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### Oral History Interview: Karen Porter

Karen Porter

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Karen Porter  
(Signature - Interviewee)  
Branchland, W.Va  
Address

Porter, Karen

Date 7/25/89, 8/18/89  
8/25/89

Wanda R. Ramirez  
(Signature - Witness)

WEST VIRGINIA APPALACHIAN CAREGIVERS

WVACG. 2

AN INTERVIEW WITH: Karen Porter

CONDUCTED BY: Diana Parnicza

DATES OF INTERVIEW: 7/89

7-25-89

8-18-89

8-25-89

TRANSCRIPTIONIST/TYPIST: Gina Kehali Kates

DP: I'm Diana Parnicza and I'm continuing my interviews of Appalachian Caregivers. This is July the 25th, 1989 and I'm conducting Interview A with Caregiver #2. But it will make sense to know...and

CG: ...he will always will start out with...when he starts talking to you and starts making a statement, his statement is a legitimate statement, a statement that would fit in but then it trails off and you get into a completely different subject matter, so as far as if you were to try to talk with him and ask him questions, you know, daddy wouldn't be able to respond to you.

DP: And you just...you wonder sometimes what all he understands or do you think you pretty much understand?

CG: I think he understands more than doctors give him credit for and for example, he most always has known my husband; he's always...he has almost always known me and he sometimes doesn't know my mother but he often does know my mother. So, he is to the point now, that he knows somebody's around and if you smile at him, he smiles at you. If there's a smile walks in his room, and my philosophy is you don't walk in unless there's a smile plastered on your face, I don't care how miserable you are, because that's what you get back. And uh, .....he knows....he knows when you enter the room or whatever, but as far as him saying, "oh, there comes K. or there comes E.", or whoever, I don't know in his mind what he is knows. He calls me S., cause that's what I grew up him calling me. (mmmh) But he's also called me O., which is my mother's name, so.

DP: Does he get any....is he on any medication?

CG: No.

DP: So he get's no shots or anything?

CG: Un-huh. He is tube fed. (okay) He can't eat by mouth because he has Parkinson's.

DP: Okay, let me see. He needs...you need to turn him right? (turn him) and you do get him up in a chair? (get him up, we get him up, yeah) You need to dress him and give him a bath and everything, don't you?

CG: Change him

DP: Okay. And you give him...he has a ...a tube in his nose or a tube in his belly?

CG: In his stomach.

DP: Okay. Okay. What about his bowels? Are...he's incontinent. Okay. What about his bladder? Does he have a catheter? Or is he incontinent?

CG: He does not have a catheter. But he is incontinent. (okay) However, most every time I go to change him, he pees...as soon as I get his diaper off, he goes. It's funny. (unh) He will...he frequently wets his clothes, but sometimes I'll...I'll change him and I get him these diapers, you know, when you stick 'em, you can't restick 'em; the diapers. (yeah, yeah) But uh, I'll stick 'em and go to change him and he won't be wet, and I'll go, dog gone it dad, and so as soon as I get 'em off, he'll wet, you know, so. Sometimes I say he knows when he has his pants off.

DP: He doesn't have any dressings, does he? (Well, the one

around the tube). Does he have any sores on him or anywhere?

Okay. And you change that every day?

CG: Twice a day.

DP: Okay. And he doesn't require suctioning or have a trach?

CG: No, uhm, up until we had...up until the tube was put in his stomach, because he has Parkinson's disease and it has progressed to the point that when he swallow's, a portion of his food was going into his lungs. And he was ...he was keepin' pneumonia. And he was in and out of the hospital constantly, on medication constantly and three different times, the last three times he was in the hospital, each of those times his doctor....well, one doctor told us that he would not leave the hospital...that he would not make it this time. It was just too bad. And of course, the Lord knows these things, the doctors don't know anything, but anyway, uh, daddy has the will to live and he overcame it and so, they found ...they decided that because it was the food particles that was keeping him in pneumonia, that that was the only route we had to go. And it was a really hard decision make, cause my mother....she....she just said, you know, I can't make the decision, you know. But it had to come from her. I told her...you know, she was leaving it up to me and some of the other kids and I said, it'll have to come from you, mom, I can't....whatever you do, we'll just pray it's the right thing to do, so we finally got up the ne to have it done and it was....it...for him, it was the best thing we'd ever done, but I have said many times, through

the hard...I've had to do many hard things in my life, you know, everybody does. Two of the hardest things I've ever had to do and still is the hardest is ...is to accept the fact that my dad...a strong, virile man that I looked up to so much and had such great respect for, so independent, has come to the point that he has to be changed like a baby and I knew in my mind if he had any realization how it would break his heart. And the other one is to not be able to put food in his mouth. He loved to eat and it ...for us it was hard, and it's still hard to be able to feed him, but he has gained weight, he has gained strength, and so that, ....

DP: He doesn't get the pneumonia all the time.

CG: He hasn't had pneumonia. He hasn't had pneumonia since uh, March or April (when did they put the tube in?) ...but he was going in a week or so every month. That tube was put in then. And he was so bad that they couldn't put it in...he wasn't up to...didn't have the strength, so they wanted to put the tube in his nose first. And I said uh, daddy won't need that tube. So the doctors said we'll have to tie him down. I said, forget it. I will never tie him down; we tied him down the first time he went in the hospital. And uh, I said I'll never ever put him through that again. And he said, well, he's not strong enough, for us to do... I told him, I said, well, just pray harder and and we'll just hope for the best and so finally he...after about a week he got strong enough that they, put it in his stomach, ...and he's done just marvelous with it. The only thing is,

which is we're at the point that tube needs to be changed and they...think I can do it, and I don't know how to do it, even though they show me; I need somebody...if someone would...you know teach school and I teach little kids and I know that ...show me how to do it; don't just tell me, show me how to do it and I can do it. But don't just tell me. So I need somebody to show me how to do that so I can do it. If I can't get...see, I was hoping a nurse from where I thought you were coming, would come out here and show me, but one came and she said uh, a long time, she said, ain't no way. And that was her words. She said there ain't no way that I'd change it. It needs...he needs to be taken in to the hospital. So I...we took him in to Dr. G. because of that. Oh, there was a...it got very raw around it and I done everything they told me to do; I ....I treat him just as I, you know, he's just like my baby. You just watch over him like a little baby. I did everything I'm supposed to do but it got this little irritation and so we took him in an ambulance all the way to H., and Dr. G. said, this is ridiculous; there's nothing wrong, you're doing just fine. Keep up what you're doing. And we asked him about changing the tube, and he said, you can change it. It's no big deal, so we told him what the nurse had said, that there's no way that ...that I should change it. Or she wouldn't....you know what kind of nurse she was! [laughs] So...but...up...you know, the tube except for the fact that it is having difficulty draining, and I know the they told me the stomach acid eats up the balloon (uh-



huh, uh-huh) and I know that that's probably getting what's happened, but other than that, he's done real good.

DP: Was this a nurse from the health department or....

CG: This was a nurse from...from the (C. County Health Department) well, the one that comes from, like, through St. Mary's but it goes through Cabell, it's Mary something.

DP: M. C.?

CG: I don't know who it is. I've got her card in there. She said she would not ...I don't know whether...she ...that's who's card I've got, so it must be her.

DP: A lot of it depends on the tube. Now I've just been visiting ....

CG: This is a new tube ....new style., Dr. G. said.

DP: Okay, so does it have like one tube that goes in and one tube that goes this way, across it?

CG: It's one tube that looks like (foley catheters?) ...it's a catheter is what it is.

DP: So that's just a tube that's coming out? And that's all?

CG: And on the end of it is a little thing where you would put the water in.

DP: You know, I've changed those all the time.

CG: I've got everything. They gave me everything and they stood there and they told me how to do it. But listen...I'm not a professional and if something were not...if something were amiss...(you wouldn't know) I wouldn't know. I don't want to do anything that would cause any problems.

DP: Is...there are newer tubes even, cause I've...when I was

Home Health Nurse here before, there was a man from the VA that had a foley catheter in his belly, take it out and put another one in and then place it in water.

DP: But now like I've been visiting another patient out in uh, S. and they've got a tube that you know, the doctor said, no one can change it at all and she has to measure it to make sure it doesn't go in so much and it's marked and it's got another tube going up this way.

CG: Well, they told us, Dr. G. says when you take it out (mmm-hmm) find how far it was in the stomach (okay) and mark it on the other tube (okay). It's all you do, he said. (okay) And then put it back in and that's all there is to it. And then this other little thing you take lose and they gave me a syringe and they gave me a bottle of water for it and that's to fill the balloon up. And I...I'm not...listen, I have learned that I can do a lot of things I never thought I could do, but I haven't...but I don't want to do something that may cause problems, so, I would rather show me and then I'll do it the next time. You know what I mean?

DP: Oh, yeah, I'll go in there and look and see. It sounds like....I don't know why M. couldn't do that.

CG: Well, that's who's card I have and she said ...is she a heavy-set woman? (un-huh) Okay. There's no way.

DP: Okay. So he doesn't require suctioning or a trach does he?

CG: Oh, I was gonna tell you about the pneumonia. I have uh, a machine that I can suction out his throat, whatever he calls

the uh, (have you had to use it?) Yeah, I have used it. But it's not one that goes down. It just goes into the mouth.

DP: Okay. And does he need oxygen at all?

CG: No. I hope we never get to that point.

DP: Now, let me ask a little bit of information about you and then I've got a form you can just sit down here and fill out, and then, and then we can go in and look at that tube. Uh, let's see. You're married, right? (yes) And how old are you?

CG: Forty....forty uh, forty-four.

DP: Okay, and this is your father. Do you have any kind of special religion?

CG: Baptist.

DP: Okay. And you're a schoolteacher. Elementary? (mmm-hmm) You teach here in L. C.? (mmm-hmm) Which school do you teach at?

CG: B. , a mile up the road.

DP: Uh, so you've gone through four years of college, right?

CG: I have my master's plus 45 hours.

DP: Ohh. Would you believe everyone else just about I've talked to has gone through the sixth or eighth grade and that's it. Plus 46 hours? (45) 45 hours. Okay. Uh, roughly what is....well, when I ask for income, of your father and your mother, roughly that you have to use to help take care of them, roughly what is this?

CG: What is their income per month? About \$1600.

DP: Okay. Uh, do you have any kind of health problems?

Diabetic or hypertension or...

CG: I have Pericarditis and which is a heart condition. (oh, yes) (you're on medications for that?) I have just ended, well, one of 'em is supposed to be continued but I was on medication; I've been hospitalized for it and I had a very, very bad summer last year. Last summer was sheer torture cause...and on top of that I had to have a emergency gallbladder surgery when they found that, they found that it wasn't my gallbladder at all, that it was my pancreas, so I had pancreatitis (oh) but uh, ....but all in all I get along.

DP: But so far, like right now, you're doing okay?

CG: Well, I'll tell you...I know you....last summer I fell cleaning the bathtub and you know those sliding glass doors to the shower (mmm-hmm) when I was getting in my tub, I had sprayed scrubbing bubbles or one of those things (yeah) and so I stepped into this and as I stepped, my foot slipped...well, I held onto the doors and didn't fall, but the metal piece that stands up the tract, my legs scraped it; it scraped it to the point that I had a 14 inch bruise from here to here and it was 12 inches this way, which ended up as a blood clot, so I had to....a lot of problems with that. Well, the...that...I was probably taken into emergency about 8 times with that, because what happened, one of the clots....something broke lose near the lung and I had all kinds of problems and then I started having this heart thing [laughs] so last summer was ...I just didn't know if I was gonna live from one day to the next and I don't

know....I'm a firm believer in the Lord and I just prayed constantly. I went back to work and the doctor told me he didn't want me to go back to work; to take a least three more months to try to get over the pericarditis, but I went back to work with restrictions on me. Okay. The whole time...it was so hard cause I was taking care of daddy and mommy's health started failing, worse and worse, which I know it was the stress and the strain from losing her spouse. You don't live with someone 50 years and no longer have them to converse with and share joys or sorrows with and get over that just like that. And it was just about ....got my mom down. So anyway, I just kept praying that the Lord would ...I just ask him to give me strength to take care of mom and dad, you know, don't make me...don't make me feel better for myself, but for the people that need me. I really feel that I was needed, although there's 10 children; mom and daddy have 10 children, I'm the one that's here, you know. I'm the one....and I think I was put here for a reason so let me take care of them to the best of my abilities, so I got till I was you know, I couldn't even sleep at night, cause when I laid down, it ...it was just like when you're heart was gonna quit and you couldn't get any air in your lungs and I was having a time, but I got stronger and stronger and gained. I had lost so much weight....but that part was all right; I gained it all back [laughter]. But uh, I finally you know, you may not be a person that believes it, but I believe that through prayer...cause

there's churches ....I have relatives everywhere that call me from long distance and tell me we're praying for you all and I just think that's what pulled me to my feet so that I could take care of them and uh, as far as my health problems, I've got 'em but I try very hard to overcome it. You know, I don't know what else to do, you know. I just...I just do what I have to do and hope and whenever I lay down at night, I thank the Lord we got through this day and I'm thankful that I wake up in the morning. You know, just give me strength to get through this day and that's all I...you know, that's all you can do. That's all I've got to...

DP: Yeah, and I think that attitude's probably what's kept you going, cause a lot of people will just lay down in the bed and not get back out (un-huh, no).

CG: No, I have to...I have to be thankful because for every inconvenience, there are three or four more blessings, and you just have to take it that way.

DP: That's a good attitude. Okay, let's see. Your mother lives in the house with your father, right? (mmm-hmm) And you live next door. (well, my house is there) but you basically spend the night...(I live here) okay. So, then it's you and your mother and father. (mmm-hmm) (oh, my family...my husband ...they stay with me at night, but during the day when they're here a lot, they're just back and forth). Okay. How many children do you have?

CG: I've got two children.

DP: But they stay there with you?

CG: At night, we all stay there at night. They won't...

DP: Okay. And you have a car. And you've got running water and a telephone and electricity. Now how long have you been taking care of your father? Be a year in August?

CG: That's when...that's when it was full-scale, full-time type thing.

DP: Okay. How many hours per day would you say you spend caring for your father? I've had some interesting answers.

CG: I think you underestimate how many hours you spend, because you know, I would have to think long and hard because like I do this thing, I run over to my house and put in a load of clothes and come back, you know, and just sit down and actually put my time together, I don't know. I don't know...let me think. I have...for example, his bath. His bath takes me 30-45 minutes, depending upon his shampoo. I have learned to shampoo his hair every other day, and not necessarily when I give him a bath. I shave him every other day. I use to shave him every day, but ....now that...and now I finally got him an electric razor, cause daddy was one of these hard old-timers and that did this, and I used it up until he got another stage of the Parkinson's disease put him in till he chews constantly (ohh) it's like you would just think he's chewing gum constantly. And that is another stage in the Parkinson's or at least that's what the doctor told us, so when he started doing that, and we've had to take his teeth out of course, it was very hard for me to shave him with his razor and I was cutting him and I

couldn't stand that, so I started doing him every other day. Well, uh, about two weeks ago, or so, oh, I started....then I thought, well, I'll use my husband's razor, because, you know, it takes a beard that's been shaved, this way awhile to get use to a electric, so I started using my husband's and I thought let's get an electric razor for him, and so we did. And with that now, I shave him every day with the electric and like I said, it's hard to get all of it, but uh, to put down how much time it takes, I'd say 45 minutes for a bath, it takes me about 30 minutes to shampoo his hair, because of the way I get him back into the tub. Uh, to feed him, feed him...I feed him through the night. He's to be fed every uh, supposedly four hours, uh, so I fed him every four hours like the doctor told me even through the night, which is six times in a 24-hour period. Then, it may sound selfish of me, but it got till getting up at 2 and feeding him and getting up again and going to work at 7, I was getting very tired, so what I did, what I have done, and I found that it works just fine, I feed him 3 1/2 hour periods through the day (mmmh) and I feed him at 9 at night, and again at 1. And I go to bed at one and I get up at ....get up and feed him at, which is only a six-hour span there, (oh, yeah) so that gives me about 5 - 6 hours of sleep. (And he gets his six cans in a day); he gets it. But...and the doctors told me that just like get 'em in, but you cannot; I have found you cannot put the feedings too close because he has not absorbed them and it's not gone through his system and it causes a discomfort, so, I ...it took me awhile to get



me a routine or whatever like that. Uh...and to change him, I can change him by myself. I...I've learned to change him by myself. I can get him up out of the bed and in his wheelchair by myself. I won't say it's not hard, but I...but as my son says, I'm turning into a uh, oh, that Sylvester Stallone character, Rambo (Rocky or Rambo) Rambo (Rambo, yeah) [laughs] Rambo mom. And I used to...I used to was very, not a very, very strong person (mmm-hmm) at all but I've learned to do. I think it's an inner strength that you draw upon or something. I don't know, but I just whip him up in that bed and sit him in the wheelchair. But now it's very hard for me ...he has a recliner, he sits in it alot. There is a glider on the porch that I cover with uh, what was at one time, a mattress pad, you know that soft stuff (oh, yes) and I cover it with that. And I put uh, a soft cushion on it, and I sit him on there and when he's tired of sitting, I turn and lay him on there. So that he can be outside; we bring him out here. He sits there for hours and hours and hours, you know whenever he...in the past few years. So we bring him out here as much as we can. But with this humidity we can't hardly bring him on the porch (mmm-hmm). But I...I...the hours that I take care of him, the waking hours, I would say at least ...cause if you jam all that together, probably 5-6 hours a day, uh, and that might be under ...that might be under...because I don't just take care of his needs and leave.

DP: That's right. I mean, I wouldn't be surprised if you said pretty much 24 hours a day.

CG: Twenty-four hours a day as far as now 24 hours a day as far as your conscious ...you're always thinking (mmm-hmm) but you know, like I have to set timers sometimes for my feedings, you know, I've gotta remember this. But as far as if I were to take his bath and his feedings and (physical...) and everything that I do physically and put it and time it, I would say probably close to 6 hours. But now when it comes to the times I just sit and talk with him, the times I rub lotion on him, just and just to be so he's not by himself; we try never to leave him. I can't stand for him just to lay in his room awake very long. Cause I don't want him to feel like he's a lone. I don't know but what it feels like I'm alone here and I can't get out of here, so, if he's awake and I'm here, he's out of there as much as possible, out of his room. And uh, so you...you spend a lot of time almost to the....just as a companion. See my mom used to do that a lot, but anymore she's...

DP: She's gotten sick to where she can't do that?

CG: She....she sits with him; she can't hear him. She's lost her....her hearing is so bad that she can't hear what he's saying and I talk to him whether I understand what daddy's saying, or not, I talk...I converse with him just as if we're on the same level. [laughs] Like I understand whatever.

DP: Okay, I need you to fill out this form and this will be...I usually...I have been like I say with the people I've interviewed before, I've been reading this to them, because

they haven't wanted to read but you can read this. Uh, it's a family environment scale and it consists of 90 sentences, and all you need to put is T or F beside it; just true or false. Only thing I need to know is when you answer these ques...these...when you put true or false, like it says, "family members really help and support one another", or "it's hard to blow off steam at home without upsetting someone", and "being on time is very important in our family", you know, it's just general questions like that, and some of these are hilarious but, who would you consider your family? Who would you be thinking of when you ...when you look at this and answer these? Probably you and your husband, right? And your children or you and your mother and father or...

CG: My family is my husband, children and my parents.

DP: Okay.

CG: You know, that's my family. But I've got a big family. But when I answer these, I'm...I'm referring or should consider only those of us who take care of daddy? (mmm-hmm) Cause my 16 year old son, I said, I probably have the only 16 year old son that is standing beside his grandfather's bed at 1:00 on Saturday night helping me change him.

DP: Oh, my goodness, you're right. Well, what about the other children? Your other brothers and sisters; do they help?

CG: Well, my ...one of my brothers was just in from Florida, uh, if they're here, but (but they live out of state?) if they're here, just...you know, they do anything I can do. I

mean, they do anything I would do. Just like, we just took a trip to Myrtle Beach and uh, while I was gone, I ...I set up a schedule for everybody. I had an aunt that came from Ohio and stayed. I had a brother and his wife that came from Ohio and stayed some time. And I have a sister that lives who's house I was hanging wallpaper with her today, she comes down, but see she goes to...she's a student...she decided to go back to school, so she's been going to summer school this summer, and she went through the fall, so as far as S., what she did, she would come uh, two days a week while I was working and then I....I had a girl I hired that came three days a week while I was working, so, but through the summer you know, I do it. But uh, if I'm not here, I make arrangements for someone else to be here. I don't go unless there is someone else to do it. You understand what....

DP: Yeah, yeah. Okay, why don't you just...

CG: So when I'm doing this, do I just consider my immediate...the ones I don't consider the ones who come in and help me when they're around or do I just consider those of us that are here?

DP: Well, I tell you, that's been a problem with that because....

DP: This is Diana Parnicza. It is August 18th, 1989. And I'm conducting Interview B with Caregiver #2. ....help that you get and pretty much open ended questions. It's not like the true or false that I asked you before. Let me ask you this one question...and you just respond from the top of your head and then I'm going to ask you some more specific questions, but it's looking at all...what I call social support but all kinds, the different kinds of help that you get in taking care of him. Okay. How do you manage caring for your father?

CG: Actually I just give up everything else to care for daddy. You know, daddy comes he comes first, and then mom comes second, and my family comes next, somewhere along the line. But I do...I have...I have to take care of dad before anything cause he can't do anything for himself.

DP: Okay, uh, let's look at physical help. Who helps you do all the physical kinds of things, like bathing him, feeding him, cleaning the house, do the yard work, stuff like that. Who all do you have to help you?

CG: Okay, I bathe daddy. If I...if I'm working, you know, when I'm working most of the time, I bathe him. Now my mother you know, for a long time would help me or maybe she but she can't any more. [inaudible-fading out] So I do the bathing, I shave, I do the shaving, I shampoo his hair, I do all that. Uh, as far as the house, okay, we get him up out of bed when he's finally awake in the morning, and he's had his bath, he comes out of that bed and we keep him up you know, from the time he gets out of bed and we

bring him into the den or if it's nice enough, we take him outside we can lift him, my son, my 16 year old son, is just...is indispensable to me. He's really...now I can hoist daddy and do alot myself, but I do have this...this heart condition and I had been back to the doctor a couple of weeks ago and I'm getting worse all the time, so I'm having to rely more on our son. Now in the evenings, my husband gets home between 6 and 6:30. I can just turn it over...I can turn everything over to him you know, except for changing his diaper. They can do the feeding, the can do...[tape ends]

[side 2 ]

CG: ...my son and my daughter, my 12 year old daughter, J., my son, runs the sweeper. I never run a sweeper; he does the sweeping in both houses and I've got a big house that he runs the sweeper in. Uh, S. does the dusting. She makes the beds; as far as the laundry, I do the laundry here, but my husband does the laundry in our house. I have trained he and my son to do all the laundry and my daughter puts folds & puts it away so I have a lot of help. I have to have help; I couldn't do it by myself. Uh, as far as the yard, I don't do anything to the yard. Now, I like to work in the rose garden and things like that when I can, but, uh, I never, never mow, never do anything like that. I never did; even before I...well, I use to. I use to do uh, when I was healthier, but I haven't for years done anything like that.

DP: Okay, what about going to the grocery or things like that?

CG: Okay, my son does most of the grocery shopping as far as a list, but occasionally I will actually coerce my mother into going, just to get her out of the house (mmmh), and you know, sometimes I will go. But when it comes to the groceries, it's my husband, my children mainly. And my sister; my sister and her husband run a grocery store and she frequently, mommy just gives her her list and she'll frequently bring those in.

DP: What about cooking? Do you do all the cooking?

CG: I do the uh...I do the cooking, yeah, any more now I do. Now, my mother use to do her own cooking but since dad doesn't eat, she can't bear to cook (ohhh) it's...it's just unreal what's happening to my mom. Uh, she won't eat unless we make her. I mean, she doesn't have the heart to do it.

DP:

CG: I just think it's losing daddy. You know, I mean, I, like I was talking to someone yesterday, we have daddy physically, but as far as a companion, mommy's lost him. She's just about lost herself also her health has plummeted.

DP:

CG:

and raised 10 children and 27 grandchildren and so many great-grandchildren, which the love of their life is their family and mom you know, every Sunday my brother's and sister's that's far away, that cannot come and visit, except you know, maybe once or twice a year, uh, they call every

Sunday and conversations with momma, but she...she'll always go to dad and tell him she just talked to so and so and they said to give you a hug and a kiss and tell you they love you, and she does that but she's crying when she tells him, cause she...you know, she don't know what he's taking in so much, you know? And to not ...not be able to share her children any more with their father it's just...just...and like so many things about the house, you know, repairs of the house, things that need to be done, she will not, she won't ask anybody for anything. Things that daddy would have done. You gotta kind of catch it, and doing 'em your...you know, cause she feels it's her responsibility you know, we have a hard time with her wanting to be independent and can't. Uh, my sister, she lives about 15 miles away. She...she comes when she can, cause she also goes to school. She comes when she can and uh, if, say if I wanted to go on Wednesdays, my daughter has a lot of appointments and it's real hard during school time to do these, and she'll so many different things she's involved in, and I schedule 'em, Monday through Wednesdays I try to schedule 'em till they follow each other so that it's one trip (mmm-hmm) and uh, you know, I have...I have my sister to come and be here and help do that.

DP: Like if you have to leave, you have someone to come in and watch him.

CG: Oh, yes. She's never...my son stays here; if I have to go



to the doctor, if there's anyplace I have to go, and I can't and my sister's not available, he ...he is...he's just...he's indispensable.'

DP: Uh, okay, so basically, he helps you with everything in caring for your father, it's your family and then you've got the one sister that can help.

CG: S. helps me. Now also, I have uh a couple, a I have a brother and a sister-in-law over in Ohio, uh, they come down every weekend and uh, you know they're here. They don't stay overnight or anything, but they come up here if we need 'em for anything. I have two brothers in the Huntington area that can come up. If I need 'em, like if mom has to go to the doctor, and I have to be here with dad, then I call my brother, one of my brothers and they will take her to the doctor and things like that.

DP: So you feel comfortable that in calling them and asking for help?

CG: Oh, yeah. I have one brother that ...one of my brothers just can't leave his job, cause he's a, his job is...you can't even reach him during the day. He can't...but my other brother is a manager...he's the manager...the assistant manager of the Huntington Water Company (mmmh) and uh, any time I call him, he's...he just comes. But he like myself, has and he's just you know, about every 3 months, every 2 or 3 months he's laid up in the hospital for a week at a time, strapped to i.v.'s to his hand so it seems like in that respect, my sister that lives R. and my brother in H., and myself, and my 16

year old son, we all have pancreatitis and we get these attacks that just lay you up you know, you're just a mess for about a week or two. Now, it's kind of ironic, but week before last, all four of us were having a pancreas attack and he ...he was serious. I was trying to go on pain medicine and function at home, so was my sister and my son was having a mild one. But now it was rough and I still, you know, still real swollen, till I feel like I've got a football in there. It's just...it's familial out of 10 children, there's 6 of us that has it. My father when he was a young man, but he never had it after his married life. Isn't that ironic? And (well your son has it) my son was diagnosed when he was I think 9 years old. We took him into a specialist and she was a, a stomach, children's stomach specialist in at Marshall, but I have a nephew that has it. He's been through uh, several clinics in the Florida area, Gainesville, there's a Gainesville, Florida, I think they've taken him to and his father has it. And my two sisters. I have a brother who's so we have pancreas problems spread all through the family and there's no alcohol involved; you know, at first they accuse you of this type of thing.

DP: Yeah, I know with me, it's the first thing I think of, but now, the...this doctor in Gainesville from uh, a big clinic there, they're doing a study, a case study on this family as far as that, because it's rare they say to have it in the family so many times. But there's nothing they can do for

you.

DP: Do you know there's nothing they can do for you; it's excruciating pain, to try to control the pain.

CG: Well, anyway, uh, I have help in a lot of ways, and uh, ...

DP: What about emotional help, what about...is there something you like to do, something like you read or just someone you can talk to? What, you know, what about emotional help?

CG: I feel my mother's emotional help is me uh, and there's uh, she has a sister that's coming in from Ohio today, that's...that's emotional help for my mom. They're very religious; my mother's very religious and she has a couple of sisters that are extremely you know, just very good christian women and she can talk with one of them especially, cause she'll come and stay a week at a time with mom. You know, just leave her home and she'll just come over just to be with her. Especially if dad's in the hospital. Uh, or if I'm sick; if I'm in the hospital, which I've uh, my aunt will come and she'll just stay. But as far as my emotional help, my husband and my son; my son's...has I needlepoint. I love to sit and I do that often at night when I you know, I sit down and I quilt. I'm working on a quilt now. But I quilt. Uh, I read mysteries. I love murder mysteries. I read them when I can. Especially Agatha Christie. Uh, ...

DP: But all of that, the reading and the sewing, and talking with your son has been

CG: Yeah, my doctor told me, I use to walk and I got...I got my

leg burnt real bad, it's a place about this big (mmh) and I couldn't walk for six weeks, so that kept me from walking . I never went back. I started again, and then I got a blood clot in the other leg and couldn't walk so, my doctor told me a couple of weeks ago I'm going to have to try to start walking again for my heart's sake. So I've started walking again and I had a pancreas attack. Could exercise and walking cause the pancreas to do that? Yeah, they don't seem to know what causes it (yeah, yeah), but is there any way that could cause an irritation or something?

DP: I don't...I wouldn't think so but I don't know. I mean, I would think walking would be the best, you know, one of the best things you could do.

CG: But after I'd walked about a week I tell you I...just well, I still have so much pain, but I thought well, yesterday I started the exercising again, but, then about the middle of the night last night, I thought oh, god, I'm dying, so I don't know if maybe it's swollen and you know to do these type things, but [both talking at once]

how it feels, it gets real inflamed and it's...mine they said one time was about five times what it should be that's how enlarged it was. And it was just...it was smothering me to death. I felt like I couldn't get any air; I couldn't sleep. And uh, I think, well, if it's swollen, if it's swollen, like you'd break a toe and it's swollen, does that mean it takes up more space? If it does, it only seems

natural that it'd shove everything a little bit tighter and therefore you would try to do exercises, it would cause problems. So that's why I mean, like I said, I started back yesterday but then I had a real rough night.

DP: You might wait till the swelling goes down.

CG: It might take weeks....I mean, it takes weeks for the swelling to go down. Now last time, it was three nights before I had any...it was awful so I don't know. But uh.

DP: [inaudible-fading]

CG: I don't know either. I don't know. I just...of course I was walking and exercising, too, so maybe it was just the exercise. But I...I'm never bored. You know how...(I can't imagine how I would be) I can't imagine cause...they go shopping cause they're bored, you do this because they're bored...I could never get in trouble cause I'm bored, cause I've never ...I can't imagine having free time. Every minute, especially when I'm working, when school starts, I have to make ...account for every minute cause I have so much ...I have so much to do.

DP: [fading]

CG: I don't uh, there's just so much. And like I said, my mother's health has gotten so bad and it's really like I'm taking care of my mother now. She uh, you know, cause she's....

DP: Uh...do you have anyone that you pay, that comes in to help you?

CG: I did last school term. She stayed here while I was at work. Uh, but she was very...I could not...she was not

reliable, so I'm in the process of interviewing now to work for me and also, a matter of fact, a lady comes tomorrow that I hope...hope she'll work out. Uh, also, last year, I...through St. Mary's, but I don't know if St. Mary's gave me her number, this Home Health Service they have in C. (mmm-hmm) they told me that L. C. was trying to start that, and we could get in touch with a certain person, and I called 'em last year. They said they were trying to get something started, okay, and they would call me if they did, well, yesterday I called again, and they're having a meeting and they are...they do have something going, but they don't know how it's gonna be worked out yet.

DP: What is it? What...

CG: It's where there will be a through this home health service, there'll be someone from there come into the home and stay, uh, from my understanding they will come and check the patient (mmmh) and uh, stay for a certain amount of time or something. I don't know...I don't think their's is gonna work like C. C.'s does. See C. C., they come in three days a week and check and check on the patient. That's what...

DP: I know they have aides that come in and bathe the patients and things like that. Uh, if the patient has a catheter or needs any kind of skilled nursing, uh, and then the nurse comes every other week.

CG: Well, this nurse told me that that the three days a week they check on the patient. Now, I don't know (okay) what the time that is...

DP: Okay, you might...okay, it may be some of the other home health agencies that do; maybe some of the private home health care.

CG: I don't think hospital, I mean, I don't think it's like that. It's just like this is starting on it's own. It's not even in....okay, we have a L. P. C. C. (mmm-hmm) they're not even affiliated with it.

DP: Where is the meeting and stuff, do you know? Where is the meeting?

CG: No, she just told me they were having...I don't think it's a public meeting.

DP: Okay, okay.

CG: Because she said we're having a meeting the 22nd

whether the patient will have to pay so much and how it was gonna be worked out, and they said they'd be calling me. But uh, when I'm working, I have to have somebody here, cause mom can't take care of dad, by herself. So I'm having a nurse to take care of him.

DP: But that's why you're working and then when you're out in the summer, you...you...

CG: And when I come home, you know, nobody's you know, I don't ever have anybody here cause I pay them by the hour and I can't ...

DP: How much is that usually? How much was it last year?

CG: I paid the girl \$3.50, but see the nursing home pays \$3.85...I don't know if they pay...they start you out at minimum wage and they go up. I know one lady that

\$3.85 an hour, so if I pay 'em \$3.50, that's more than I can pay, actually.

DP: Uh, okay, so like you say, you're interviewing; would you put something in the paper?

CG: I put an ad in the paper, and I've had probably 15 calls and I ask specific questions before I even...you know, that's what I tell 'em, I ask 'em these things I've got down; I want to know specifically how they work with a total invalid cause daddy is...if he needs to be turned, you turn him. And...everything needs to be done for dad; you do it. And uh, I ask, and uh,

no smoking in the house. They have to be able to lift. Like this one woman had ...she sounded like she would work out fine, except she couldn't lift 30 lbs. so there's no need for her. But...then I ask specific questions in the initial call when they call me. And then if they have...if they are a strong possibility, and I ...I go back and I shuffle usually that's what I did last year. And uh, I tell 'em, you know, I expect a person to be neat. I don't expect a person to come in here and feed my daddy and change my daddy and I have light household chores to do and that's what I want them to do. I ....cause it's just taking care of dad's needs; a person could do that and sit down for two hours and not do anything else, so I leave a list of things I want done that day, and uh, I want them to be very compassionate; I don't want them to go change his diaper and say, oh, my



God, and this type of stuff, you know, I don't...that person is going to have to take on my personality with him as far as compassion. I have learned that I'm a very compassionate person. And I...and I don't think that dad deserves any less. Uh, I never in his presence that he doesn't see a smile on our face and he knows it. He knows when I'm coming. You know, like what mom said yesterday, I don't know how, you can always because I'm always smiling at him. [laughs] You know, you can...I think...you really don't know what's going through their mind. You have no way of knowing cause daddy tries so hard to say things to us and ...and he'll start out just well, I'm just thinking this morning. And he'll start out that way so you've got to speak with him such as you knew what he was thinking and put some words there and have a little bit of a discussion with him. And not show him depression. I think he picks up on depression; it's written all over your face. It's just...

DP: Yeah,

feelings and emotions and non-verbal behavior and how your facial expressions are.

CG: I think that we underestimate him.

And I'm convinced that daddy goes through periods of depression. I'm convinced that there's times that daddy realizes trapped and there's no help. He said to my brother that was visiting from Texas, and I was right in the room and he was holding his hand and



that, you had to be a strong person. And uh, he just...you just have to respect that. And the way she said it just hit me

DP:

CG: Yeah, well she hadn't seen him in a long time and uh, but then again, I think what bothered me most was to say that in his presence cause that bothered me and...

DP:

CG: No!

DP:

CG: Well, we don't know. You know, they're saying that people like daddy, they don't know and understand, but how do you know that? You know, it's just like years ago, people who were deaf mute or blind, Helen Keller, I mean, they thought this person should be locked in a room, and she wasn't able to...she wasn't able to communicate. That's where she was you know, a cripple. Who knows but what the same thing as cases like that and you know, you just don't know. And I and when I say, daddy how are you this morning, and he says back that he's fine or he don't feel too good, in which he does sometimes, I don't feel too good today, I'm assuming that he knows what he's talking about. And I'm not going to...

DP: Uh, okay, you don't have anybody any kind of nurse or any kind of medical person that comes in do you? Only that one experience with a nurse coming in

CG: We've had 'em three times. We've had 'em once that we pay a nurse to come here. Well, they thought, okay, one time a

nurse came, and what was it? Because he had a temperature, Medicare paid for it. If there's the slightest little thing, they'll pay for it. If he has a bed sore and it needs dressing. It's the stupidest thing, but she says, doesn't he have a bed sore or anything so I can write this up so you don't pay nothing? I mean, I'd rather just pay the bill. And uh, as it turned out, he had a low-grade fever. And ...she took blood.

DP: Okay, so that was last year...

CG: No, she came because...I called the home health service, uh, I called the number they give me when we left the hospital and uh, ...seems like he was coughing or something and rather than put him in an ambulance and take him, I called to see if a nurse would come and check; and she took blood in which they paid that. Okay another time I called and one came; we've had 'em twice, three times so far because there was nothing to justify coming in here and looking at him and checking things out to

DP: Well, you find that with the whole health insurance and everything. They do not pay for any prevention; they only pay for illness. Okay. Okay. What...describe ...describe an average day from the time you get up till the time you go to bed. What uhm...what pretty much do you do during the day?

CG: I put 24 hours in a day. [laughs] I get up and take care of daddy now, not when I was working. (yeah) But like

through....like this summer, I get up at...my husband gets up to go to work at 6:30. He wakes me up and we change daddy. He always helps me take care of daddy before he leaves and I feed him. Usually he's fed by 7. And then typically what I'll do, is any type of quiet housework I can do, maybe I'll clean the bathroom, maybe I'll strip the beds, help clean my own, but I mean, strip the beds, usually I'll start loading daddy's laundry cause I have at least one load of daddy's every day and I sometimes, if we have a rough night, where he has wet so much that he's wet his pad, up, if he's back to sleep and my mom's back to sleep, I'll go over at my house and do laundry or maybe strip the beds. Maybe uh, you know, do something at my house, like...like it took me I believe it took me three days to clean my upstairs foyer closet. clean it out this summer; it took me three days cause what I'd do, I got everything out in the foyer I mean the hall upstairs. But even to organize, in which I love things in order to organize that, the way I wanted it, I had to work a little bit and come and do something else. You know, maybe come over here and take care of something or take care of something here or there, whatever. And then I...it took me three days to get that closet put back together. That's typical...you know, it's hard for me to do things like...like that, you know, that need to be done but I can't...I don't often have 2 or 3 hours that it would take to do it. I have to stop....it took me 2 days to clean the garage out. I carried everything out of that garage and I was

two days getting it back. But you know, it seems like during the school year I can't get things done like that. Things get messed up till I can't stand it, uh, I will uh, do laundry or I start ; if I'm going to do any baking, I bake a lot, right now I'm in the process of baking pies. Uh, I will do that, bake those real early in the morning, cause it's uh, if it's something I can use a mixer I will do that. Uh, I make or uh, like this summer I canned beans, put corn up and things like that, things like that that you can do before it gets hot. As far as cleaning house, I do very...I do very little as far as topical cleaning. Now when it comes to down to cleaning, you know, where you can't depend upon the kids to do, uh, maybe one day I'll see how I'm gonna do this uh, getting ready to wallpaper my bedroom, so that may take me three days, you know. I just have to do things. I have found much to my dismay, that I can't start something like I want to, like I use to. You know, this is something I wanta do today. Uh, I'll have to stop and go change daddy, to bathe him, I try to get his bath done, everything done before 11:00 because uh, I like you know, I like for him to have the afternoons to be up and out of sleep, if he wants to. Uh, you know, I clean the refrigerator, I ...I....refrigerators double, the cabinets uh, I do...I do the mopping. Now, there's not a lot of mopping to do. Uh, my mother's kitchen and the front porch...her front porch. Uh, at my house the

only thing linoleum is my kitchen. And one small bathroom, so. I do the mopping, like I said, I don't run the sweeper. Uh, I try to wash windows, sometimes I do two of 'em at a time, and then maybe be a week before I get back to another window, cause I got a lot of windows. Things like that; I don't know, it's just...if you could imagine trying to run two households and trying to do anything and go on, because in the meantime you've gotta be fixing lunch and you've gotta be feeding, you've gotta be changing, you've gotta be giving medicine, uh, now I shampoo my mother's hair. I've always done my mother's hair, as far as styling it and everything, but uh, she can't shampoo it herself shampoo her hair. Uh, my daughter is a cheerleader, and uh, she has to be ran a lot. My son does most of it, and I do very little of it, but I...I help her with her hair and her clothes and things like that. Things like that. And...and she...she takes a lot of it, and I tried especially piano, try to listen to her some cause she...she seems to uh, though I sometimes, very rarely she takes violin lessons she takes gymnastics and ballet and one Wednesdays she chiropractor and she goes to gymnastics on Wednesdays and she goes to ballet and gymnastics she goes to piano. So I do...I try to after school

Now that my son drives,

Like I said, it's very rare that you'd have a 16 year old boy at 1:00 in the morning standing by their grandfather's bedside helping change his diaper, rather than out running around with drugs and all, so, I thank God

DP:

CG:                   very                   He's a straight A student and always has been. He has the highest grade average in his school. He scored the highest that's ever been scored on the CTBS test in Lincoln County in years.                   And yet he's a very caring ....he's very caring. Yeah. I just hope he goes off to college; he wants to go to college. Marshall...he wants to go off to college, cause he went



DP: This is Diana Parnicza. It is August the 25th, and I'm doing Interview C with Caregiver #2. What I want to do this time today is just go over and make sure I've got some things right and everything and then you just tell me if it's right or wrong or add more to it and stuff, okay? Okay, let's see. You were born ...you were born here in Lincoln County? (yes) Okay. And uh, you've always lived here...no, you've always lived here in this house?

CG: Not this house, but I've always lived here. I've always...I mean my parents live here. Dad bought this property in uh...48 and built a house, so they've lived here since 48. I lived uh, when I married, I lived uh, over at Pleasant View for awhile, not very long. And then we put a mobile home out here and then built. (Okay, so you've always...)I've always lived here.

DP: Okay. You have, is it 8 brothers and sisters?

CG: There are 10 children; I'm one of 10. (okay)

DP: And some of 'em live within a half hour or an hour's distance away but then there's a few that live pretty far away don't they? Up in Ohio?

CG: Uh, I have three brothers in Florida (oh, okay) and one brother in Texas, and a sister in Indiana.

DP: I don't know...who was the brother then that was here the first visit? And sister-in-law? Where are they from?

CG: Ohio. (Ohio, okay) And I have a brother in Ohio.

DP: Okay.

CG: Two brothers in Huntington. And a sister in Nitro. (okay)

DP: But you ...you've taken on the responsibility of caring for

your father. And it wasn't like a decision or someone said you do it, or whatever. It was just something that you personally felt...

CG: I'm here so I do it. I'm the one that's most likely to do it because I'm the one that lives here.

DP: Okay, and you...and you live here because...again there is no reason to; it's just that you ...it's what you've always...

CG: I just never wanted to go anywhere.

DP: Okay. Um, you...you have a job; you're a teacher. You've got your Master's plus more; plus what, 45 hours, isn't it? Your close to your doctorate. Uh, you do have some health problems; you've had problems with your heart, with pericarditis and also, with your pancr...pancreas, with pancreatitis. And that...you have good days and you've got bad days, basically, right? And when you...you can really get sick, well, with the pancreatitis, but you still...put caring for your father first, as much as you can. Now, your brothers and sisters are there to help and they do come and visit, uh; but like you say, with your one sister that lives in Ranger, it's still hard for her to deal with her father.

CG: She just It's from the very beginning. It's just hard for her to accept the situation, I think. To see daddy like this, she's still carrying?

DP: Okay, let's see, your father, he was a miner, right? (yes)  
And he was born in 1908, that makes him 8 ( )yeah.  
And he has been bedridden since August of 88, right? Uh,  
and he has a G-tube that you feed him with. Or that he eats  
because he has problems getting pneumonia a lot. You do get  
him up in the chair, uh, you do have to take care of all of  
his bodily functions when he eliminates and, and washing  
him and hygiene, turning him, pretty much  
everything you have to take care of. I mean, this has been  
going on well, it's a year this month. So, when you're  
working, then the days that you are working, you're  
gonna...you have someone that will come in, won't you?

CG: The days I'm working, uh, last year my sister came and I had  
a girl that came; she was scheduled to come three days a  
week. Sometimes she didn't do that. But the days she did  
not come, my sister came. (okay) And when I came home, uh,  
they...my sister would have to leave in time to get home for  
her child would be coming home from school, so it was just  
within a half hour or so before. And this year  
I've hired a girl that's supposed to work for me and I  
have hired her for 3-5 days, cause once again I don't know  
S., is a student at M., she's decided to go back  
to school and I don't know how her schedule's gonna work out  
whether she can be here one day or two days, but she  
wanted...she will try ...she tries to be here when I can't.  
It's just like I have to on Wednesdays, I told you I have to  
take S. in to H. all the time because of all the  
things, and she comes over and stays if I have to go or when

I go. And uh, so, during the school term last year, she was here at least two days, and sometimes she'd have to come more if the girl didn't show up. I'm hoping this one will be reliable. And S. won't have...you know, I'd like for S. to come you know, at least one day a week (mmm-hmm) because mom needs that. And she comes to visit. you know, she comes a lot to visit, but to come and stay the day and take over for me. If I'm here, nobody does that. But now she use to try and tell me "I'm here, you go on home and do something." And you know I would a little bit, but it's awful hard living next door. But she's tried ...

DP: Okay, uh, now your mother lives here with you. Uh, but she's not able to take care of him and you have to watch and be with her and all. And okay, so you live next door. And you...but you sleep here. (I have a house next door) Okay, yeah [laughs] that's a good way of putting it. (but I stay here) okay.

CG: Like I said, I go back and forth, I...I was over to the house when you came, I went over to get dressed cause I hadn't my ...got my self dressed. And uh, I go over to do my laundry and sometimes if I have a lot of laundry, I bring some over here and do it, you know. Uh, depends on how mom is. If she's feeling particularly bad, I ...you know, I may load some things over here. And I go home...just like I've got to try today to clean some of my house, uh, about everything's been cleaned, but I'll do the bathroom and I'm

down to the bathrooms and

so you know things with my aunt here, I feel like I can just go over and clean not having to worry about ever 10 minutes checking on 'em. That's what...that's one of the hardest things for me is knowing you've got something to do, somewhere else. And to know that ever little bit you've got to check on something here, your mind's not really free to concentrate on something. Therefore, you take longer to do it. (mmm-hmm) If that makes any sense. So, if someone is here that I know can ...they can get me if they need me or I don't have to run back right away to check on something, then I...I feel like I can concentrate on doing my other job. Now, honestly, things that I do, you know, I told you about how my children and my husband do a lot of things for me, but there are things that I do. I'm the one who organizes drawers, and organizes closets, which I'm fanatic about. I'm the one to do certain things that nobody could ever do to please me. And it's...it would take me months to get some of those jobs done that you know you can do in a day. But I just have to do it...and like this whole week I have mostly just laid, cause I'm having a lot of problems with my heart this week, I'm hardly can even change daddy I've been so weak this week, so, it's been a particularly rough week for You know, so...

DP: Have you gone to the doctor...

CG: Yeah. I have uh, [fading out]

DP: Are you getting any better or do you feel like it's

getting worse?

CG: Actually this morning I feel a lot stronger, but went up the stairs. Which he told me I could climb the stairs once a day, (slowly) I went upstairs to get dressed and I came out in the foyer, you know, it's kind of, it just feel like ... your heart's going to stop...weakness, that I actually take deep breaths sometimes to get my heart going. And I don't think I really do, it's just that it feels like if I don't get some air in there right away, it's gonna stop. (mmm-hmm) You ever have anything like that?

DP: No, but I can you know, that makes sense.

CG: I'd love to think it was only anxiety or something but I have such pain, you know, he uh....I've got to have extensive testing; we've got that all set up, and we'll go through that mess again, so.

DP: That's a pain to go through, but...they may find something.

CG: That's what I'm afraid of.

DP: But it may be something they can treat too. take care of it. When are you going to start with these tests? Have you already started with them?

CG: Some of them. But it....

DP: You mean, like an echocardiogram?

CG: I've got to do that, and the treadmill again. They've already did some; they did the ...

DP: Well, probably all the blood work and stuff.

CG: Did the blood, and they did the uh, what's the one...(EKG?) EKG. The did uh, well I did some walking and they monitored it. (okay, I was gonna ask you...) But not the

treadmill...cause...I...it was just where I didn't walk any. They had me going up and down. I've never done that one before. Now I've did the treadmill last year.

DP: I...I wondered too, does it...well, I know it causes anxiety and it scares you with the fact that you're not feeling well, but then, does even lead on into if you really get down in the bed and you get sick for awhile, who's gonna take care of your father, do you have that anxiety and that worry and stuff?

CG: Oh, yeah. Do you know that... I have a constant prayer that I'll just get to take care of things...that's all I ask. Just let me be all the things I have to be. Uh, because I know you know, I don't...I don't know why...how it sounds, but I feel that nobody can fill my shoes (mmm-hmm) and I don't mean to say that in such a way (you're not bragging) no, it's just that I'm responsible for so much, that I don't...well, while we went on vacation, and I scheduled uh, six different people to fill in for me for five days and you know, when you do something that you get six people to do, then you say to yourself, who's gonna take over if I can't do it. (mmm-hmm) And it wasn't that one person could have came and did it, it's just that you wouldn't ask that of anybody. You know, I could ask my sister; she came and stayed. And I could have said, this is all I do, but you don't ask that of one person, because it's too much. Yes, you do. I'm sure that most of the people you've talked to will say to you, if that was me, I don't know what would happen to them. So,

I...that's where I am, and maybe that's a burden that's on me that shouldn't because if something were to happen to me, it would be taken care of. It would be taken care of. But...I feel I'm supposed to do it, you know. But I feel that it would be handled good, whatever it took, that somebody would...I mean, I'm sure that they would all see to it that it was taken care of. I don't think anybody would let anything slide. You know, but...but like I said, I just...I just ask the Lord every day, constantly through the day and night, to just let me, you know, keep me well enough to do what all I have to do. Because I know how I'm needed. Mom just depends on me so much. And uh, feels guilty about it...her depending on me makes her feel guilty and it actually makes her sick, so you see it's kind of a...(mmm-hmm) paradox.

DP: Um, okay. Talk a little bit about all the things that you do for your father, uh, and as far as the help, the biggest help is your son and your husband. Uh, especially your son. But they're both there to help you with lifting him, they help you...your son stays here at night with you and they're there and they're a big source of support. You do have a sister that you can call on and you have this lady that you've hired while you work, to stay with them. You have no medical person that comes in here, no nurse or aide or anything that comes in here. The lady that you have to come in while you work, you're paying out of your pocket. As far as his medical bills and things, Medicare takes care of most of it, right? (mmmh) And like his bed and equipment and



things like that. Uh, the church really doesn't...you made a point the last visit uh, with...I'm just thinking of the different kinds of help right now, like one thing with the church and how they do not furnish any help. At the very beginning you said he became sick, they would bring him food, which wasn't something that you all really needed uh, your mother, to this day, feels like friends, a couple of her friends from church really helped her a lot, but after about so many weeks, they just kind of quit and that's been it with the church (mmm-hmm)

CG: Mmm-hmm. for a long time they had weekly visits, uh, a committee...what they do they have a... I think they call 'em committees and they...they're visiting committees and they go to the ill, the one that are sick and the ones that cannot come to church because of sickness. Or just all the people like in the winter you can't get out, you know, like widows who can't get out and come to church; they...there's a committee that goes once a week to visit these people, and then there's different committees go different places and they just kind of take turns but, you know, for months they came every Tuesday to see mom and uh, talk with her and things, and ...and uh, I don't know if it was her...when she was in the hospital or see, she and dad both were ...at one time, now mother was in the hospital with bronchial pneumonia and my dad had pneumonia. My husband and I both had strep throat that went into pneumonia; we were all laying sick. Now mom ended up in the hospital;

that's what caused my heart problem or at least that's what the doctor said. (oh, okay) The germs settled around my heart (yes) and uh, since then my mother has had severe leg problems, there's times she can't even get up, we have to help her up, so, that particular virus, whatever it was, left it's mark on all of us. And we have...somebody had to come in and take care of us. Of course, like I said, mom was in the hospital, but even before she went, she was in bed for a week, and I was sick trying to take care of her, so my sister from Indiana came and tried to take care of all of us. Uh, I don't know ...it seems like...seems like not long after that, the visits stopped, and it could be because we were in such a turmoil, that we were so sick that you didn't really wanta see anybody. I mean, you're so sick, that you can't get up, you know, and maybe...I know at one point uh, they ask me, a group of 'em asked me, if it was ...if my mother was uncomfortable with them coming or whatever, and I said to them, explained to them again that my mother doesn't hear well, and when someone comes and talks to her, she's embarassed because she may not...they may ask her or say something that she doesn't know. And so I...I have...repeatedly said when you talk to my mom, you talk to her directly. To get her attention, speak to her. And uh, you know, maybe things like that. But now in the past...this week, there've been two or three different people call and a lady has came out. (from the church?) Yeah, and I don't know why but the lady that came said the pastor got up and said that he expected the people

to get out and visit the sick and they...and he specifically named mom's family, you know, mom and dad. And I don't know why...I don't know if uh, well, they got a new pastor for one thing and he...he use to be pastor up at the church and when we were still able to go to church, when mom and I were still able to go to church and he...when daddy was ...when I was in the hospital, he came to see me, you know, he came and we had two or three times and then dad in the hospital this last time, he came to see daddy. Well, the pastor that's been up there's never come, not the first time. He's never come; never called, nothing. And my mother a member of the church. So, the other pastor's back in, he came to see daddy twice this time in the hospital, and he told the people to get out and visit the sick and make a point to see the L.'s, and so, I said well...I told her, I said, listen, don't come to visit mommy cause the pastor told you so. If you do not want to come, don't, please don't. She said it's not that, she said, I've just... and I know, she lost her husband recently and she's been in this deep depression, she's a good friend, but she's been in such depression that she can't hardly so I can ...I told her, I said, I'm...I cannot say I know what you're going through, but I don't, you know, I don't feel as you need to apologize to me for what you're going through. But she said, I just want you to know why I haven't been in touch with you for awhile. She said I just ...and she said Brother Z. made me realize that I had to get out of this

and I had to go about people who were just as needy as I was and we can help each other. And uh, she said that she you know, that type of thing. But I thought it was kind of ironic that we were talking about that, I think last week (un-huh) and then I got a phone call...well, that was Friday, and I got my first phone call and talked a long time to one of the church ladies and then I went out to the store, and I saw about three of em and they all just ...course now, like I said, if you see 'em out someplace, they always come and talk to you and want to know how they are. And a lot of them tried to talk to my mother and father; she just can't understand them. And uh, that's one reason they...they try to call when they think I'm here and then they know I'm so sick and the first thing most of them would say to me, I know you're real busy but I just wanted to let you know. So I think...I think maybe they think that we, you know, are too busy, cause a lot of people don't have nothing else to do but sit and talk on the phone (mmm-hmm). I don't have time for that, but you know, I never let anybody know that; I always talk until they're talked out or listen. But I did get some calls this week, or mom did. So, I thought that was kind of ironic.

DP: Yeah, it is.

CG: They read my mind I guess.

DP: Un-huh. Uh, okay, neighbors, you have one neighbor and...but she's older and really can't help a whole lot but she has a son or someone who you could call on and you had to call on (grandson, she doesn't have a son) okay.

CG: She's the one she lost her daughter and son-in-law, I think they were within 18 months of each other, and then a few months later her husband died, so she had three very deaths there in two years, that she just...she's a mess. But she has a grandson that he is a...he's adopted son of her daughter and son-in-law who died and he's out there by himself, but I didn't know it. But in the past couple of weeks, he's got...he's working now, you know, where I could call him of the day if I needed him, he 's not there. But like I said, through the summer, I've got my son. I never even let him go you know, sometimes he goes off in summer visits, so, maybe my brother in Florida or my sister in Indiana, and he stays a week or something. And I...I couldn't let him go this summer. He wouldn't anyway. Because I just needed him too much. And uh, but as long as he's here, I'll be fine, cause he's...he's strong and he's good...and of course, my husband is home of the evenings. Uh, my husband is a reservist...an army reservist, and has been in for 25 or 26 years (mmmh) and uh, one or two weekends a month he goes for drills. Which is like a work day. He goes...he gets in about the same time he would if he'd gone to work. And then three weeks, although they advertise it spend two weeks a year, you go on training, he goes three cause he's...he's uh, he's an instructor so he has to go longer so that three weeks he was gone was rough this summer. Cause as it turned out, I was real sick, part of the time. And it was hard while he was gone this summer.

but typically, unless it's something like that, he's home in the evenings. So I've got them, thank the Lord.

DP: Yeah. And that's basically it. Uh, and like you say, you're here all the time, and if you do have to leave, like if you all went on vacation, you have to find people that take care (I do, yeah, I get the family to come and stay and take shifts). Okay. Now, that's all the physical things and the physical help. Uh, emotionally well, we've...the laundry and the cleaning and stuff you and your children take turns with that and the yard work, your children do that too. Emotional help, you talked about uh, you have a lot of problems, you like to needlepoint and quilt and read mysteries and things like that. And you do have some friends you can talk to and your son and your husband. Uh, you didn't mention religion, your faith or anything, but I see that a lot in you. Now, I see that as maybe a possible form of emotional support because a lot of times you say well, you've gotta have faith, you know, taking care of different things like that. But...

CG: But I never even thought to mention that, cause that's me. That's ....to me that's what gets me through the day. (okay) I am a uh, Christian although it's been very hard for me to ...I haven't been to church for a long time. But I...I hope and pray that my soul was saved and if it were not, I feel in my heart, if it were not for the Lord, I couldn't go one step to another. It just gets real hard and it's only by his grace that I'm able to go. And I felt that way even before you know, I've felt that way for years.

It's just ...that's just me...that's just...

DP: Uh, now, when we looked at some areas that you would like to have help in or would like to see some things done and stuff, one was uh, having some kind of medical professional come in and ...once a week or every other' week something like that and just checking about it. And someone you can ask questions about, is this right or is this wrong and I'm seeing this, what is this mean, and someone who can like take his vital signs and check him over and see how he's doing. Another thing you said that possibly be a help would be some kind of support group, where people like you who are taking care of relatives at home, get together and talk about some of the problems and help solve them and things, also, some educational courses , people teaching you different things like that.

[daughter S. talking to CG]

CG: Have you met D. before? This is my baby, S. [CG talking to daughter]

DP: my daughter (really?)

DP: Okay, let's see, okay, the two things, well two things, having a professional come and visit and some kind of support group and some kind of training uh, you felt would be a lot of help, but also, uh, let's see, I've got intermittent caring for him. Uh, maybe we were talking about like giving you a break for a few days or something like that, but uh, I don't know, I don't know what that means. But you...okay, with ...if there was someone that would come

in and spend a week with him, from...uh, someone who was trained to do this, to go into homes or just spend a couple of days, with him and stuff, would that...would you like something like that, like during the summer, for you to get away or anything?

CG: You asked me that before and my...my response was only family (that's right, that's right). I would not leave mom and dad even over night, with someone outside the family. I would...I hope I never have to. You know, you may have to. But I don't know, and that goes back to my faith in my fellow man or trust, but, I uh, I

DP: And one other thing, I noticed that you're you know, your belief and your faith is very strong, uh, you may...one thing you made comment which I thought was important to me was that taking care of your father was a lot like taking care of babies, of your children when they were babies, but you knew that they would grow and develop and you could watch them grow and develop, whereas your father, who was, well, you said heartbreaking. Because

CG: Yeah, they're so similar yet so different, you know, you've got the similarity's in their physical care and also the emotional care. You know, you're the one that keeps them smiling, you're the one that let's them know they're important to you. You're the one that puts all the hugs and kisses you can possible shower on them. And spend time with them. You know, I spend ...I spend a lot of my time trying to be just where daddy is. Just like...you know,



just like if I've got him in the den, especially on the couch, a lot of times I lay over and put my head on his shoulder, you know, he'll just pat me, just to be with him, just to let him know he's not alone. You know, that's when I'll do a lot of something with my hands. And I try not even really to read, you know, I may read through the newspaper but all the time I'm reading, I'm looking up to see if I can see...if he's looking at me or if he looks like he's got a scowl or something on his face, I...I want to try to let him know he's not in the room alone, cause for all I know he may not even see that he's got a companion there. Uh, and my mother's the same way. We try to be ...we try to put him where we're going to be or where....[end of side 1-tape 2]...I don't want him to think for a moment that he's alone. Because...he has made statements in the past year that you know, they...they've just astounded me with his perception of his incapacities, you know? And by him saying things that make me think he's aware of times that things are all wrong or things or not like they use to be. I wondered to what degree he does know and I would hate for him to think I am laying in this bed all day long, and nobody even comes in this room. I'm sitting in this chair and nobody even says a thing to me. All these people in this room, no one ever says a word to me. I would hate to think that he was aware of that and we didn't address it. So, when he's in the room, and I encourage my children to do this, if my children come in the room to say something to me, I will often tell them to look at grandpa when they're

talking to me because he may think they're talking to him, and he may respond in some way. And they do. They do that a lot. And...and even though he may not be sitting there conversing with us, as we are, I don't want him to think no one even cares enough to say something to him. And the words you say, in a room, a room full of people, or a room with several people, if you say something, it could be addressed to anyone in that room, I feel you should address it to the person who's least likely to just join in, you know what I mean? (mmm-hmm) You know, you can have a room full of people and if you're sitting there talking, and if you make a point to talk, I mean, you're just talking...there's going to be somebody that's gonna automatically respond. But you should be courteous enough to pick up on those people and address that. Mostly to the person you feel would be least apt to respond because of shyness or inhibitions of some kind. So, I'll try to do that with daddy, so he'll feel that he's a part of us. That he's still a part of our family, but we still talk to him...I talk to him about things, what...I have asked him, just yesterday I asked him what he thought about me doing such and such, you know, do you think it'd be alright if I go ahead and do that, and he'd...he'd say, well, I think that'd be alright. Well whether or not he understood what I was saying, I don't know, but he responded. And he knew I was talking to him. He responded as if he was talking...I was talking to him, so you know, you can...I think there's a lot of

what...it may be a combination of things, but that's just the kind of person you are. You're a very caring and sensitive person, and you love your father and you love your parents very much. I think that has a lot to do with it. Uh, it could be the hope, you know, having that hope and also it could be the fact that you're all very well educated and ...

CG: I have...I have a lot of insight; I've always...(I was thinking of that) I've always been able to put myself in somebody else's shoes, you know, and you should put yourself in a sick person's shoes...

DP: Have a lot of empathy.

CG: ...and it just...it makes a lot of difference. And like I said I can't imagine sittin' daddy all day in a wheelchair. never talking to him, never moving him, never looking at those poor little blue legs that they would be blue at one time; I can't imagine that.

[end of interview]