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### Oral History Interview: Ivory Fulks

Ivory Fulks

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ORAL HISTORY

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Date 5/11/89

Ivory Fulks  
(Signature - Interviewee)

Address

Date 5/11/89

Wanda R. Pennington  
(Signature - Witness)

WVACG-16  
Fulks, Ivory

WEST VIRGINIA APPALACHIAN CAREGIVERS

WVACC 16

AN INTERVIEW WITH: Ivory Fulks

CONDUCTED BY: Diana Parnicza

DATES OF INTERVIEW: 5/11/89  
5/18/89  
5/25/89

TRANSCRIPTIONIST/TYPIST: Gina Kehali Kates

DP: This is Diana Parniczka and I am continuing my interviews with caregivers, and It's May 11th, 1989 and I'm Interviewing Caregiver #16. This is Interview A.

CG: ...sugar.

DP: Yeah, okay.

CG: It's low now. He takes ten units of insulin.

DP: Does he eat pretty good?

CG: Not too well, to me...

DP: That's probably why it's low, then.

CG: Well, it got lower in the hospital...

DP: It's been [inaudible]

CG: [inaudible]

DP: Oh!

CG: The doctor said his <sup>?</sup>heart is his [sniffs].

DP: I bet he has a lot of heart pills then, isn't he?

CG: We've heard of 8 different kinds of pills. I don't know what they're all for.

DP: Okay. Now, what...what I'm going to ask you and...and don't...well, I'll....Okay, let me explain this. I've got 90 sentences, 90 of them and it's about family and all you have to answer is true or false. Now, you can take this and read it if you want to and just answer true and false to yourself, but most of the people have been wanting me to read it. 'Cause some if it's hard to understand and things like that.

CG: That's me. I can't read anything .....I can't understand it.

DP: Okay, okay. When I want to tell you some of these sentences are funny, some of them doesn't make a whole lot of sense so, but it....we...so far the people I've talked to who answered this and stuff, we've kind of enjoyed it...it had...it's been interesting. One lady actually said it was fun and stuff, so. But there's a lot of things that's hard to understand so just ask me if you want me to explain things and I'll do my best. Now, first of all [clears throat], tell me about your family, who do you...what...how big is your family and things like this?

CG: How many children?

DP: Okay, yeah.

CG: I've got 6 children.

DP: Do they live around here?

CG: Well, my youngest boy moved down there [inaudible]

DP: Everybody else lives in another state or somewhere else?

CG: Yeah, yeah. All but my oldest daughter; moved to Akron, Ohio. My other two daughters lives plum up around White Springs someplace between White Springs and Virginia [inaudible] some place near Kentucky (okay, okay) and then my other son, he lives in Michigan.

DP: So, you've got what....two, three daughters and three sons?

CG: [inaudible]

DP: And do you all get together much during the year?

CG: Yeah, it's hard to get them together at one time. [laughs]

DP: So, basically you've got your two boys, who live around here

(to talk about)

CG: yeah, yeah, yeah.

DP: Okay. Let me start asking you these and then I guess when I ask you this, you can think about, well, I guess you may be thinking about your kids. Do you have any brothers or sisters that live around or any brothers-in-law, sisters-in-law that live around? So it's mostly your family then it's just your children and in particular, the two boys that live close by. (yeah, yeah)

CG: Two boys that live close by.

DP: They work, they work during the day?

CG: They're truck drivers.

DP: So they're gone alot, too.

CG: Well, they're gone about all week long.

DP: Do they have...are they married? Are they married?

CG: Oh, yeah.

DP: Do their wives sometimes help and stuff like that? (yeah, yeah)

CG: Yeah, any time they come up, yeah, [inaudible]

She keeps this lawn mowed there in the summer time you know. (okay, okay, okay) Then she goes to the store for me, takes me to the doctor, she can drive [laughs] I can't drive (I see) She comes over and takes care of me...takes me to the doctor.

DP: She's a big help. Okay.

CG: Oh, yeah, any time I need her.

DP: Oh, that's nice. Okay. Let's see...number one...family members really help and support one another. Okay, that's

true. It's sounds like it from what you just told me.

CG: Yeah, any time you call them, they're here.

DP: Okay. Family members often keep their feelings to themselves.

CG: Yeah.

DP: They pretty much not talk a whole lot about their feelings? We fight a lot in our family.

CG: No, we all get along good.

DP: Okay, that's good. We don't do things on our family...wait...we don't do things on our own very often in our family. Do kind of work alone or do you pretty much work together?

CG: Yeah, pretty much we do together.

DP: We feel it is important to be the best at whatever you do.

CG: Sure, yeah.

DP: We often talk about political and social problems.

CG: No, I don't know about that.

DP: Okay. We spend most weekends and evenings at home.

CG: Yes.

DP: You especially?

CG: Yeah, they do too....

DP: Okay.

CG: [inaudible] The boys just come over on the weekend, on Sunday, go to church and Sunday School and back you know. [inaudible]

DP: Family members attend church or Sunday School fairly often.

CG: Yes.

DP: Activities in our family are pretty carefully planned. Is everything planned...what you're gonna do?

CG: We don't plan much.

DP: You just call up and say, hey, I need to go to the store or anything like that?

CG: Yeah, that's right, go to the store for me.

DP: Family members are rarely ordered around. That means you pretty much someone pretty much tell people what to do or you all just...

CG: No, we know what we have to do. We all get together - kids come in and the kids take care of what I ask them to do [inaudible] [laughs].

DP: We often seem to be killing time at home. Do you seem to be pretty much, not a whole lot to do? Or does he keep you pretty busy?

CG: No, he don't keep me too busy, you know, give him [inaudible] fix him a little bit to eat.

DP: So, okay, you do watch t.v., wash dishes, stuff like that?

CG: Yeah, I get to watch t.v. all the time.

DP: Do you think, if he, what did you, before he got sick, do you all go out and a lot of things or did you all stay around home?

CG: No, we just stayed here at home, because he didn't [inaudible] anywhere.

DP: Did you all participate in any kind of church activities or things like that?

CG: No, we just went to church.



DP: What did he used to do, was he a fireman or...

CG: Well, he worked in the mines, he was a coal miner.

DP: Which is how he got the black lung?

CG: [inaudible]

DP: Have you always lived here in this house?

CG: We moved in here, I think it was, 1932, 33, and we moved away from it six months.

DP: Why was six months, where did you...

CG: Well, he uh, went to Lake Heirston, New Jersey and got him a job and he took us out there and we stayed six months.

DP: Then you came back here.

CG: Then we came back here and been living here ever since.

DP: Were you born here in Lincoln County?

CG: Yes.

DP: Was he born here in Lincoln County?

CG: All my kids except two have been born irhgt here in this house.

DP: Oh, my goodness.

CG: [laughs] [inaudible] so sickly and they  
[inaudible] And the first one I had her  
right here in the holler.

DP: Did you help, mid-wife, neighbors come and help?

CG: I had a mid-wife, his mother was a midwife, and she delivered all the kids.

DP: Your husband's mother, oh.

CG: Yeah, she was a good midwife. Her grandfather [inaudible]

DP: I heart he retired, Dr. McLenan retired.

CG: Yeah, I heard that he was selling all his stuff out from under [inaudible] I figure that he's sick.

DP: He's been working so long.

CG: Yeah, people will miss him.

DP: You know, when I had...when I took care of patients here he was really helpful. He'd see me whenever I had any questions talking about his patients and everything; he was always helpful. Okay. We say anything we want to around home.

CG: Yeah [laughs].

DP: Unfortunately, sometimes, ha?

CG: Yeah.

DP: Family members rarely become openly angry. You all, do you keep it to yourself? Or do you all tell each other about it? Keep it to yourself?

CG: Keep it to yourself.

DP: In our family we are strongly encouraged to be independent.

CG: That would be true.

DP: Getting ahead in life is very important in our family.

CG: I say it is, should be in everybody's family.

DP: We rarely go to lectures, plays or concerts.

CG: [inaudible]

DP: Friends often come over to dinner or to visit. Do you have a whole lot of friends around here?

CG: Well, I think of them all as my friends. If I was to call on them, they would be right here.

DP: Okay, all your neighbors.

CG: They see if I need anything; they're right here any time he gets sick; I didn't even want my neighbors in the house live right across the road here .

DP: We don't say prayers in our family.

CG: Not out loud, anyway, we say ours.

DP: We are generally very neat and orderly.

CG: Yeah.

DP: I can tell by looking. There are very few rules to follow in our family. You have any rules you follow or?

CG: No.

DP: We put a lot of energy into what we do at home.

CG: Oh, I guess we do.

DP: It's hard to blow off steam at home without upsetting someone. People usually your son, your people, that they usually get upset if you're angry. Can you tell them how they feel things or do you even talk it out?

CG: [inaudible]....talk it out [inaudible]...

DP: Family members sometimes get so angry they throw things.

CG: No.

DP: We think things out for ourselves in our family.

CG: Yes.

DP: How much money a person makes is not very important to us.

CG: No way.

DP: Learning about new and different things is very important in our family.

CG: I don't think so too much.

DP: Nobody in our family is active in sports, little league, bowling. Does uh, do you have any grandchildren?

CG: Sure, I've got about 16 or 17...

DP: Oh, my goodness.

CG: Twenty-something, great grandchildren.

DP: Oh, my goodness.

CG: And expecting two more.

DP: Oh, my goodness. De...Decide...do they have your sons that live around here they've got grandchildren?

CG: Oh, yeah, they've all got grandchildren but their littlest daughter, she don't need to have no children. [laughs]

DP: Oh, my goodness.

CG: And she's only 20 years old.

DP: We often talk about the religious meaning of Christmas and other holidays.

CG: No, we don't never get together to talk about stuff like that.

DP: Do you...okay, do you all get together at Christmas?

CG: No, Thanksgiving sometimes family comes over here and come to dinner.

DP: Okay. It's often hard to find things when you need them in our household.

CG: Not too hard, no.

DP: Okay. There's one family member that makes most of the decisions. What about you, do you make most of the decisions or do you talk about them with your children or do you talk about them with your husband?

CG: No, I never talk anything like that over.

DP: If something needs to be done or fixed, you go ahead and do it.

CG: Yeah, yeah, I do it, if anything needs to be done around here, I go do it. I just tell them, tell them that it's done.

DP: Okay. There's a feeling of togetherness in our family.

CG: Yes.

DP: We tell each other about our personal problems.

CG: Yes.

DP: Family members hardly ever lose their tempers.

CG: Sure

DP: We come and go as we want to in our family.

CG: Yeah.

DP: We believe in competition and may the best man win.

CG: Now what does that mean?

DP: Does that...like your (every man for themselves?) no, it's like, like I was trying like in contest that one man, one person against another person and you believe that you're out for yourself and hope that maybe the best man win. You know, your trying one's trying, to always be better than ...than the other person.

CG: No, not in this family...[inaudible]

DP: Well, that's what I'm finding out. Well like one some...one lady had a daughter and a son-in-law that she could talk to alot about 'cause her husband can't talk or anything, like that pretty much people believe in keeping in their feelings.

CG: Yes, we discuss none of our problems [inaudible]...

DP: Okay and work it out yourself.

CG: [inaudible]

DP: Yeah, I think that I'd...that's family...we are not that interested in cultural activities. That means going to I guess concerts and eating food from different (Latin inns) and stuff like that.

CG: No.

DP: And we often go to movies, games, camping.

CG: No.

DP: See what I mean by some of these questions. This one lady, it was funny, I was listening on a tape she just started laughing cause it was just (yeah)...okay, let's see, we don't believe in Heaven or Hell.

CG: Now I believe in Heaven; I believe in it strong.

DP: Being on time is very important in our family.

CG: [inaudible]

DP: There are set ways of doing things at home.

CG: There are some things that are [inaudible]...

DP: We rarely volunteer when something has to be done at home.

CG: [inaudible]

DP: It sounds like maybe your children they jump right in and volunteer (oh, yeah) that's what from talking sounds like. If we feel like doing something on the spur of the moment, we often just pick up and go.

CG: Yeah...[inaudible].... (okay) See we don't plan anything ...something comes up (happens you can't do it)

can't do it, that's right.

DP: You know, I'm I'm sure I like to plan things I like to have do this and this, and this and this. But I'm finding by talking to ...to people like you and stuff, and I'm finding with my own self that you're right once you plan something, something usually happens. So you got to take it as it comes and (yeah) make the best of it (that's true).

CG: You wanna go someplace, throw a few things in a suitcase and go on and stay a few days. No, not planning no, we don't plan.

DP: Okay. Family members often criticize each other. There's very little privacy in our family.

CG: Yeah, our family has plenty privacy.

DP: We always strive to do things just a little better the next time.

CG: [laughs] I imagine just about all of us do that (yeah, I yeah).

DP: We rarely have intellectual discussions. That means talking about educational things and stuff like that [pause]..

CG: ??

DP: Everyone in our family has a hobby or two. Do your children have hobbies, things they like to do or do you have any hobbies or your husband?

CG: No (Okay) the kids might have a few they like to do li kes to now (really?) yes.

DP: I've never done it but I've talked to people that have and they love it; they go all the time and everything (??) Does she live around here, no, she's probably out...

CG: No, she's in Kentucky...

CG: Down they call it, I call it up.

DP: You know, I used to live in Pikeville, Kentucky, but it's not....I don't think it's that close; I think she lives more central. I think Pikeville's more . Okay, family members have strict ideas about what is right and wrong.

CG: I imagine.....

DP: People change they're minds often in our family.

CG: No, I don't think they do.

DP: There is a strong emphasis on following rules in our family.

[pause]

CG: Well, I reckon' try to follow the rules

DP: Okay, like when things that you should do that are right, verses things that are wrong, things like that.

CG: Uh-huh, yeah.

DP: Family members really back each other up.

CG: Yeah.

DP: Someone usually gets upset if you complain in our family.

CG: Yeah, I know I do.

DP: Okay, family members sometimes hit each other.

CG: No, no.

DP: Family members almost always rely on themselves when a problem comes up.



CG: We try to.

DP: Family members rarely worry about job promotions, school grades, and things like that.

CG: I don't think so.

DP: Okay, someone in our family plays a musical instrument. Any of your children play a musical instrument?

CG: No.

DP: Family members are not very involved in activities outside work or school.

CG: [inaudible]

DP: We believe that there are some things you just have to take on faith.

CG: I think that's true.

DP: Family members make sure their rooms are neat.

CG: Yeah.

DP: Everyone has equal say in our family decisions.

CG: [inaudible]

DP: Okay, you mean like...

CG: They decide on their own.

DP: You pretty much let them decide on their own.

CG: Yeah, I don't try to tell them what to do, they're all old enough to know what they want to do.

DP: Okay. I see. Do you...do you sometimes I think that my parent, my mother was.....do you sometimes say like I disagree with what you're doing, but you can go on and do it or do you even say that you don't say anything at all.

CG: No.

DP: You feel like (That's for them) that's for them. They don't

need to know how you feel about it.

CG: [inaudible]

DP: Has any of them gotten "burned" or had to get a divorce or anything like that?

CG: "Nutty" did, but his wife went off and left him, 'cause that was his fault.

DP: Yeah, but he...did you, did you he need you or did he need your support at the time and stuff, like that, or he pretty much stayed to himself.

CG: Well, he has three boys; one of them came out here and stayed with me 'cause he had to work you know, and goes to school.

DP: He has three boys?

CG: Three little boys, they were small too. He raised them, raised them boys.

[end of side 1???

DP: This is Diana Parnicza, continuing my interviews with caregivers. This is Interview B on Caregiver #16. And this is May the 18th, 1989.

CG: ...came in here and sit down and forget all about it. Look in there and see all the smoke [laughs]. I happen to think about it and go in there and maybe it's burnt. [laughs]

DP: One time I did that. I left something on all night. And I just had to throw the pan and everything out. Okay. What I wanna ask you today is, I want to get some information about you and then I want to get some information about all the different kinds of help. People and things that come in and help.

CG: [laughs] That's easy.

DP: Yeah, I was...I was thinking, but anyway. Let's see. How old are you?

CG: I'll be 75

DP: And you're married and you're his wife and do you have any special religion?

CG: No, [inaudible-fading out]

DP: Okay. And, let's see, did you ever work anywhere?

CG: Yeah. I worked two terms up here at the school house helping to cook.

DP: Oh, okay.

CG: Matter of fact, I think it was 60s. [inaudible]

DP: Most of the other time you stayed here at the house.

CG: (and worked here?) Well, uh, I worked for uh, his uncle,  
Welfare paid me. (Mmm, okay) [inaudible]

But I'd come back home every day. I got the weekends off.

DP: How long did you do that?

CG: I think it was a year.

DP: Did you work anywhere else? (no) Okay. How far have you  
gone in school? What grade did you go to?

CG: I think it was about the sixth grade.

DP: Okay. And about how much money do you all make a year? Is  
it below 10,000 or 10-15,000, or 15-20? Just roughly.

CG: Well, we only draw....they rased our social security and  
black lung to nine hundred and somethin'. We started out at  
about or something, and then they took a raise

DP: So you got about nine hundred a month? (yeah) Okay.

CG: [inaudible]

DP: Okay. And that's his social security and everything.

CG: Social security and black lung.

DP: Okay. Now with your help, you say you've had problems with  
uh, kidney stones before, right?

CG: Un-huh, kidney stones....

DP: And, what else?

CG: [inaudible]..... bladder operated on.....

DP: Does it leak?

CG: No, it's out. [inaudible]

DP: Okay. And just you and your husband live here, right?

CG: Yeah.

DP: Now, do you drive? If you need to go somewhere, your daughter-in-law....

CG: My daughter-in-law takes me.

DP: Okay. And she has a car, right?

CG: Yeah. [inaudible]

It was just sittin' down there in the garage .....(and no one was using it?) No one was using it. He can't drive and I can't drive. [inaudible]

DP: Yeah, did it run pretty good when you all used it? (oh, yeah - inaudible) No one in family needed it?

CG: Well, my grandson sell it, he'd buy it,

DP: Okay, and you've got a telephone and water and electricity and plumbing. How long have you been taking care of your husband?

CG: I've been taking care of him, well he hasn't been down bedfast, but I've been taking care of him about 17 years.

DP: How many ...how long has he been bedfast?

CG: I'd say he's been bedfast about 2 months now.

DP: Okay. Okay. And if you came...about how many hours...how many hours a day you spend taking care of your husband?

CG: I don't know. [inaudible]

DP: Okay, I...24 hours, pretty much?

CG: [inaudible]

DP: Because he's up at night?

CG: No, he's not up, he's just wantin' something you know.

[inaudible]

DP: So he just hollers (yeah he...) hollers and wakes you up.

CG: He just hollers at me and I get up.....

....sit up maybe an hour or two at night.

DP: Then you don't get much sleep, do you?

CG: [inaudible]

DP: Okay. This is about the different kinds of help that you get. I'm just gonna ask you this question and you tell me just what comes to mind. How do you manage caring for your husband?

CG: Well, I cook for him and I feed him and bath him, change his bed....whatever has to be done for him.

DP: You pretty much do it all?

CG: I do it all, yes.

DP: What is there anyone that comes in and helps you do anything in the house?

CG: [inaudible]

DP: Okay, you do everything for him on your own. Does anyone come in and help you clean the house?

CG: Well, my children comes and goes. They come in [inaudible]....

two or three months or something, or just whenever they can get off work.

DP: What about cutting the yard and stuff? Do you have ....

CG: Well, now my daughter-in-law does all that mowing and her husband, my son. When he's at home, he helps with the mowing and stuff.

DP: Okay. What if something breaks down in the house? Do they come....are they the ones that you'd call to come and get it fixed?

CG: Well, if he was at home I would, but they ain't home though. They're truck drivers and they're on the road all the time, gone, all week. On weekends....

DP: Is there someone else that you can call or do you just let it stay broken till they get home?

CG: [inaudible]....just mostly let it go.

DP: And for the grocery, then you go whenever your daughter-in-law (no...) she goes?

CG: She goes to the store for me all the time.

DP: You give her the list, that's right.

CG: .....been to the store, let's see, the first of this month [inaudible] below Branchland and got me two cans of pop and that's the last time I've been in the store or anywhere.

DP: So you haven't left this house since then.

CG: No, I don't leave the house. I hardly ever get out in the yard.

DP: So, then, when you do get help, it's mainly your daughter-in-law and son. Right? (yeah)

CG: [inaudible]

DP: Yeah. Uh, the nurse just came and took blood, that's all she did, wasn't it?

CG: Yeah, but she hadn't been here though in just, I didn't know if she'd come this week or not; she come last week.

DP: Do the laxatives kind of help him? Do they help his bowels to move?

CG: Uh, well this is the first laxative ...I mean uh, pills I've give him. I give him Milk of Magnesia and they...it moved his bowels but the last they give him

DP: How long has it been since his bowels have moved?

CG: I don't know. I think about 3, maybe 4 days (okay) They generally move well they moved good every day and then they just quit. They move about twice a week. The nurse said that every 2 or 3 days was...

DP: And it was fine. (yeah) Okay, let's see. What about...talking about help, we've gone over pretty much the physical help you get. Things people do. What about emotional help. Do you feel like you ...you need emotional help or is there anyone that you can talk to or anything that you can read or is there any certain t.v. show that helps you emotionally or...

CG: Oh, I watch t.v. a lot. Off and on, you know, when I'm not taking care of him.

DP: Do you read? Is there any thing that helps you, like when



you get really depressed or when you get frustrated or...

CG: Yeah, my daughter-in-law down there, she gets these little uh, true story magazines and this uh, guide post, they call it.

DP: And you read those?

CG: Yeah. I get the reader's digest.

DP: Okay.

CG: I read them.

DP: Is there anyone you can talk to if you've got a problem? Like if you get really tired or anything or feel frustrated or anything...there's no one that you know of that you can talk to? Not the minister or the neighbor or your daughter-in-law or anybody?

CG: Well, if I'd call 'em they'd come, yeah.

DP: But you usually....

CG:

DP: But they...usually you just ....keep it to yourself?

CG: Occupy my mind with something.

DP: Um, with your daughter-in-law that comes in and helps you and and your neighbors, do you have to call them or do they pretty much just come in on their own and volunteer?

CG: Well, I'd probably have to call 'em if I needed 'em. (okay)  
But they never come in and do anything.

DP: And checks....

CG: [inaudible]

DP: Now, so, pretty much though you just have your daughter-in-law in to help you and your son when he's around, and that's

pretty much it, isn't it?

CG: That's pretty much it.

DP: When the nurse came to get his blood, is ....how did you find out about the nurse coming here?

CG: Well, they told me at the hospital. When they released him from the hospital. That uh, they'd be a nurse comin' about once for three weeks but they come for four. (to get his blood) And they always call before they come.

DP: Okay. Do you pay your daughter-in-law or son or anyone or anything? Okay.

CG: No, they do it free of charge.

DP: And let me see this. Your daughter-in-law and son, if he's there, they come and clean the house whenever they can and get the yard cut. Take you all places that you need to go to; they go to the grocery for you; and like take him to the doctors' if he needs to go or things like that. (yeah) Do you get to go out to church or anything?

CG: No....(Church doesn't come in here?) No.

DP: Okay. Uh....and basically your daughter....I say, how often she comes. Basically it's ...she at least stops by every day. (not every day she don't). About every other day? Or...

CG: She comes over down here.

DP: Um, so it looks like to me if you had to pick the kind of help you get, that's the most important, it'd be your daughter-in-law, wouldn't it?

CG: Yeah. Oh, if I'd call 'em they'd come and do it. They'll

come and do anything you want 'em to. [inaudible]

I've been healthy most of my life and and uh [inaudible]  
never did have to call on nobody to help.

DP: Then you ....like to keep it that way as long as you can.

CG: Yeah, yeah, as long as I can. [inaudible]

I just make my bed and strip his bed and wash and bath him  
and cook for him. [inaudible]. . . all I have to do is throw  
my clothes in the washer and hang 'em up to dry. I don't  
have to [inaudible]...

DP: That makes it nice, doesn't it?

CG: Yeah it does.

DP: If...if, someone came and said, we'll give you anything you  
need or do anything you want us to do, to help you take care  
of your husband, what would it be? Can you think of  
anything that you need help with that you're not getting  
help with right now?

CG: [inaudible]

DP: So you pretty much can't think of ...what about...would it  
help if someone could come in here and bathe him every day  
for you?

CG: Yeah, it would help, yeah, but...he don't need bathing every  
day.

DP: Okay. Uh...

CG: Now, in the summertime, after it gets hot, I have to...

DP: You know they have an aide here in the Health...here in  
Lincoln County that does go to people's homes and bathes  
them.

CG: I don't know if there are or not.

DP: Yeah, there is. Uh, I might mention it to the nurse just to see. If you're interested in it.

CG: Well, I'd like them to if they could.

DP: Okay.

CG: Cause it just about gets me when I have to bathe him and shave him. My back hurts me so bad, you know....

DP: Maybe the next time I come and visit, we can plan it to where you're gonna bathe him and shave him, and I can help you. (yeah) We....we'll see. I can ...uh, there is an aide and I'll see what needs to be done to get her out here. To help you. I know one family I visited, she goes out there every day and it takes about an hour. And she bathes him and shaves him and does whatever needs to be done (yeah). Uh, but I don't know the cost that Medicare pays, how much they pay and stuff like that, but (I don't know either) I'll...if nothing else, I'll have one of the nurses call you. I'll tell 'em that you're interested and just to see and maybe they can...I'll have 'em get in contact with you, or else they tell me and I can tell you. Okay?

CG: Yeah, we'll see about it.

DP: Okay. Uh, so there's nothing really, except maybe the bathing, you...the washing isn't bad. You can do that okay. (yeah) of course we could always use more money. (yeah) What about you? Would you like to have...if someone said I'll come here and sit with your husband, for the next 4

hours in the afternoon, and you can go do whatever you want to do, would that be important to you to do that?

CG: I don't know.

DP: You know...

CG: He worries too much when I get out of his sight.

DP: He likes you right there. And what about would you worry if you left? And went someplace, too? (yeah, yeah) Yeah, okay. Uh, do one more thing for me and then I'll be through. What I'd like for you to do is tell me...describe an average day for you. What you do during the day...about what time do you get up? Now this...we're assuming that you've sleep all night, okay? [laughs]

CG: I get around 8 o'clock. (okay)

DP: And what do you do then?

CG: I fix his breakfast (okay) give him something to eat and feed the hens, and then I fix my own breakfast. (okay) Make my bed (okay) and that's about all I do.

DP: Okay (wash up the dishes; sometimes; sometimes I leave 'em). I'll have maybe a couple of saucers and teacups. [inaudible]) Yeah, you're like me. When they start reachin' the ceiling, you know then you need to ....[laughs] might need to wash.

CG: I pretty well keep 'em clean.

DP: Okay, after you get your breakfast and make the beds and stuff then, if it's your day to bath him, do you go on...do you bath him then?

CG: Yeah.

DP: Okay.

CG: I stripped his bed this morning and cleaned it while he was sittin' up.

DP: Okay. And you usually do that about twice a week? (yeah) Okay. Okay, then after that, what do you do? You come in here and watch t.v. or (yeah) or walk around the house or pick up and stuff?

CG: No, [inaudible]....(you watch t.v.?) I watch t.v. mostly. There ain't no kids here and [laughs] there ain't nothing to pick up.

DP: Except for yourself, huh. You don't care about that, huh?! Okay. About what time do you all eat lunch?

CG: I generally try to have something about 12:00.

DP: Okay. So then you fix lunch for him and then something for you. (yeah) And then after lunch, pretty much come back and watch t.v. (yeah, if I ain't got nothing else I wanta do) Um, do you sew or (no) anything like that (no) okay.

CG: I use to but I don't any more.

DP: And then....

CG: ....I make quilts. [inaudible]

DP: Why don't you any more?

CG: [laughs] I don't

I give 'em to my kids and grand kids (okay).

DP: What...about what time then do you have uh, supper?

CG: Well, I don't have no particular time that I have that. I'd say between six and seven o'clock (okay) most of the time.

DP: And then you fix his and fix yours (yeah). And then about what time do you...do you have to get, like get him ready

for bed and stuff?

CG: Oh, he's already in the bed [laughs].

DP: Okay, so, he just...what time does he go to sleep, then?

CG: Oh, I couldn't tell you.

DP: Okay. Just...(sometimes it's late in the morning before he goes to sleep) And then you just pretty much watch t.v. until you go to bed?

CG: Yeah.

DP: About what time do you go to bed?

CG: I try to get to bed about 9:00 (okay) I try to give him his last medicine and...

DP: Okay. That's right...you give him his medicines, don't you?

CG: Yeah.

DP: And you give him his insulin shots, don't you?

CG: Yeah. [inaudible].... as the old saying is.

DP: And you get him ...help him to the bath....potty.

CG: Yeah. I help him out of the bed and back in the bed.

DP: Mmm. I can't...well, I'll be back again; I'll go over this and see if I can figure anything. (yeah) But I'll uh, check on that aide, about coming in and ...cause I think that would help you a lot.

CG: Yeah, I know it would.

DP: I'll get all the information that I can. It may be...I'll have to see. It may be that he might ...I'll just check...I'll just check and see, let's see, this is...I'll check and see and see what I can find out. And I'll call you. It may be a couple of weeks, okay? Before you hear

from me. But if uh, if you want to, you know, if the aide's not startin' out here and something happens, whatever, well when I call you we can see, maybe we can plan it on a day whenever you hav...whenever you're gonna bathe him and stuff and then I can bathe him for you. You can just help me get the water in there. And I can bathe him. This one lady, I washed her husband's hair and shaved him, cause she had arthritis real bad and can't do that. (yeah) I don't mind do that at all.

CG: [inaudible]

DP: Well, it's kind...it's....

CG: [inaudible]

DP: Yeah, you might need to go to the doctor and get...you might have a bladder infection or something maybe, that's causing your back pain, too.

CG: I don't know what it is.

DP: But it seems like it's gettin' worse.

CG: Sometimes it is.

DP: Cause I can tell the way you're sittin' in the chair and trying to get comfortable that it...it's hurtin' you. (yeah it is) and you might need to ....

CG: It didn't hurt too much yesterday evening....

[end of Interview B]



This is Diana Parnicza continuing with my interviews on Caregivers. This is Caregiver #16 and it is May the 26th, 1989. You know this is...this is my last visit (well) with you. So I just want to make sure that the things we've talked about I've got right, but also, I'll probably call you. I'm gonna try and find...get some information today. I'll either call you this week or next week and let you know what I found out about someone...if someone can come in and help you. What do you have...allergies?

CG: I ...something. I don't know what it is. I've had it three years. My head stops up on me and....[laughs] ...here it is 10:00.

DP: It's later than....half the morning's gone. (yeah, yeah, it sure is).

CG: ....but not so long, but the [inaudible]...and the nights are supposed to be shorter, but seem like they get longer. [laughs]

DP: Well, I'll bet they do because he's in the bed (yeah) and he can't do anything.

CG: [inaudible]....well, I said, there ain't nothing you can do. I said, just lay there in the bed.

DP: Does he like to...can he...you think that he could, if it was ever pretty outside or anything, do you think he could make it outside?

CG: I don't know if he can or not. I'm kindly afraid to take him out right now. [inaudible]....and him so weak and everything.

DP: And there's a wheelchair out there. Does he do pretty good in the wheelchair?

CG: I never have got him in it. (ohhh) We always, when we was takin' him to the doctor, we'd put him in a wheelchair and take him out to the car and put him in and [inaudible]...

DP: Okay.

CG: [inaudible]

DP: Who does he go see...who's his doctor?

CG: Uh, Charles Turner.

DP: Okay. Uh, did Medicare....Medicare help you get the wheelchair and the bed, things like that? (yeah) Now, do they pay for it or do you have to pay every month? Pay something on it every month?

CG: I don't know. They nev...I have never got nothing from 'em or nothing. They said uh, Medicare would pay the 80% and then my benefit pays 'em 20, so I don't know.

DP: But now uh, you had to have a doctor to tell 'em that you needed one, right?

CG: Oh, yeah, [inaudible]....

DP: Okay. Well, like I say, I'm gonna see what I can find out about someone coming in, and helping out. But I don't know if I'll have any luck or not, but I'll let you know (yeah). There's a couple more places I'm gonna call and see. Uh, but basically, but let me make sure I've got this right. You...you pretty much...all your days and nights and everything pretty much take...center around you taking care of him. (yeah) There's not...anything else that you do. I

mean, you've got someone that goes to the grocery (oh, yeah) for you and stuff like that now, and basically the people that help you are....is your son....two sons and daughters-in-laws, right?

CG: Yeah, that's about the only ones that uh, helps any, and they don't do too much. They don't come in and help with him. They just do the work outside.

DP: They do outside and then maybe come in here and vacuum or something.

CG: Well, they would, yeah. But I never have asked them.

DP: Okay.

CG: [inaudible] stayed with him while I had to go to the doctor myself and she stayed with him.

DP: Okay. And do the other daughters-in-law take you to the doctor?

CG: Yeah, she drives and ....

DP: So you can't...you don't leave the house unless you've got someone that stays here and watches him, right?

CG: That's right. And I don't hardly leave the house. Last Saturday, I believe it was, I went over to the store and stayed about 30 minutes. I get out of his sight [inaudible]

DP: Does he...can he stay by himself? If you like...when you went to the store, you had someone to watch him when you went to the grocery last time?

CG: Yeah. My son, he lives down there in the trailer, he stayed with him. [inaudible]

DP: Are there things that you would like to do? Go...are there

places you'd like to go, things you'd like to do? If you could?

CG: If I could. [inaudible]

He comes first.

DP: Okay. And...well, I remember with this one lady I talked to, she said even if she does go someplace she worries all the time. (yeah) About...she takes care of her mother; she says she worries all the time about her mother when she's gone.

CG: [inaudible]

DP: He wants you right here so he can...knows you're okay and everything.

CG:

DP: And you know what he wants and needs and everything and that helps.

CG: Yeah. Yeah.

DP: And you...it's basically been like this what...uh, since this winter? (yeah) Where you can't go or do anything cause he's pretty much been in the bed. (yeah)

CG:

DP: Okay. Uhm, and the only time you've had someone besides your family helping [tape fades out-end of side2]

[side 1 of tape 2]

DP: You know you had family that could help you; your sons and daughters-in-law and if you'd ask them to come and help you, they would, but you don't; you don't want to ask them.

CG: No.

DP: How come...how come you don't...

CG: I was always able to do what I wanted to do myself and I always ...I don't know I just can't ...can't ask them to do nothing unless I just have to...

DP: I...your not the only one that said that. Three people I've talked to so far have said that and that's why I'm...I'm wondering that you know what it is that, and I guess it is that feeling of trying to take care of yourself until you just really can't take care of yourself (yeah, yeah, that's right).

CG: I said that if he got to he couldn't, couldn't get out of the bed, then I would ask for some help.

DP: Yeah, they'd have to lift him and stuff like that (yeah, I can't lift him). Yeah.

CG: [inaudible]

DP: Have you thought about that...what happens if he gets to where he can't get out of the bed. Have you talked about that with your children or anything? (No) Just pretty much wait and see when that happens.

CG: Just wait and see what...what...what happens. Well, the doctor told him when he ...when he released him to come talk to him when needs help [inaudible]....

DP: But that...but the doctor got your family together and told them that you'd need the help.

CG: Yeah, yeah, yeah.

DP: How did they...what did they say?

CG: Never one of them has ever said a word (hmm). Not a one has said a word.

DP: Have you ever thought about putting him in a nursing home or personal care home or anything like that? (he's going to stay where he's at) You're going to keep him here as long as you can.

CG: Yeah.

DP: That's what everybody I talk to that's what they say.

CG: I said no.

DP: He wanted ...he did want you to put him in a home.

CG: [inaudible]

DP: Well, I can't ....from what I've seen, what you've done I mean it's just....and there's not too many people who would do that, you know and I wanna tell you that everyone I've talked to, this is what I think is

Everyone I've talked to is the same. They want them here at the home until they possibly can not you know (yeah) no longer do it and there's just no other thing to do. That's the way it should be and that's the way they want it to be (that's the way I want it to). [clears throat]

CG: He has to have medication.

DP: I think though sometimes people surprise themselves. I've been in the homes where they've had tubes down their nose and in their stomach to be (yeah) feed or they've had the cathater and things like that and once they're taught how to

do it and stuff, they do it. Just fine (yeah). They really surprise themselves (yeah) what they can do. But I agree that if it got that bad, you would need the extra help (yeah) and of course you could have the help that way and stuff (uh, yeah). So, you basically feel that with the help that you're getting, okay, and you've got neighbors who can help (oh, yeah anytime I call them). But that's if you call them. But you really haven't called them (no, I haven't had to) for anything. Because you ....okay, because you haven't had to.

CG: Yeah.

DP: But basically you feel...you feel like you're doing okay.

CG: Yeah.

DP: You feel like sometimes you could, you wish, well, we talked about that last time about having someone come in and bathe him and stuff (yeah) tht would help a lot because that is especially when you got and your sick yourself. It's hard on you and everything.

CG: Yeah, but I do the best I can. That's what I told the doctor. I'd do the best I could do. That's all I can do.

DP: Uh, I think the fact that he doesn't have any sores, you know, a lot of times they get sores like that you know and he doesn't have any sores and you know he looks ...his still even though he's lost weight he looks good and everything like that. But it wears you down, doesn't it?

CG: Yes, sometimes.

DP: Having to stay up all night and....

CG: [inaudible]

much as I can everybody (yeah)....

DP: Yeah, see if I'm right here from talking to you and talking to a lot of the other people I've talked to, it seems like even though they're some things you can't do, that you want to do and even though it wears you down, staying up days and nights and can't leave the house and things like that, you wouldn't have it any other way, would you? (CG: inaudible)  
This is the way you want it.

CG: [inaudible] (Makes you wonder).

DP: That may change; it may not.

CG: Yeah [inaudible]

DP: But like you say, he worries and then you worry.

CG: Yeah.

DP: Well, can you think of anything else you'd rather say or anything.

CG: No, not anything.

DP: Well, like I said before I'll ....

[end of Interview c]