitute carrots for cookies and tapes for books, but driving into town whenever I wanted, hauling wood from the lumber yard, and picking up Michael for an afternoon of fishing, those things were my life. Now they were gone, and I was going to have to do without them. How was I supposed to do that? How was I supposed to just turn into someone else?

My neighbor came over one day to show me something he found on the Internet about something called bioptic glasses that might help me drive again. I asked my OT about them at my next appointment. She explained how they worked and let me try on a pair. It wasn't what I expected. It was hard to find the telescope part, and they made me dizzy. She told me that, if there had been a chance I could use something like that, the doc would have evaluated me, and they would have taught me how to use them. It

was time to move on. I was through with driving, but the OT said she would help me work around that like I was learning to work around everything else.

When I was a boy, I was afraid of a giant gorilla I knew for sure was lurking in my bedroom closet. Then, when I got older, I guess it decided to go somewhere else for a while to scare other little kids. But sixty-five years later, when I started losing my sight, the danged thing came back, big and mean as ever. And that's when my rehab team came marching over the hill to help me face it. Well, guess what. That big mean gorilla turned out to be nothing more than a skinny little monkey.

When my eyes started going bad on me, I didn't want to admit it, but I was scared. Scared of the changes my low vision was making in my life, scared of changes in my relationships with my family and friends, and scared of changes in my health and lifestyle brought on by my vision loss. I was also angry. Angry at the changes I had to make in the way I was living, angry at burdening others with things I had always done for myself, angry at the struggle and extra time and effort it took to keep doing the things I had enjoyed for so many years like reading, fly fishing, and working with wood.

My low vision rehabilitation team helped me break through my tangled feelings and see that I could still do many of the things I loved to do. They also helped me understand I was still in charge of my life. I could decide to learn new ways of doing things. I could decide which low vision aids and techniques worked for me. I could decide to let my family show their love by helping me do things I could no longer see well enough to do, like driving my truck. I could choose to learn new tricks like using different types of magnifiers and using a computer with screen magnification software to pay bills, play fantasy football with Michael, and shop online. I even joined an online support group.

It is so easy to give up and let others do everything for you when something like this happens. I was scared to leave my rehabilitation team, because they helped me make so much progress. They helped me see what I was doing to my family and to myself without even realizing it. They provided me with tools to help me use my remaining vision, and they showed me new ways of doing the things

I love, like tying my flies, making Papa's tamales, and working in my woodshop.

I quit driving, but there is usually someone to take places when I need it. With my desktop electronic magnifier I can still read Field and Stream. I can still work with wood by using good lighting and magnification. I can still do my crossword puzzles, and I can listen to detective novels on tape.

I eventually started laughing again, too. Oh, I still get depressed once in awhile, because losing vision is no stroll through the park, but I gradually stopped being so sad and scared. Part of the reason for the change was that I was getting used to seeing in different ways. I felt like other parts of my brain were beginning to pick up where my vision left off. Most of the reason, though, was that low vision rehabilitation opened doors. I could choose to go through them or stay in a dead end hallway. Knowing I had those options gave me hope, and I gained more confidence with every new accomplishment.

Losing part of my sight was like falling into a deep hole. It was dark, and the sides were steep. But before I gave up, my low vision rehabilitation team threw me a rope and told me to climb. Sometimes I slid back, sometimes I had to stop and rest, and sometimes I felt like I wouldn't be able to make it at all. But the team never stopped encouraging me to hang on and keep trying. With each pull up the rope, I felt myself getting stronger, and that strength helped me get through the inevitable relapses.

Juanita and the kids also helped a lot by reminding me how important I was to them. Maria even flew home from California to see me on Father's Day, and Kevin started bringing the grandkids over more often. Of course, Anna was a rock to both Juanita and me through the whole thing. My family was my biggest motivation for climbing out of that hole, and I don't expect I'll ever end up back in it.

An Email From Michael

Hi Grandpa,

I can't believe you actually e-mailed me! So you're a computer geek now? Or maybe a computer geezer (ha ha). Seriously, I'm really proud of how well you're doing. I know it was rough for awhile, and you didn't think you could do it, but look at you! Mom says you get around great, and no one even knows you have "crooked eyes" unless you tell them.

I still drive your truck all the time, but I'm being really careful. Like you said, you might want it back someday if the CURE comes, so I better not put any dings in it. I take it to college every day, where I would never have gotten to go if it weren't for that truck, not to mention the money you saved for me. Someday, when I'm a rich doctor, I'll pay you back, I promise.

It's cool that you still go fishing and even still tie your own flies. And you walk to the mailbox every day, even when it snows. And you can read your own mail, too. Maybe not like you used to, but close. Sounds to me like nothing has changed, which really surprises me. I mean surprises me in a good way—not like I didn't expect it, but like WOW. You know what I mean.

Anyway, I know it sounds corny, but you doing so great makes me believe anything is possible. Like if what happened to you ever happens to me, I know I'll be okay, because you're okay. And if you can do it, so can I, being your grandson and everything. And I promise I'll take care of my eyes and eat like you said, and not smoke anymore (sniff), because I know being your grandson maybe

doesn't mean that all I'm going to inherit is your good looks. Ha.

I'll be home next weekend, Grandpa, and we'll go for a ride and watch some football or something. You can keep e-mailing me if you want, because I like hearing from you, but someday you gotta learn how to text.

Maybe I'll show you how when I get home. Can you do that, or do you have some kind of high-tech software I never heard of that does it for you? I never know what to believe anymore when it comes to you!

Well, I have some studying to do now, so I better get to work. I just want you to know how much I appreciate you for showing me the kind of courage it takes to deal with whatever life throws my way. I just hope I can be the same kind of role model for my future grand kids.

Take care of yourself, Grandpa, and I'll see you soon.

Love,

Michael