



Faces

of Long Term Care

Residents speak about
Long Term Care:

A message to the
2005 White House
Conference on Aging

A project of the North Carolina Regional Long Term Care Ombudsman Association
NCRLTCOA is a subcommittee of the NC Association of Area Agencies on Aging

"FACES of Long Term Care..." was produced by the North Carolina Regional Long Term Care Ombudsman Association in response to the many local "Mini White House Conference on Aging" events that were held throughout the state of North Carolina in 2005, leading up to the official White House Conference on Aging (WHCOA) in December of 2005. Many of the recommendations sent to Washington, DC from our state will affect residents living in long term care facilities, but may not have included *input* from them. This document was presented to the North Carolina delegation to the National WHCOA in early December, 2005.

The stories you are about to read come from people who will be directly affected by the outcomes of the WHCOA. These are the words of those who must live with the results of social and fiscal policies that will be set by our government in the coming years. Some of the residents' words are narratives; some are direct quotes. They've been edited for space in some cases, but we've tried to maintain the spirit of their words, however uncomfortable those words might make us.

The North Carolina Regional Long Term Care Ombudsman Association hopes this document gives you a glimpse into the often unseen world of some of our most vulnerable citizens. We hope you come away with an understanding that they have valuable input to give in the direction our Nation's leaders take around aging issues. We hope you will come to know them not as patients living out their remaining years in helplessness, but as self-determined human beings who still have life left to live and valuable contributions to make in our world.

Heartfelt thanks goes to the amazing residents who agreed to share their stories and their ideas with us. To me, they are heroes and teachers; their determination inspires me to get up in the morning and do the job I do.

Andrea Reese, Regional Long Term Care Ombudsman
Editor, FACES of Long Term Care



It is far too easy to become so focused on the nuances of rules and regulations that we lose sight of their purpose. It is even easier for those not directly involved in or aware of long term care to lack understanding of life in a care facility. As we travel the highways and byways of our state carrying out our daily activities we pass homes and facilities where caregiving is underway without ever giving much thought as to what the lives are like for those who call these places home.

I want to thank the NC Regional Long Term Care Ombudsman Association, with support from the NC Association of Area Agencies on Aging, in bringing the faces and voices of residents to us and for reminding us of why we do what we do as public servants, advocates, and providers.

As I read through the profiles of these nursing facilities and adult care home residents, I am struck by the frankness, resiliency, and strength shown by these individuals who others often consider frail or impaired. These residents show us that people of all ages and backgrounds can need long term care at some point in their lives for any number of reasons. We are reminded that while most long term care is provided informally by family and friends in the home, others see the necessity and value of care in a group residence or facility and can adjust well to this major life change.

The residents' comments also illustrate the challenges of group living and identify the many opportunities for providers and the community at large to help address issues that run from mundane to complex. These individuals illustrate the importance of being consumer-centered. Their voices echo a tremendous desire for people to make a difference in the lives of others. Their voices are articulate in sharing what can and should happen to improve the quality of care and living for those residing in facilities. They want to be valued for their continued contributions, not just viewed as users of services.

The Faces we see and the stories we read in this document should provide hope for our own futures and greater resolve to create an awareness and appreciation of efforts to support residents as they strive to maintain their dignity and quality of life. We must become increasingly committed to listening to the voices and seeing the faces of those currently receiving long-term care services and supports, whether care occurs in the home, community, or a facility setting.

Dennis Streets, Director
Division of Aging and Adult Services
NC Department of Health & Human Services

Once every 10 years our nation's leaders convene a White House Conference on Aging focused on Aging and Older Americans. The mission of the White House Conference on Aging is to provide a national forum focused on major issues that have impact on Older Americans and aging in our country today. There are thousands of knowledgeable, capable and socially conscientious older Americans living in long term care facilities across America who contributed their influence, skills and talents to shape our great country. Their collective wisdom and life experiences merit that their voices be heard as decisions about new directions in national policy are being forged at the 2005 White House Conference on Aging. In this spirit, the North Carolina Regional Long Term Care Ombudsman Association created "FACES of Long Term Care" as a vehicle to empower the voices of long term care residents from North Carolina who are interested in contributing their thoughts to the decision making process about future aging policies that definitely will affect older and disabled Americans who will rely on long term health care outside of their homes in the coming years.

Sharon C. Wilder
North Carolina State Long Term Care Ombudsman



I want to thank the NC Regional Long Term Care Ombudsmen for helping us focus on what is really important about what we do. It is the people we serve. They are not just residents, statistics or cases, they are people of all ages and backgrounds who needed long term care at some point in their lives for any number of reasons. So often we forget about what lives are like for those that call long term care facilities home in North Carolina.

The profiles shown in this FACES project show us the strength, talents, and remind us of past community contributions of these individuals which are often seen as just impaired or frail old folks. Their comments show us the challenges of living in group facilities, but at the same time provides us with opportunities to help address issues, whether great or small, that they face on a daily basis.

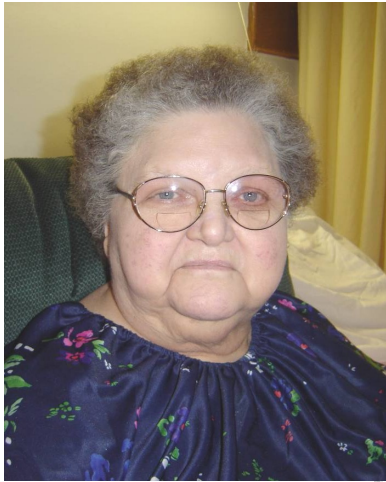
The stories that we read should make us resolve to create an appreciation for the efforts of those like the Long Term Care Ombudsman and the Community Advisory Committees who work diligently to help these residents maintain their dignity and quality of life. The North Carolina Association of Area Agencies is proud of the work that the Ombudsmen do and are committed to listening to the voices and seeing the faces of those currently in Long Term Care and those who will reside there in the future.

It is our sincere hope that this project will help put a FACE on long term care residents when we are talking with those who make policy, create rules and regulations and approve funding for the vital services that you provide.

Mary P. Barker, Chairman
NC Association of Area Agencies on Aging

**For my part I have two eyes which I make
use of, one fixed on the ground on the
lookout for practical things immediately
realizable, the other looking upward
toward the ideal.**

John Burns



Pauline H.
Alexander County, NC
Age: 74
Years in long term care: 2.5
Occupation: Gas Station Cashier
Accomplishments: "Accepting the Lord, because, if you have the Lord, you can go a long way."

"I was the 3rd oldest of five girls... We were very poor but we made it along. We lived way out in the country and we did not have a way to travel to town. We had to walk everywhere. I always enjoyed going to church... I married my husband when I was 15. He used to come by my house on his way to work. He worked at the sawmills. One day he saw me and I saw him. We

fell in love and got married six months later. He was the best husband... (He) died of a massive stroke in 2003. We were married for 57 years. I have five children..."

On Aging: "I take one day at a time. What's to be will be and I try to make the best of it. I think I take it pretty good. Sometimes, like the other day, a lady brought a big apple and I thought if I was at home I would make a pie. Sometimes I think about cooking for the family at Christmas and holidays... and I miss that. I don't have any fears about growing old."

On living in a nursing home: "Everyone so far has been good to me. If they weren't, I would have a lot of complaints... The food is alright. You can't have what you want at every meal, but I'm satisfied..."

On improving long term care: "... It would be nice to have more private rooms and the price not increase."



Veorah M.
Robeson County, NC
Age: 74
Occupation: Raising her children and factory work

Veorah raised seven children and says family was an important part of her life as a child.

On growing older: She does not like the idea of growing older, especially in a nursing home. "Old people are not respected like they used to be."

On living in long term care: Having visitors to talk to is the best part of her day.

On improving long term care: The way food is prepared has been the most difficult adjustment for Veorah. "The food is not the way I would cook it... especially the seasoning." She also feels that the facility needs more help with the patients because the CNAs [certified nursing assistants] have too many residents.

Ray M.
Watauga County, NC

Age: 72

Years in long term care: 3.5

Occupation: President of Local 1552 of the Machinists and Aerospace Workers Union for 25 years, Cleveland, OH

Accomplishments: Watauga County Long Term Care Resident of the Year, awarded by Adult Services Coalition of Watauga County (2005)



Mr. M. grew up in Watauga County and moved to Ohio where he worked for 25 years. His interest in country music led him to produce and direct concerts and benefits. Ray also wrote the script for an edition of Hee Haw. He says it was the one with the moonshine still in it.

On aging: "It's horrible. All of a sudden it gets you."

On living in long term care: Ray says he tried hard to adjust to living in long term care and to get on with his life. He found worry does not help. He continues to use his "organizing" skills to coordinate the facility's Spring Fling and arrange for the musicians who perform at the Friday night "Good Old Time Music" activity. He serves on the Resident Council. A good day is "having company and exercising my mind." Ray's greatest challenge has been trying to walk again.

On improving long term care: More privacy and freedom. Work to find ways to allow residents to use their skills to contribute to improvements in quality of life.

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When I stand before God at the end of my life, I would hope that I would not have a single bit of talent left and could say, "I used everything you gave me."

Erma Bombeck



Betty B.

Wilson County, NC

Age: 59

Occupations: Worked for Diversified Opportunity (Rocky Mount & Wilson, NC)

Accomplishment: Raising her 14 sisters and brothers

Betty was born in Wilson County and was the oldest of 15 children. She attended public school in Wilson County where she sang in the choir and participated in many activities. She never married and lived with a sister before moving to assisted living. She loved to attend church.

On being disabled: Betty was hit by a car when she was 5 years old and the accident left her disabled. She has a manual wheel chair and is able to maneuver herself around the facility. She doesn't want a motorized chair because her chair encourages her to exercise. She doesn't have any problems with her disability.

On living in long term care: This is the first facility Betty has lived in. She moved to assisted living because her sister worked and she was unable to stay alone. She states she had no problems adjusting to the placement and enjoys living there. The staff is good to her and most days are good. Her family visits her all the time, and she goes home often for holidays. She loves working puzzles and participating in activities.



Lavaun C.

Ashe County, NC

Age: 91

Years In long term care: 6.5

Occupations: Housewife, Mother, Farmer's Wife

Accomplishments: Got first public job at age 55 as a drapery-maker



Lavaun was the 4th of 12 children. Her parents were farmers. She says as kids they never got bored. When the children got old enough, they worked on the farm, too. She describes her parents as hard-working, living by the "Golden Rule."

On aging: "Sometimes aging is a blessing; often a very real hardship. However, whatever time God grants to me is a blessing."

On living in long term care: "When I could no longer remain in my own home, I visited all the available facilities in the county so I could make a sound decision... At this stage in my life, I am totally dependent upon staff for my care. A good day is being up, communicating with the staff and visitors. My greatest challenge has been accepting being totally dependent."

On improving long term care: "Private rooms for everyone would be great, or at least larger rooms to share."

Rhonda S.

Age: 43

“Today is my 43rd birthday. I was born with a physical disability. I lived at home. I lived independently. Now, I live in an assisted living. I have a wonderful mother. My sister and brothers have gone their separate ways.

“I have the advantage of living all my life with my disability. For many of the other residents—not accepting that they are not able to do all they want to do creates real problems for them. I try to reach out to them every day. They come from all kinds of backgrounds and all have a story to tell me. My strong faith in God makes me able to do for others.



“Life in an assisted living environment is not easy. There is not a lot of variety. I wish there were more activities. I tried to start a sewing crafts class, but it never worked out well. So I do my own crafts. I make things for my friends and my family. I am always making something new.

“I have to share something with you. When I came to live here, I never spoke up about things. Now, I do. I found I could tell the administrator what I did not like. Sometimes it made a difference, sometimes it didn't. But, I am no longer afraid to tell people what I think.

“...I know this may be my last home.”

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Genevieve B.

Nash County, NC

Age: 85

Years in long term care: 8 months

Occupation: Housewife

Accomplishments: Reared three children. Now has five grandchildren and five great-grandchildren

Genevieve was born in Rocky Mount in 1920. She never worked outside of her home. She was a housewife and reared three children. She had an aneurysm and is very proud to be 85 .

On aging: “You don't dwell on it and it is part of life. In order to live, you have to get older.”

On living in long term care: Genevieve lived in an apartment with her best friend. When her friend moved, she decided she didn't want to live there any longer. Her son visited the facility, picked out a room and put a down payment on it. He asked her to visit the facility. She refused at first but later decided to go visit. When she arrived at the facility she became very upset and left. She was very hesitant at first but thought about it and decided to go. She became very depressed the first couple of weeks because it was the biggest change she ever made. Each day the adjustment to the change got better. She has adjusted and doesn't want to leave the facility because she likes the staff and the residents very much.

Gracie and Lechter R.
Ashe County, NC
Age: Unknown
Years in long term care: 8+



Gracie and her brothers grew up on a landlocked farm near the New River in the North Carolina mountains. She and two brothers lived and farmed on their homeplace with

their parents. Their home had no indoor plumbing or electricity. They could not get an easement to have a road to the house so they had to walk out and wade a stream to get to the paved road. After their parents passed, they stayed on until the house caught fire. They were placed in an adult care home. They considered this home until its license was revoked. They were inappropriately moved to another county off the mountain. DSS made arrangements for them to return to their home county. They have lived in the nursing home ever since. One brother passed last year after being married in the nursing home. Gracie does not know how old they are. She said she was born on Old Christmas (January 1).

On aging: Gracie says she is “kinda nervous” as she grows older and does not rest as well. She is very religious. Gracie says she would like a private bathroom. She washes daily at her sink beside the door to her room and is always afraid a man will walk in. In general, she is happy there. Lechter says he is very homesick. He would just like to be back home and have a few chickens and a garden and to keep bees. Gracie is well aware of her rights, but is very tolerant. She looks out for her brother.

On living in long term care: Lechter says, “I hate to be housed like this; it’s not good for you.”

Look, I don't want to wax philosophic, but I will say that if you're alive, you've got to flap your arms and legs; you've got to jump around a lot, for life is the very opposite of death, and therefore, you must at the very least think noisy and colorfully, or you're not alive.

Mel Brooks

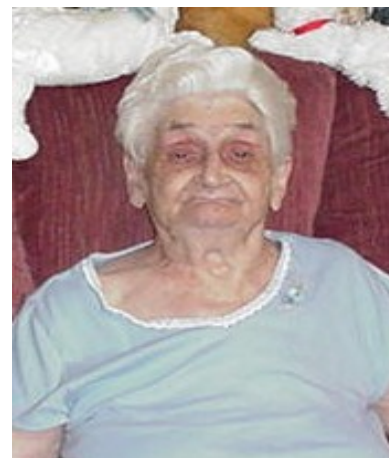
Emma F.
Wilson County, NC

Age: 83

Years in long term care: 2

Occupation: Lunch counter worker at Kerr Drugs for approximately 10 years

Accomplishments: Received "You Make a Difference" award from staff at her home and crowned Valentine Queen on her wing.



Emma was born in Greenville, NC and moved to Middlesex. She lived there prior to moving into the nursing home. She was Baptist, but later attended a Presbyterian church near her home.

She loved the church because the members were so nice and kind to her. Her husband passed away when he was 47 years old. She has six children, one son and five daughters. She has 11 grandchildren. She also has some step-grandchildren and step-great-grandchildren. She and her children are very close and they enjoy spending time with each other. When she and her daughters make plans to do something together, go on a shopping spree or trip, her son always has to accompany them. People always make comments like, "they have never seen such a close family."

On aging: Emma stated that she never thought much about getting older. She is just happy that God allowed her to live to be 83 years old. She doesn't mind getting older. She knows it is something you do.

On living in long term care: Emma had never lived in a nursing home. She made the decision to come to the facility after her doctor recommended placement for her. She loved being in the facility from the time of her admission. Her family had a hard time adjusting to the placement. They cried and didn't want her to go. The staff and residents are very sweet to her. They treat her well all of the time. She is able to do some things for herself. When she goes to the hospital or leaves the facility she always returns waving to everyone. One of her children visits every day and that makes it a good day for her.



Mary H.
Macon County, NC

Age: 70

Years in long term care: 6

Occupation: Working in restaurants

Mary is especially proud of her family. She is married and her husband works at Angel Hospital. She has had surgery on both of her feet and is hoping to return home by the end of the year. Her favorite activities are bingo, word puzzles, and eating cake and ice cream.

On long term care: "They take good care of me."

"I'm proud to be part of the booklet."



Hester D.
Caldwell County, NC
Age: 76
Years in long term care: 4
Occupation: Administrative Assistant

“I was born in Granite Falls, North Carolina along with my twin brother, Lester. My mother died birthing me. My father was not able to care for us. I lived with my Aunt Hazel-Lean and my brother lived with my Grandparents Emma and Arthur. One day, I overheard my Aunt Hazel-Lean talking to my Uncle Sam and she said she had too many mouths to feed. I ran away and slept in the school house for a couple of months. I was about 5 going on 6 at

this time. The Janitor found me sleeping in the school and he took me back to Aunt Hazel-Lean. I refused to go in the house. I was adopted by Mr. Horton and Florence Jane Horton. I used to keep my nephew and my adopted mother would give me one dollar a day and my adopted father would give me \$2.50. I buried it in a coffee can in the Garage. At age 14, I asked my mother if I could go to New York to visit my sister. My mother told me that she could not give me any money. I told her that I had my own money. Mom asked me where I got the money and I told her I had been saving it. I fell in love with New York. I finished high school and went to college for 1 year. (I got) a job at the hospital as an Administrative Assistant. I lived in New York for 50 years. I did get married to John. We had a little girl. She was born 2 months early and only lived for 3 months. I believe she died because I was going through a nervous breakdown around the time of her birth. I had found my husband in bed with another woman. I tried to shoot him in the heart but I missed him and hit him below his heart. I am glad that I did not kill him because I would have blood on my hands now. I knocked the women’s ass out the window because she was trying to keep me from shooting him. I had to go to court about all of this. I told the judge what happened. My husband wanted to keep everything. The judge asked my husband if I helped to pay for the house and the furnishings. He said “yes”. The judge decided that I could keep the house. They threw out the attempted murder charge.”

On aging: “I count my many blessings and I name them one by one ...and thank God for what He has done.” I have been sick all my life but I know that God will not take me until I am ready. Sometimes I lay in bed and I cry because I feel like I don’t have any friends. Many nights I sit in here depressed but then I talk to God and He helps me. Sometimes the nurses come in and ask me who I’m talking to and with. I tell them I am talking to “my man.” One nurse said I don’t see him. I told her it does not matter because I can see him. Then I explained that I am talking to God so they would not think I am crazy.”

On living in long term care: “I feel disgusted - I really wish God would have taken me before I had to come here. It’s just not like home. I can’t explain it. The people are nice to me. If I stay in the room too long staff will come and check on me. The doctor told me that I need to eat more. I told him to eat it for me and tell me how it tastes. The doctor told me he has never had a patient to talk as much junk as I do. He told me I have to eat and I told him that there are only 2 things I have to do - to stay black and die.”

On improving long term care: “They really should have security guards because when you are not in your room people come in and out. They have people that come and go at all times of the night.”

Vernella R.
New Hanover County, NC
Age: 101
Years in long term care: 4
Occupation: Caregiver



“Let me tell you about me. I was born in a time when black people had a hard time. My grandmother... was a freed person. She would tell me about when she was young and she would make torches to light the way down the streets. I was raised by my sister. We did not have electricity or indoor plumbing.

“My earliest memory was when I was eight years old. Everyone was in the field picking cotton. I was so tired. And this man told me to go sit at the end of the row, and he would finish my row for me.

“Before the war (WWII) I moved to Wilmington, NC with my daughter. We took a room. I cared for other people. I kept their house. I kept the wood for their woodstove. I swept the yard. Yes, in those days we had sand in the yard, and we swept it clean around the house. At the store, I could buy sugar for three cents, bread was two cents, and a piece of meat was 15 cents.

“I thank God I am in my right mind. I can look a person in the eye and tell a lot about them... I get taken care of good here. I tell the girls what I want. I don't like them to move things around on me. I used to be Methodist, but now I am a Baptist. I like the singing better.”

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Linda S.
Henderson County, NC
Years in long term care: 3 weeks
Occupation: Employed with Salvation Army, restaurant manager

Linda was born in Asheville, NC and grew up in the mountains with her parents and one sister. As an adult, she lived in Minnesota for 15 years. She moved back home to be closer to her family after being diagnosed with advanced breast cancer. “I was shocked when I found out about the cancer. The hardest thing was to get up and keep going, but I had to make the best out of a bad situation. I have learned to be thankful when I open my eyes in the morning.” She openly talks about her faith in God. “He is the only reason I am still here.” Linda is a selfless, courageous

woman and describes herself as “a happy person who tries to uplift and encourage others” no matter what the situation.

On living in long term care: “At first I was afraid and didn't want to talk with anyone... I knew that I had to have a positive outlook in order to keep on going.”

On improving long term care: “I would make sure that all the residents got individual attention, encouragement, and were always made to feel special. A good activity program is also a big part in creating a community. It always brings people together.”

Maggie B.

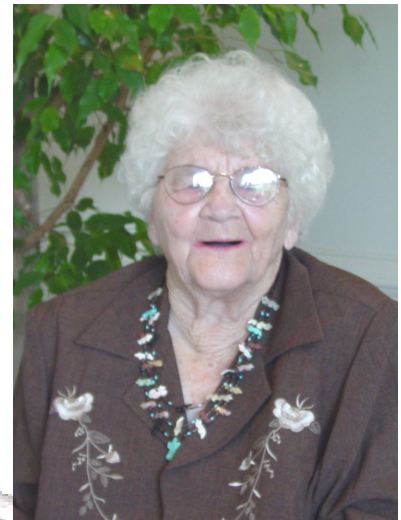
Robeson County, NC

Age: 96

Years in long term care: 14

Occupation: Tobacco farmer

Accomplishments: Raising her 9 birth children & 3 adopted sons



Maggie recalls attending a school for Native American Indians with one teacher, a potbelly heater and long benches. She recalls seeing her first automobile at the age of 14 when the only roads around were dirt. She collects soda tabs and sends them to the local hospital to cover the medical cost for those who have no health coverage. Several of her children, staff and friends help her collect the tabs. She feels fortunate to have her "right mind."

On growing older: Maggie says she doesn't mind growing older and that it should be a good feeling to outlive so many other people.

On living in long term care: Maggie could not continue living by herself and says she loves living at her current home (an Eden Alternative facility). She loves having the animals around, especially when she is sick, because the cats will lay in bed with you and the dogs will lie by the bed. She feels they can sense when something is wrong and they want to help you.



James B.

Cumberland County, NC

Age: 72

Years in long term care: 15 months

Occupations: Military (2 yrs.) and automotive mechanic (44 yrs.)

Accomplishments: Worked on JFKs parade car when he visited Fort Bragg in 1962.

James was born in Fayetteville (formerly known as 71st Township), is married, and has two daughters who live in Atlanta. "I have always been intent on taking care of my family."

On growing older: "I know times have changed and parents need to get better control of their kids like they did when I was a kid. I think kids do not have any respect these days and I would like to talk to them about it."

On improving long term care: "The State should put some more money into the VA. Bush said he is going to cut the per diem for veterans and we need more help!" In addition, "The food could be better. Sometimes they have breakfast for dinner."

You must be the change you wish to see in the world.

Mohandas Gandhi

Kay and Steve A.

Madison County, NC

Age: 49 and 63 (respectively)

Years in long term care: 2

Occupation: Steve: Salesman (of moonshine at one time), truck driver, farmer

Accomplishments: Kay: "I was told I couldn't do it because of my CP, but I proved them wrong. I had a baby girl (now 19)..."



Kay was born with cerebral palsy and was adopted at six months of age. Steve is from central South Carolina. Kay was the first graduate of the Asheville Orthopedic School (now Thom's Rehabilitation Hospital) and attended for 15 years. She received her education and learned to walk with crutches. Her daughter is now 19 and she has a 5-month-old granddaughter. Her daughter works at the facility as a CNA on a different hall. Steve's medical problems began eight years ago with colon cancer, followed by a range of infections, doctor/hospital errors, and heart trouble. He entered the facility with a decubitus ulcer as deep as his spine and "deep enough to put your fist into." "They gave me up for dead," he said. With good, constant medical care, the ulcer healed, and he has made a home and found a community in this rural skilled nursing facility.

Kay and Steve met as residents, shared a lot of time talking, "courted" for about six months, and were married in December, 2004. This was the first wedding ever held at the facility. The wedding took place in the dining room, complete with a best man, maid of honor, and a big reception with lots of ice cream for all the residents and staff. They now share a room, of course. "We get in arguments, sure, but the best part is making up. Sometimes it's worth starting a fight just to make up," says Steve. They also spend many hours together volunteering at the facility. Every night from 6-9 p.m., Steve and Kay answer the main switchboard. They also deliver the mail each day to all the residents.

Both say that their biggest challenge when moving to the facility was losing their independence. Steve misses being able to travel and go whenever he wants. As a truck driver, he has been to every state in the U.S. Kay misses living in a house and doing the things she wants to do, like cooking and grocery shopping. She and her first husband and daughter had their first home for a number of years. She remained there on her own for several years after he left, then eventually moved back to her parents' home until her father died and her mother just couldn't provide the physical, personal care that she needed. Her mother still lives close by and visits often.

On improving long term care: Steve would make it more orderly and organized. "There's no consistent person to do the little things like close the doors, empty the trash, pick things up. Often meals aren't what the menu describes." Kay says, "Please don't treat me like a prisoner! Don't tell me I have to do things their way all the time. They tell me what time to get up, what time to eat, what to eat, which activities I can attend, what time to go to bed... Just because we live here, they think we can't think and make decisions like some of the older residents with dementia, but we can. We still have a brain and want to live our lives as best we can here. Give me back my freedom!"

Charlene S.
Buncombe County, NC

Age: 52 1/2

Years in long term care: 3

Occupation: Employed in retail for over 9 years

Accomplishments: Earned her BA in Political Science from UNC Asheville.



Charlene was born in Concord, NC and moved to Asheville when she was 11. She was born with spina bifida and was raised by her grandparents until her grandmother's health failed. Her memories of childhood are painful with no contact from her birth parents. At age 11, she moved to Asheville to attend the Asheville Orthopedic School and lived on campus until it closed. She lived independently for 30 years.

On being disabled: "It doesn't bother me as much as it bothers other people!" She hates for people to ask her questions like, "What happened to you?" or make comments like "Oh, you poor little crippled thing." Her grandmother instilled in her a strong sense of self respect and always encouraged her to stand up for herself. She grew up in the 60s and, with a degree in Political Science, she learned to advocate for her own rights and the rights of all physically disabled people. She felt discriminated against by having to go to a special school for physically handicapped children and was pleased when public schools required children like herself to be mainstreamed.

On living in long term care: Retail work became too stressful, especially with crowded, busy conditions around Christmas. She chose the facility she lives in now because they have cats. She loves cats and was able to adopt the facility cats as her own. She also loves to sew, do embroidery, and make "fuzzy posters." She felt welcomed in the facility initially because the Activity Director and Social Worker took time to talk to her individually and ask what she would like to do to feel better emotionally about living there. However, the food was worse than what she made living on her own! The best thing that has happened to her since moving into the facility was the day that two of her friends, both residents, got married. It made her feel so good to see them so happy.

On improving long term: At first, Charlene said, "Tear it all down and start over!" However, during the interview, she elaborated more. She felt that our government should make it easier for people to stay at home. Medicaid pays her cost of living in a facility, but not for the support she would need to live at home. In addition, she says, "Our personal needs funds need to be increased. How can you purchase anything with \$30 per month? This allowance hasn't been increased in over 20 years! Our shared rooms should be much bigger. My roommate and I both can't get in and out of the room at the same time with our wheelchairs. It's like living in a cell! (And) there are never enough staff to take care of the number of people who live here."

John H.
Burke County, NC
Age: 85
Occupations: Former military, antiques dealer

John lived in Burke County his entire life. Before working to restore antiques and run his store, White House Antiques, he served in the 32nd Division Weapon Platoon and Machine Gunnery stationed in New Guinea and Japan. He is a wonderful story-teller, and his skills as a craftsman were well-known throughout the Southeastern US.

On living in long term care: After his wife passed away, John realized he needed some help. He chose to move into assisted living. Even though he believes that no facility could replace living at home, he felt he needed to make the compromise to get the care he needed. He is a diabetic and understands the importance of good care.

What makes a good day? "The weather is important to me." He says he stays active for the sake of his health. He pushes his wheelchair on long walks (in case he gets tired and needs to sit). "I like to get outdoors, and the workers don't have time to take me." This is the first facility he has lived in, "There are probably worse, probably better, but I am treated good here." He says he enjoys his freedom to leave the building with friends whenever he chooses.

On improving long term care: "Staff turnover is too high. We need better trained attendants. They seem to get the cheapest labor they can get, and those people don't care and they don't stay around." John believes the workers are not interested in their jobs, just the pay-check (and even that sometimes is not enough to entice them back). "Especially on the weekends, everyone is sick at the same time and unable to work on the weekend. There needs to be better management of employees on each shift."

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Nell B. (and Gata)
Robeson County, NC
Age: 74
Occupation: Hotel management and family care home supervisor

Nell is a mother of two girls and has four grandchildren. "I never imagined that...I would be a resident in a facility. I enjoyed my work when I was a Supervisor-in-Charge and I really cared about the residents. They felt like my family because we spend so much time together." She lives at the facility with Gata, and said she would never have considered coming to the facility without her.

On aging: Nell says she welcomes the idea of aging as long as she can continue to "do for myself."

On improving long term care: Nell feels facilities need to realize the close bonds shared with a pet and the loss someone feels when they have to leave their pet behind and enter a facility. In addition, "staff need more training and patience when working with and caring for people with dementia and Alzheimer's." She also feels staff need to show more compassion and understanding to residents and have more people dropping in unannounced to ensure residents are taken care of.



Billy L.
Transylvania County
Age: 51
Years in long term care: 3
Occupation: Ballet dancer

Billy was born in Greenville, NC and lived in Columbus Georgia as a child. He lived in New York City as an adult. Always athletic, he began studying Canadian Ballet in Atlanta, and later became a Ballet dancer. He worked with the New York City Ballet and danced at the Lincoln Center. Well over six feet tall, Billy was a very unique dancer. Later, he taught ballet and was the treasurer for the NYC Ballet. He has a Masters degree in Literature and speaks four languages, "French and Russian are my favorites."

Every day is a good day when he has a book. "I drive the local librarians crazy." He came to long term care when he was diagnosed with advanced colon cancer. He suffered several serious side effects from the chemotherapy and radiation. Although his condition has stabilized, he continues to require 24-hour care.

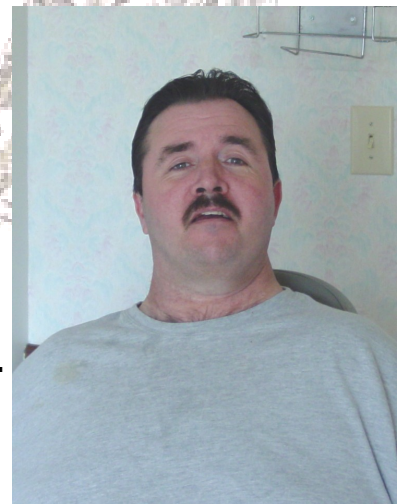
On living in long term care: Billy says one of the worst things is the isolation. He misses his students and the social contact. "I miss the way things happen when you're still part of the world." His mother has asked him to live with her but he says he's determined to live in the facility and become part of that community.

On improving long term care: "These are real people who have real needs. Don't categorize them and put them in a slot. Even those who are confused will feel left out and not cared about. We can't think that they have reached a point and don't matter anymore." Billy feels activity programs are very important. "The activities make a difference in people's lives and make them feel like part of a group... but you will never catch me playing Bingo!"



Harold B.
Robeson County, NC
Age: 50
Years in long term care: 5
Occupation: Carpet cleaner and volunteer firefighter

Harold came to long term care after being diagnosed with Multiple Sclerosis. He is most proud of his 17-year-old daughter and the 16 years he dedicated to volunteer firefighting. He lives in the same facility with his mother and enjoys being close to her.



On being disabled and living in long term care: It has not made him "mad or angry." He enjoys being able to get out of bed and visit with other residents each day. He believes his day is made better by visiting with other people.

On improving long term care: "CNA staff have a lot of people to care for, and it gets too much for some."

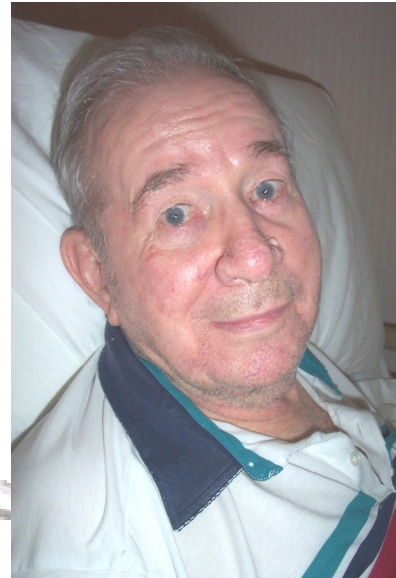
Richard B.
Forsyth County, NC

Age: 77

Years in long term care: 2.5

Occupations: Railroad man, residential home appraiser, salesman

Accomplishments: Salesman of the Year with Bostich



Richard grew up in Asheville, NC and describes himself as having had a nice life. His mother passed away when he was young, and he recalls, "I did the cooking in my teen years" for three siblings and his father. In later years, he enjoyed raising a garden. "I had green beans, corn, asparagus, zucchini, squash..." He has been married over 52 years and recalls that, at first, his wife couldn't cook at all. Now, his wife appreciates his cooking "at times." He and his wife had seven children who all finished private school and college. One is an airline pilot, one owns a medical supply business, four are nurses and one is a legal expert. He says a good day is a day "full of Bingo. They don't have it enough." He is President of the facility Resident Council and works regularly for the benefit of the other residents.

On growing older: "I don't mind growing older so much as (being) without my legs, but I'm trying to do the best I can do. (If the) nurses look at me as a patient and treat me as a patient, then I don't mind growing old. It's something that must be done, so let's face it."

On living in long term care: Richard says his hardest adjustment has been losing his legs and not being able to move around as easily. "I like to move!"

On improving long term care: Richard believes there are not enough nurses to do what needs to be done. He further states there should be more training for nurses, and there should be improved pay for those nurses. The nurses should "leave their personal problems at home" since the residents have their own problems to deal with.



Ruth G.
Jackson County, NC
Age: 102
Years in long term care: 11

**Youth is a gift of nature, but
age is a work of art.**

Stanislaw Lec



**Cecil "Big Rou" R.
Forsyth County, NC**

Age: 64

Years in long term care: 3

Occupations: Body guard for Malcolm X, Director of Recruiting for Dudley Cosmetology, Salesman for Prepaid Legal Services

Accomplishments: Top Salesmen, Southern Region (Prepaid Legal Services), first Black high school student to chosen for All State Honors (11th Grade, Elm City, NC), chosen by "Guys & Dolls" as one of the "10 Best-Liked Blacks in Greensboro" (1974)

Cecil has led an illustrious life with many notable accomplishments. He served on President Clinton's Committee on Civil Rights Issues, has spoken about Malcolm X at many colleges and universities, and was named on the National

Chamber of Commerce list of "Outstanding Young Men in America" in 1972, to name only a few. He was Chairman of the Woodmere Park Improvement Association in Greensboro, NC and helped create an open occupancy ordinance.

Cecil was born in Elizabeth City, NC. When he was four years old, walking to the corner store with his Grandmother, he saw several white kids riding along the railroad tracks. When he asked if he could go play with them, his Grandmother said, "No, they don't play with colored kids." Later, he learned what "colored" meant, and it motivated him to research the contributions that "negroes" have made to society. He spent time thinking about how to "make a positive contribution to black people." He said, "... (when I grow up) I want to help my people."

On growing older: "I don't feel like I'm growing older. I get younger everyday. I stay young in my mind."

On improving long term care: Cecil expressed that activities are very important to him. Activities should be all-inclusive. There should be more outside trips.

**Not everything that is faced can
be changed, but nothing can be
changed until it is faced.**

James A. Baldwin

Ralph P.
Cumberland County, NC
Age: 73

Years in long term care: 16 months
Occupations: Master Seargeant in the Army (22 years of service), worked in auto parts (20 years) and currently runs the PX at the VA Nursing Home
Accomplishments: "Serving my country. I was in Korea and Vietnam. And, I have read the Bible three times and still don't understand it."



Born in Natural Bridge Station, VA, Ralph had three brothers and four sisters. His father worked on the C&O Railroad until he accidentally fell from a bridge and died when Ralph was 11 years old. Ralph started his first job at the age of 12 at a sawmill. He married his wife (of 47 years!) after knowing her for ten days. He has two children, seven grandchildren and two great-grandchildren.

On growing older: "It is something I really do not dwell on."

On improving long term care: "I would like to see politicians or someone donate some money to this home for things it needs, like a bus. Transportation is one of the biggest problems here if people want to go someplace."

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Conell N.
Forsyth County, NC
Age: 55

Occupations: Wrecking, cotton mill, roofing, driving a forklift
Accomplishments: "I love to work. I'm not what you'd call a lazy man."

Conell was born in Roanoke Rapids and finished school through the 11th grade. His first job was in roofing. Throughout his life he has worked in farming (tobacco, peanuts), and worked 23 years at a cotton mill. He moved to North Carolina hoping to make better money . He has a fiancé and considers her daughter part of his family.

On growing older: "Growing old is alright. Being disabled is not."
Conell expresses some frustration with not being able to do things for himself such as cooking or laundry.

On living in long term care: At first, "(I) didn't like it here." He says he has gotten used to it. His family doesn't visit very often because they live in New York. He has other family in the area, but it is too expensive to call often. For him, a good day is one "when the aides look nice and pretty." He says he wants to be able to get up and walk and do things for himself. He finds the days go by when "the CNAs cut up with you."

On improving long term care: "Home is the best place."



Marie S.
Davie County, NC
Age: 66
Years In long term care: 1.5
Occupation: 20 years as a CNA in home health

Marie grew up in Fayetteville, NC. Her father rode a motorcycle and she remembers getting to ride with him once. When she was six, her father was killed riding his motorcycle. She then moved to Winston-Salem and was raised by her Grandfather. She has one younger sister who now lives in California, but she keeps in touch with her. When she was a CNA, she worked with babies as young as three months and with adults as old as 100 years. She has a great love of animals and currently has one dog, "Baby" who lives with a relative. In the facility, she enjoys reading the newspaper, having bible study (5 times a week), playing Bingo, having people coming in from churches, and parties. "They keep you busy around here."

On growing older: "I don't like it too much because, when I sit down and think about it, I remember the old people I used to keep... some of them were worse off than I am."

On living in long term care: "It's nice. They let me have my birdfeeder." She describes her first week in the facility as difficult. "I resigned myself that I have nowhere else to go."

On improving long term care: Marie feels that staff should be more attentive to residents' needs, such as checking on them when they ring their call-bell. She stated that larger private rooms would be nice. In addition, she felt there should be more staff, especially after 5 p.m. and on the weekends.



Hortense S.
Alamance County, NC
Age: 96
Years In long term care: 5
Occupation: Traveling salesperson for Champion Map Company
Accomplishments: Executive Secretary of the Alamance County Arthritis Foundation and won several awards for fund raising



Hortense is very proud of her accomplishments over the past 96 years. She supported her family and cared for her parents and her husband.

On growing older: She complains about her aches and pains but does not let them slow her down. She is still driving!

On living in long term care: She is an advocate for the other residents in the facility and while she would like to be living in her own home, she feels that the other residents need her voice.

On improving long term care: She feels there needs to be more staff and better food.

Clifton O.

Forsyth County, NC

Age: 56

Years in long term care: 2.5

Occupations: auto parts, construction, built and ran a convenience store and gas station

Accomplishments: Raised two boys



Clifton was born and raised in Forsyth County. He was married for 25 years before his divorce.

On being disabled: Growing older “doesn’t bother me.” He says being disabled “drags me down, especially at an early age. If this had happened to me at an older age it would have been easier. Sitting around just doesn’t get it.”

On living in long term care: Clifton feels his current facility is one of the best and he says he would live there again. He appreciates the staff who work with him because the joke with him and they’re like family. He says his first week was hard because it wasn’t what he wanted for himself. “I felt that I was too young to be in a place like this.” But he says he has adapted. A good day consists of therapy (he does 1,500 pulls two times a day to strengthen his upper body) and believes his physical therapy staff is good. He enjoys and looks forward to planned events, such as going to the Dixie Classic Fair. He says his biggest challenge is transferring in and out of his wheelchair to the commode.

On improving long term care: Clifton believes there should be some differentiation along the lines of age. He is younger than many of the other residents and often finds living with those who are much older or have dementia to be challenging (due to behaviors such as crying, hollering, and screaming). He says that activities are important as well.

**A rock pile ceases to be a rock pile
the moment a single man
contemplates it, bearing within him
the image of a cathedral.**

Antoine de Saint-Exupery



Susan R.
Yadkin County, NC
Age: 40
Years in long term care: 2.5
Occupation: Housekeeper

Susan was born in Kings Mountain, NC and describes herself as having a “bad childhood.” She has lived in several long term care facilities and says it is often difficult because she misses being able to see her family.

On being disabled: “It doesn’t bother me... sometimes it does.”

On living in long term care: Overall, Susan describes her experiences as fairly good. She likes that people are very friendly when you first arrive. Her challenges have included getting used to rules and then following them. In addition, it has been challenging getting used to living with other residents, people of different backgrounds and needs. She says she feels safe living in the facility. She expressed that she would like to live on her own, but she knows there needs to be many supports in place to make a successful transition.

On improving long term care: Susan suggested the needs for more freedom and better food. She felt that supervisors should listen to residents more instead of ignoring them. In addition she felt staff could do a better job protecting the privacy of residents by keeping other residents out of residents’ rooms and not discussing a resident’s personal business where others can hear. Staff should try to understand the residents and treat them with respect.

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Mayonie D.
Nash County, NC
Age: 89
Occupation: Domestic services and child care for others
Accomplishments: Reared six grandsons who all attended college or trade schools, have good jobs and now take care of her



Mayonie was born on a farm in Halifax County. She had four brothers and one sister. She had one son who passed away about three months ago; however, she raised her six grandsons. She lived in her own home with her grandson prior to coming to the facility. She did not go to the nursing home because she was sick. She was unable to take care of her home and couldn’t stay alone during the day. Her doctor wanted her to come and he found a good place for her to stay. She was a member of St. Paul’s Baptist Church in Enfield.

On aging: Mayonie doesn’t feel any different now than she did when she was 50 years old. She can still do quite a bit for herself. She does not depend on the staff for a lot or complain about anything. She treats them the way she would like to be treated.

On living in long term care: She says she adjusted to the placement just fine. For Mayonie, the staff, family and others visiting makes for a good day.

The NCRLTCOA wishes to thank:

The Ombudsmen who took time out of their busy schedules (where often there is little or no spare time to give) to speak with residents, hear their stories, and compile the information;



Those at the Regional and State levels who have supported this effort;

And, most importantly, the residents who gave their time and energy to speak frankly about their experiences living in long term care settings.

