

HOPE'S CAFÉ

Written and Performed by
Webster County, West Virginia
Cancer Survivors and Their Families

The Webster County Cancer Education Project is a grass-roots coalition partner of the Appalachian Community Cancer Network. Located in Webster County, West Virginia, the Webster County Cancer Education Project addresses access-related health disparity by increasing cancer education and screening in its small, rural county.

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We open to Carol/ waitress clearing off the table, and one of the plates has a half-finished hot dog on it. Mike and Phyllis walk in to take a seat and Anita hands him a menu. He looks over it as the other two converse. She shakes her head, makes a tsk-tsk sound, and begins her conversation with Anita/cashier:

Carol: You know I wish we grilled these buns like they do in Craigsville, I'd never get enough of 'em. Even when I was having chemo Ray couldn't drive by that restaurant without me crying and him trying to make me happy by getting me some of those hot dogs. My head was hurting, my hair was falling out, my emotions were all over the place, but I couldn't pass up those hot dogs.

Ann and Deb enter the restaurant during this conversation. Carol hands them menus with "Hope's Café" on the cover. Mike and Phyllis gesture for them to join them and sit down.

Mike: So you traveled 3 hours to Parkersburg and 3 hours back and waited until Craigsville to get something to eat?

Carol: Yeah. Those trips were something else. I can remember every trip to the surgeon, the oncologist, and chemo treatment. At least there was always something happening that kept me going. Funny little things we'd seen or heard, and we would just try to find the humor in it. *(Carol adds funny story here.)*

Deb: I have a friend that went to the Mayo Clinic in Minnesota for his prostate cancer surgery, and he was going to need radiation treatments every day for 6 weeks. So instead of traveling an hour and a half down and an hour and a half back each day, he rented a place down in Lewisburg very close to the treatment center. He has had to do this 3 different times. In reality, it was to save his strength for the real battle, but I think he enjoyed meeting a lot of new people. He can find people to talk to anytime, anyplace, and has always kept his sense of humor.

Phyllis: Sometimes it's difficult to find the humor in this stuff. You know, a friend of mine had to go all the way to Charlottesville, Virginia, which was four or five hours, because they didn't have a specialist for her kind of cancer here. They gave her very, very strong treatments that did extend her life three years. She passed away in 1999 three years after her diagnosis. She was only 27 years old and left behind four little kids.

Carol: Our special for tonight at Hope's Café is beans and cornbread or baked steak. Now which one do you want?

Phyllis: Can you give us a couple of minutes to think about it? How about bringing a few drinks while we think.

Vicky: When my father-in-law was diagnosed with prostate cancer about seven or eight years ago it was really hard because we had to travel to Elkins every week for treatments. You think it's real simple since we're a large family, but that's a difficult hour and a half when you have to go over Point Mountain. And it's a whole different story when it's snowing and about twenty degrees. It seemed like that winter was the worst winter. So you have to have a four wheel drive and you know you're going to have to do this, and know you're going to be gone about five or six hours. So I realized it wasn't just the cancer slapping you in the face, it was the weather and the driving too.

Deb: When my mother-in-law was diagnosed the first time with cancer, she had to go every day for 6 weeks to Lewisburg for radiation. My brother-in-law was starting a new job, and my husband was in Charleston for the legislative session so that meant that neither of her sons could get off to take her. I was able to take her every day over Christmas holidays, leaving at seven A.M. and not getting back until four or five. After the holidays we were fortunate that my niece's husband had had foot surgery and was off for a month so he was able to take her. The second time she was diagnosed we weren't so lucky. She found a few friends who donated their time, but she still had to pay for the gas and their food. That kind of money adds up and adds to the stress. It wasn't the actual radiation that was the hardest, but the trips and the stress.

Carol walks in and serves water all around.

Carol: Have you all made up your mind?

Deb: Beans and cornbread, please.

Ann: Baked steak, please.

Mike: Baked steak sounds good to me, thank you.

Phyllis: After hearing about those hot dogs, I want one of them. Make sure you grill that bun, though.

Carol: I knew one of you would give me a hard time. If you want special buns you're going to have to travel to Craigsville.

Ann: You were talking about trips to different places for the radiation treatments. That reminds me of the hour and a half trips we made to Buckhannon. That's not a very long trip, but we had to go the long way around to avoid the winding roads. Dennis couldn't handle those roads over Hodam and up through Hacker Valley. But those trips really turned out to be a good thing.

Mike: How could these long and difficult trips be considered a good thing?

Ann: Well, Dennis is in remission now. We thank God for that every single day. And everybody there became just like a family. That plays a part in how you feel - what you experience being around people at St. Josephs where he went for treatment. We got to know all those people he took treatment with week in and week out. The thing we noticed in the 8 months he took chemo, the people that came in there, their attitudes, watching who had problems - the little ladies how strong they were - not only them, but everyone. We became a family.

Mike: Wow. I hadn't thought of it that way.

Ann: Each Thursday when we went, we looked forward to meeting those people, and seeing how they were doing. Our oncology nurse was great - when we first came in she sat us down to tell us in generalities what we would be going through and what to expect. It sure made Dennis and I awfully humble going through all this. I will be honest, I know it was bad, but we got through this thing step-by-step and with a lot of talking to God. Of course, joking around helped too. You have to find the humor where you can.

Vicky: When my friend Peggy had to go through radiation she was able to work every morning and then travel to Charleston every afternoon for radiation treatments. She always thought that by working and keeping her mind busy it was better for her. She said that she made the best of it. If she HAD to go to Charleston everyday then you better believe she was going to go out to eat and go shopping and enjoy herself.

Mike: You know, since I haven't had a family member to go through this kind of thing, I never even thought of how difficult the traveling is, or how often anyone had to go on these trips. You just hear, "Hey, did you know so and so has cancer and has to take chemo?" I grew up outside of Weston and you just had to travel the interstate to get someplace. Now that I have been living here almost 20 years I understand how far away we are from treatment centers.

Vicky: Several years ago my friend and her sister bought a small restaurant. Her husband had cancer, and having a new business was keeping her pretty busy. She knew at the time she had some health problems but just thought it was stomach problems from the stress. Six months after buying the business her "stomach problems" were diagnosed as small cell lung cancer. Her life was turned upside down. Her sister had to more or less take her to every treatment and spend weekends away from home. She had to have someone stay with her husband because he needed constant care. Their workers were very good and very helpful. They kept things going. It wasn't easy because at the time all they would give her was six to eight weeks to live.

Anita and Brenda come in and join in on the conversation.

Mike: How did things work out for her?

Vicky: Well, she has been in remission for several years. She tells everyone that it's just God's doing. They literally had to almost kill her to help her but like she says, "I'm here. That's God's will." It was a terrible, terrible struggle and still is today because she has had to resume treatments. It's the same war, but a different battle. She thanks God each and every day He lets her have.

Anita: I hear you on that thanking God. My friend Brenda here does that all of the time, don't you, Brenda?

Brenda shares how she thanks God.

Deb: You know, I also thank God for modern medicine and the medical personnel with whom He has given the knowledge to deal with cancer. If you think about our rural location, with us being so far away from treatment centers, we need to be extremely grateful to our local hospital and their ability to diagnose. Debby Cutlip found my mother-in-law's lump during a routine examination. Her surgeon and oncologists all said that Debby shouldn't have found it, because it was in a difficult place. She made me promise to always go for my annual exams.

Ann: And how hard did I have to work to get your colonoscopy? How many reminders? How many pamphlets did I have to put in your mailbox?

Deb: Well, I was scared of getting one, but thankfully it turned out fine and wasn't that bad of an experience. Now, we're working on Anita.

Anita: It's just a transportation issue.

All: Excuses, Excuses, Excuses!

Brenda: Hey, if it's a transportation issue, I could take you.

Laughter.....

Phyllis: A couple of years ago one of my friends had a kidney stone. She was having a lot of pain, and it wouldn't go way. She went to the hospital over here at Webster, and the doctor did some tests. He saw a lot of stuff that shouldn't have been there so he sent her to a gynecologist who found out she had very advanced ovarian cancer- stage 3C.

Mike: So was she like everyone else and had to travel a long distance for her treatments?

Phyllis: Really far! At that time in West Virginia there was a malpractice problem so there wasn't an gynecologist in West Virginia who also dealt with oncology. She had to make a 5 hour trip to Kentucky for an appointment the next day. The doctor did an exam and told her they were doing surgery in two hours. She was kind of numb, everything was just crashing in all at

once. She really couldn't take it all in, and they did the surgery and went through some real intense chemo that damaged her heart. There are other things that you have to fight, not just the cancer.

Mike: She really went through it, didn't she? Her head must have been spinning for her to have everything happen so quickly.

Carol brings over the food. She passes out the food and emphasizes who got the hot dog.

Mike: Ann, what about Dennis? Was his diagnosis a surprise, or had you been expecting it?

Ann: In the spring of 2005 Dennis was having a lot of stomach pains and back pains and losing weight. He would sweat so profusely, our bed would be soaked. I had to change it every day. Of course, I never thought of the word cancer.

Carol: It sounds like menopause to me.

Phyllis: Do men go through menopause?

All turn and look at Mike.

Mike: MENTAL pause maybe.

Deb: Didn't he have other symptoms too?

Ann: He was having lower stomach pain and I thought maybe it was appendicitis. I was just thinking of things I knew about and never even thought of cancer. But he wasn't getting any better and losing terrible weight. He was getting so weak he could hardly get to work and back.

Phyllis: What did you do?

Ann: So we went up to the hospital and Debby did a cat scan. She came back and she was pretty serious, and she said why don't you two go home and get lunch and we'll have the results back. When we got back to the hospital ... I remember it so clearly ... they escorted us right into a room. We didn't even go to the waiting room. And of course dummy me, and dummy Dennis ... we just thought she was going to say you just need to have your appendix out.

Mike: Well I guess that's not the news you got was it?

Ann: No, when Debby came in she just had this look and she started crying and telling us that the CT scan had showed that he was full of cancer. It was in his lungs and in his liver, but she didn't know the main source of it, but there had to be a main source - you know - where it was

coming from. So that was a very dark Friday. We had to wait all weekend to talk to the surgeon. We just couldn't even talk. It's still hard to talk about, even now.

Deb: I remember seeing you come home. I walked over to see about the doctor visit.

Ann: I just started sobbing and telling her what Debby had said. We just knew we had to go see a surgeon, Dr Pearson, in Buckhannon. He got us in for 9:00 am; the first appointment Monday morning. So we made it through the weekend which was hard. I went to talk to his Mom and Dad. Dennis couldn't go; he was just too emotional. But I went to talk to his Mom and Dad on that Saturday morning. At the same time his Mom told me she had just been to the doctor and had been given three to six months to live with cancer, but she didn't want Dennis to know. But I don't keep things from Dennis, and he doesn't keep things from me. I didn't tell him right then, I waited until a few days after his surgery.

Mike: I guess you have to be honest with each other.

Deb: I just want people to be aware that it's a hardship for the whole family and even the extended family. Some people might think that it's just that person going through the cancer, but it's not. Sometimes it's your best friend. I mean, I can relate to that. What happened with Dennis really affected our whole neighborhood. I tell you it could have broken your heart to hear the prayers that his Godchildren prayed every night. I am sure it's like that in every case where kids are involved.

Jean Tenney comes up on stage and is waved over.

Deb: My experience came from a different point of view. When I was a sophomore in high school my dad and I would arrive home about the same time, him from work and me from sports. One night I walked in the front door and Mom and Dad were in the hallway talking quietly. The next thing I knew Dad was grabbing Mom and hugging her.

Ann: Did you suspect something then?

Deb: Yes, I thought something strange was going on, but they didn't say anything. They talked around the three of us left at home. We didn't really know what was going on. My oldest sister showed up, which was strange since she was a nurse recently moved over to Philly. They stayed in the dining room and didn't invite us younger ones into the conversation. I don't think they really said much to my other two sisters who were away at college. The next thing I know Mom's in the hospital for over a week, but they never really told us what was going on.

Mike: Do you think it would have been better if they had just told you the truth?

Deb: Looking back, I'm not sure I could have handled it, but maybe it would have been better. It seemed like Mom was in the hospital for the longest time. She was cut from here to here, in those days it was a radical mastectomy. I remember her having radiation, but they never really filled us in. That was over 30 years ago, and cancer was and still is such a scary word. The good thing is that they didn't find any more cancer for over 20 years.

Jean: My story is a little similar to your story except the person in my life who had cancer was my Dad, when I was 17. My senior year in high school, mid-year my Dad got very ill. They thought it was flu. He would lie on our sofa and he would have terrible migraines and he just couldn't get over it.

Anita: What was that like for you?

Jean: That just wasn't my dad; he always seemed healthy to me. I found out later he wasn't as healthy as I had believed, that my Mom had been shielding a lot of things from me. My Dad had actually had cancer a few years before at that point. But those were the days when cancer was the "C" word. My dad was an individual that if he heard someone had cancer, that was a death sentence.

Ann: Yeah, like Deb just said, it's still a scary word.

Jean: Your mind has a lot to with your cancer, with how well you recuperate.

Carol: Ain't that the truth.

Jean: They hid it from dad and me the first time, but they couldn't hide it the second time. I was so traumatized when I finally realized that dad didn't have the flu but he had brain cancer. It was a six hour surgery. We all waited in the family room. When the doctor came out and said we took out as much as we could I knew it was a death sentence for my dad. It was the longest day of my life.

Ann: I can relate to that. I remember what it's like to be in the waiting room.

Jean: He was in ICU for a month. He didn't know what world he was in. Then all of a sudden he got better, he was my dad again. He was still in the hospital doing fine, and they were getting ready to release him. We walked in one day and there he was paralyzed, the tumor had come back again and gone to his nerves. My Dad never spoke again, and couldn't move any part of his body.

Mike: I can't imagine what that must have been like.

Jean: He lay like that for a month. Mom was making arrangements to put him in a nursing home because by that time the insurance ran out. But he died in the hospital on the 4th of July. That's kind of ironic since the 4th of July was his favorite holiday.

Phyllis: How are you now, on the 4th of July?

Jean: Not good. It's a hard day for me. My dad was 42. He was a young man, and I had to suddenly grow up. My little teenage years were gone.

Phyllis: What do you mean by that?

Jean: I had to grow up fast. I had plans for college that were changed because we didn't have the money for me to go where I was going to go. Everything changed for me.

Mike: So that's another thing. Cancer can change things and not just the person with cancer.

Carol: Anyone here want a refill?

Phyllis: I'd love a good cup of coffee.

Carol: Sure, just for you I have to go and make a pot of coffee. Always the trouble maker, aren't you?

Mike: So did your father's cancer affect you in any other way?

Jean: I had this crazy thought that I was going to die before I was 21. I thought I would have cancer, that I was going to get it, that I wouldn't live past that. The biggest shock was I did. I made it past 21. But I really didn't think I would, but that was part of the whole experience of living with someone who had cancer.

Anita: Brenda, did you have many fears?

Brenda shares her story about fear here.

Mike: Do you think that fear of cancer or the "C" word is still there?

Vicky: I think that there are all kinds of fears.

Jean: Exactly ... my biggest fear was that I wouldn't make it past 21.

Ann: My biggest fear was that I was going to lose Dennis, who was and is my best friend and soul mate, and that I was going to be a widow much too soon. Now my fears are never gone. They are the worst right before his CT scans and colonoscopies, but it's a never ending daily worry that the cancer can come back at any time.

Deb: Yeah, I remember you had a scare not too long ago.

Ann: That was tough. About a year ago Dennis found a lump in his neck. The doctor ordered an immediate scan. We were then sent the next day to an ENT who fortunately found that it was just an enlarged lymph node from a lot of dental work Dennis had been having at that time. Wow, anything with him scares us!

Jean leaves the café after saying goodbyes.

Sharon Weese and Diane Forbes come into the café. Carol goes over and gives them a great big hug.

Carol: Hey, everyone, look who is here. This is Sharon. She's the one who used to come up and trim my hair when it was falling out from the chemo. Course it didn't take much trimming as fast as it came out. Diane, how have you been doing?

Diane: I'm blessed, thank you. How is everybody? Brenda, I haven't seen you for a while. Have you felt well enough for any singing lately?

Brenda: ad lib

Mike: Brenda, I understand that you were the first in your family to have any kind of cancer. I always thought that cancer ran in families and people were "safe" if no one else had cancer.

Brenda: ad libs about what the doctors told her

Diane: Well, I'm kind of like Brenda. I was the first in my family to experience cancer. I had been having kidney stones and kidney stones and kidney stones and was being treated for them. I was drinking 64 ounces of water a day which is a tremendous amount of water when you weigh between 80 or 90 pounds. Finally I said, "I don't think this is helping, I want to go see someone else." So I went to a doctor in Lewisburg. Right away he said we needed to check a couple things, but between the weight loss and your symptoms, I think you may have cancer. And that day he did a quick little test and he said it looks like cancer. He confirmed I had bladder cancer. I got the diagnosis the day before my birthday.

Deb: That must have been hard.

Diane: Yeah. One of my daughters had gone with me to Lewisburg and the other, at the time, was living there. So we went out to eat after I went to the doctor, and everything seemed just fine. Kelly and I were about halfway home and I said, "I don't feel the shock yet," and she said, "I don't either." I said, "Well, maybe that means it's going to be okay." And she said, "Alright." And it was. It was ok. I had my bladder removed - I have the little sidekick now. We talked about the day I would have my surgery and the day Mom would get her new pee shooter.

Mike: Did you have to have any follow-ups after the surgery?

Diane: It's not been too bad. They took out 23 lymph nodes when they removed my bladder, and only two were yucky, so he prescribed that I go to Mary Babb Randolph in Morgantown. I don't think there is a better place. I know each of us has to have faith in our own physician, oncologist and clinic. I am so grateful that I got hooked up with Mary Babb Randolph Cancer Center. I had the finest oncologist in the world, who is Dr. Hogan. He doesn't take any bullhockey from me, but he don't dish out a lot of it either. My cancer has not been the worst thing I have been through in my life. You know I have been very lucky in that I haven't had radiation and my chemo treatments did not make me sick. Dr. Hogan saw to that; they gave me plenty of anti- nausea meds for which I was very grateful 'cause I hate to throw up. The fatigue was the hardest thing for me to deal with. I like to be busy all the time. I'm into things and sometimes it is things I shouldn't be into.

Sharon: *(aside)* You got that right girl.

Diane: Dealing with the fatigue was hard. I am now 60 years old. I've had a few months of chemo as a preventive. Hopefully, it was just a kick butt for whatever might still be in there. A couple of weeks ago I went back for my first pet scan after my chemo, and they did a brain scan this time which was kind of scary.

I kind of lucked out the first time. But from the looks of things I think my only problem with my bladder cancer is that it took my brain. It just leaks everything right out my little pour spout here. I can't remember things and I say the wrong things and I tell my kids to listen to what I mean not what I say. Karen Bell gave me very good advice when I told her I had a cancer diagnosis and I had to have chemotherapy. She said "You can do this, Diane," and she said this with such confidence I didn't dare disappoint her. So you can do this, Brenda.

Mike: Diane, you mentioned that you were lucky that you "hooked up" with Mary Babb Randolph Cancer Center in Morgantown. Do you think it's important for people to be their own advocate?

Diane: Oh, my gosh, it is so-o-o important. Karen had not been pleased with her first doctor. They wouldn't sit with her and answer her questions. So she decided that she had to go somewhere else. She told me that you have to be your own advocate since nobody else is going to do it for you.

Ann: I'll tell you, from the first appointment with Dr. Pearson back on June 13, 2005, I've kept a logbook of every single medical happening: surgeries, hospital stays, questions and answers to and from the doctors, what's happened at every appointment. I've had the same log book for three years now.

Carol: Is there anything else anyone wants?

Mike: No thank you. Just bring our check, please.

Carol: Don't forget my tip.

Diane: Here's a tip - don't forget your check-up!

Mike: Well, I'm looking at all of you and listening to all of your stories, and I am just amazed at the strength that you have. That's somewhere deep inside of you; it keeps you going. I'm looking at it from a different perspective. As far as I know I don't have cancer, but it just amazes me and makes me realize just where people get their strength. It's a blessing to be here and hear this but it's been a greater blessing even to be with these people that I care for and see how far they have come in their struggles.

Carol: We need to have a positive attitude. There are so many people that we can look at and believe in miracles. My strength comes from the Lord.

Ann: Yeah, Doctors Brager and Pearson always call Dennis their miracle patient. Our favorite word is HOPE. If you ever get a chance to go to a Relay for Life ... go ... it's held from dusk to dawn. I asked my friend Bruce, the Braxton County Relay for Life leader, what the significance was of dusk to dawn. He says that when a person finds out he or she has cancer, it's the darkest moment of his or her life. The dawn represents light, that HOPE you have to cling to.

Deb: You know if I just think about my neighbors who live in Hotel Bottom: Joe, who has lived over 20 years with colon cancer that had spread to his liver; John going strong 12 years after his prostate cancer diagnosis; Elaine, with lung cancer for 8 years; and Donnis, 21 years since her colon cancer surgery.

Carol: We would like to now honor all those among us who are survivors and ask you to stand up please.

Audience members stand up and say something about their cancer if they wish.

After the last honor Mark sings a song he wrote.

The End