

Interviewee: Anne Lynn Milkowski
Interviewer: Catherine Milkowski
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Place: Three Rivers, MA
Transcriber: Catherine Milkowski



Overseen by Dr. Lisa Boehm, Worcester State College

Abstract: Anne Milkowski was born in Worcester, and grew up in Whitinsville Massachusetts with her divorced mother. When her parents remarried, she moved to Falmouth, Cape Cod. She went to the University of New Hampshire for the Occupational Therapy program, and traveled around the country for her internships. She worked at a variety of facilities until getting her master's degree in special education while living in Illinois. She moved back to Massachusetts when she was 30 and eventually got a job as a special education physical education teacher and OT in a vocational high school. When her daughter was 5, she was diagnosed with breast cancer. She struggled through working, caring for a daughter, and chemotherapy only to find another lump within a year of finishing chemotherapy. She then entered an intensive experimental program at Dana Farber. She still works in the vocational high school, and struggles to deal with issues associated with the MCAS testing. She now thinks about her daughter graduating from college and retirement.

CM: Do you mind if we record our interview today?

ALM: No I do not mind.

CM: OK. This is Catherine Milkowski, interviewing Anne Lynn Milkowski at 11:30 on February 8 in Three Rivers, Massachusetts. Where were you born?

ALM: Worcester, Massachusetts

CM: Did you grow up in Worcester?

ALM: No, outside of Worcester in Whitinsville.

CM: What was it like growing up in Whitinsville?

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ALM: It was a small mill town. Like many other towns at that time, we had neighborhood schools where you walked to school, we even walked home at lunch, some of us. People came out of the factory and came home for lunch. We were fortunate enough that we didn't have to spend out summers there. Most of my summers were spent on a lake in a cottage, so that was nice.

CM: Where was the cottage?

ALM: In Douglas. It was very close so that my mother even commute back to work in Whitinsville.

CM: What was your family like?

ALM: My parents were divorced when I was young. So we lived with my maternal grandparents. I also had a large family of cousins one block away. I didn't feel like I was all that unusual being in a divorced family. I had one instance I remember of the neighbors going out to do something as a family and I complained to my mother we didn't get to go out and do things, but for the most part I didn't feel any different.

CM: Was your father nearby?

ALM: I saw him occasionally when he came by to drop off presents. He did have friends, who had introduced them, that lived down the block. But he went to sea, which had been a factor in the divorce to begin with, so I only saw him occasionally.

CM: When did you leave Whitinsville?

ALM: After I completed fourth grade. My parents had been remarried two years before that. My dad got a job with Woods Hole Oceanographic [Institute] at that time. So we moved back to the Cape at that time.

CM: Where in Cape Cod?

ALM: Falmouth. And when I say back, it was back to the home he had grown up in which he had kept all the years he went to sea.

CM: What was it like living in Cape Cod?

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ALM: It was quite nice actually. We lived walking distance to the beach. The schools were good. A little different atmosphere than the factory town, as far as the impact of the Institution, being near a big air force base, a little more mixture of people. Of course back in the 60's and 70's it was still a lot smaller than it is today.

CM: Where did you go to school in Falmouth?

ALM: Well, I started in the fifth grade and there was an intermediate school for sixth, seventh, and eighth that required a bus ride, but for high school I could walk. At that time it was called Lawrence. I was in college prep classes, I babysat a lot by that time, never went out on dates. I don't even think I went to a school dance, which I think they stopped having because of difficulties taking care of the kids anyways. But definitely not in the popular crowd. Got turned down the first year I tried out for pep squad, made it the second year. But didn't get to do anything related to the prom or anything like that.

CM: Did you feel unusual not going to the prom?

ALM: Yes. I couldn't even get on the committee to paint the scenery. And even back then proms cost enough that not that many people asked somebody out just to go to the prom. You pretty much had to have a steady boyfriend if they were going to invest that money to take you to the prom

CM: So you didn't go if you didn't have a date?

ALM: Oh, back then nobody went. It's not like today; you didn't go without a date. That was unheard of then.

CM: Was it different having your parents be remarried when you were older?

ALM: I was only seven so I thought it was great. I got to be the flower girl.

CM: Did you have any siblings?

ALM: Mom had a miscarriage, when they first got remarried, but had a second pregnancy so I have a brother ten and a half years younger than me. So she used to joke that she had two only children. People used to joke she was so lucky to have a built in baby sitter. Which I didn't always like to be referred to as the built in baby sitter.

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CM: Where did you go to college?

ALM: I went to the University of New Hampshire, which I chose because it had an inter-state program for occupational therapy and my parents could afford to send me there. The private schools were pretty much out of reach, and it ended up being a good choice for me.

CM: What was occupational therapy school like?

ALM: Very demanding in the sense of having to take hard courses, having a lot of labs which took up more time. I was not as industrious a student as I should have been, but I made it through. I had to take kinesiology twice, which made senior year more hard. And typical impulsive young person, I took up the teacher's offer for extra credit for doing two afternoons of clinical instead of one, and that's pretty much backfired because then I was that much more busy and I didn't have time to study. But I did make it through in the four years. I did pull my grades up by senior year, and back then in occupational therapy being on dean's list wasn't essential.

CM: When did you graduate?

ALM: I graduated in 1975 but I had not completed my internships. I had started early, before senior year, which is where I met my husband George, on an internship in Illinois. I had wanted to travel for the internships, so after graduation I went, well first I had one in Massachusetts which wasn't traveling, it worked out really well, in psychiatry. But the second one I went all the way to California, just 'cause I wanted to go to California. The hospital turned out to be not in a great neighborhood, turned out to be not a great learning experience, but I did make it through. Returned to Chicago to look for a job and move in with George, who was to become my husband, and because of the times being what they were I was able to find a job that I wanted in developmental disabilities relatively quickly.

CM: What did you do for your first job?

ALM: I worked in a sheltered workshop. I actually had the title of Occupational Therapy Department Head. I even had an assistant with a college degree. And I did a variety of OT types of programs including self care, motor skills, perceptual skills, and I did

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specific training on assembly tasks out in the workshop, with the most distractible clients that they had.

CM: How long did you work there?

ALM: Slightly over a year, because then my husband George looked into a job with the state radiation safety people thinking of Chicago land but there was an opening in Champagne in central Illinois and we decided it would be a good move.

CM: Was it a good move?

ALM: Long term it was a good move, although it took me a few months of unemployment before I got my first job. I almost walked out on one of the interviews just because someone was so rude about “Well, you don’t have any school experience.” Back then, public law 94142 for educating all in public schools had just been passed so not that many OTs had school experience and it was sort of a catch-22. The jobs were good in terms of the benefits for the continuing education, and it was a good learning experience. However, working as an itinerant with twenty to thirty schools was a daunting task.

CM: How long did you work there?

ALM: About two and a half years. Unfortunately, many years later I attempted to clarify the hours for my retirement plan out here. I ran into a lot of difficulties because I had been paid on grants and the records were so old that it looked like I got paid less my second year than my first year which I know didn’t happen and it was very very hard to clarify records that were more than twenty years old. But I left the co-op job when something opened up close to home in a residential center where a friend worked and I was very attracted to working on a university property so that I could get the free tuition and not have to travel. And I did give up having summers off but I also got a much better salary.

CM: Did you take advantage of the free tuition?

ALM: Yes I did. Both my husband and I got degrees at the University of Illinois while state employees. That was a time where I didn’t let myself be intimidated by how long the masters might take. The whole part of it being free helped, and being in education helped because you could get night classes. I did have unusual residentialship types of hours so some days I did work seven to three to take an afternoon class from four to seven. I knew

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that if I couldn't do it as a twenty year old when it was free then it would certainly be harder to do it older if I was a parent and commuting and that type of thing. So that part definitely worked out well. The center I worked at served severe behavior disorders, so it was a physically and mentally challenging day, but as a twenty year old I could handle it.

CM: And what was your masters in?

ALM: Special education.

CM: And did you get a job in special education, or did you stay in occupational therapy in Illinois?

ALM: Both. The program I got was for people such as myself, like therapists, working in special education. So several jobs later I am in special ed, but I am an OT.

CM: So, when did you move back to Massachusetts?

ALM: When I turned 30 we moved back to Massachusetts. There were a few reasons. The residential center had closed, and when faced with commuting to a less desirable long term center rather than a short term center a preschool job opened up. I was still working on my masters. At one point in time the preschool has been my dream job, but by the time I got it I realized that the workload for the salary was a bad match, and my husband for some reason decided to apply for a job in Michigan that year which had not been our plan. We had been hoping to move to Wisconsin. So that sort of stressed me out that I didn't know what direction he was going to move in, and I was looking into jobs in Wisconsin and Massachusetts because by that time my mother was disabled. My brother was leaving for school in the Midwest, and a lot of our friends had left town, and we didn't have a house yet. So when I got a list of several jobs in Massachusetts I applied for one, got invited out for an interview, again it looked like I had a dream job. I was at a private school, I had a really nice therapy room, but it took a while for my husband to be able to come out. He only had part time work. So it was a rough adjustment.

CM: What was that job in Massachusetts like?

ALM: Well it was one of the things be careful about getting your dreams, because it turned out again to have an extremely high work load, where as the OT I was also the art teacher and phys ed teacher. I had to test a kid a week. As a private school in a time that public

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schools were improving programs, it was sort of a another political upheaval. We had a lot of pressure to recommend certain things to get the towns to send the kids to the school, and by the second year they were divulging to us that they immediately making their payroll. So at that time I took on a part time job for consulting at Belchertown State School. Really wasn't the direction I wanted to go into, but work is what you do to support yourself even in a profession it's not just about working with cute kids, and I dragged my husband out here and needed to support ourselves. And my hours had been cut the second year at the school, and I ended up transferring or moving into the State School full time, which was good financially but I was very miserable.

CM: What was that job like?

ALM: Well it was working with severe and profound adults who had always been institutionalized. I had to do things like run feeding programs where my hands were on the jaws of adults that still couldn't chew properly. It was probably the only job I had in my life where I couldn't go out after work in the clothes I had worn because I was sure to smell. And then I became an administrator, but I still tried to do some patient contact so then that was really unusual to try to dress upscale on one hand and very washable on the other. It was a strange situation as far as just spending so many hours in meetings with so many other people and just seeing in my head how much this meeting was costing for an individual who needed pretty much total care. A lot of the staff at the institution would be what I call institutionalized to working there and very much into political organizations. So when I saw a job at a very local high school for adapted PE I looked into it.

CM: And where was that?

ALM: Pathfinder was two blocks from the house, so that was a big attraction to me.

CM: So you worked there?

ALM: I was able to get the job without lying on my resume. They did hire me as adapted PE because I had so many strong related things. However they did make me go back to school in physical education. So basically I suffered a 75% salary cut to make this move, because I was an administrator moving to a school district that had a sub-standard pay rate at that time, and then of course from moving from full time to half time. The combination was really really big. And then I had private school tuition on top of that

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because the public schools here, to go into phys ed, basically required you to be full time undergrad and that just wouldn't have accomplished the purpose.

CM: Do you still feel that was a good move?

ALM: Yes, in the sense that I wasn't happy at Belchertown State School, and yeah in the sense that I'm happy I can work close to home. And like so many things, 20/20 hindsight. You don't know what is going to happen so it's very hard to regret a life choice that way.

CM: You're still working at Pathfinder?

ALM: Yes, I am I have more than twenty years at Pathfinder. The job has changed a lot over the years, in the sense that when I first worked there I had many students who would be termed more severe, more in need of occupational therapy, and/or adapted phys ed. They have changed the programs over the years. I had picked up health as a way of increasing my hours, eventually became part time. For political reasons the program also changed, so I am doing a lot more classroom work, which isn't what I thought I'd be doing. Sometimes I enjoy the classroom work. Bottom line is I am happy to have a job in this economy, and once you become so specialized it's not that easy to jump. And I really do like the population of moderate special needs that I work with.

CM: So you're a health and PE teacher?

ALM: I am certified in PE, I get a little upset about the health because it's the one thing I'm not certified in but I spend more time doing it. No one from the state ever criticized the administration at Pathfinder for putting me in those situations, however. Before I got certified in phys ed they never got a waiver. People would come in and be so amazed and delighted that they had their own OT that some of my interviews for surveyors or auditors were very easy. There was one guy that was concerned they weren't using me appropriately, but politics is a funny thing as it related to education.

CM: Are you still having problems with politics in education?

ALM: The rules on older kids in school are quite unusual in that the kids have the right to be there until they are twenty-one, however after many years of having a waiver for the ungraded program when they could mix up the ages, following the retirement of my old boss we lost our waiver and at the same time they demanded increased academics for the

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kids so it changed quite a bit, and you cannot underestimate the impact of the standardized state testing on special ed in the sense that they lower the town scores so that the towns are eager to move them out on the one hand, and on the other hand my own school wants the money that accompanies the students but they complain about the extra burden of having a different kind of program. Some people tell me I have a very secure job, but I don't feel especially secure.

CM: Why's that? Because of the politics?

ALM: Because of the politics, and because I have been through one program closure. I think anyone that has lost a job through closure or downsizing carries that with them and even though a program may seem fabulous, the swing of politics can always change something.

CM: Do you face any challenges specific to the standardized tests?

ALM: Because my students have never passed a standardized test, when they enter our program their parents sign that they realize they are entering into a modified program that will not lead them to a true high school diploma. Our students participate in an alternative. I help with that, so it impacts me that way that I am actually doing biology with kids. It also impacts me indirectly as just somebody working in the building that the most important thing often in the building seems to be the MCAS so that it takes up most of the staff training time. It also affects me as an itinerant teacher in that I lose classrooms during MCAS administration, which also reminds my kids they aren't the same as the others. So it certainly has had a big impact that way.

CM: Do you have any children of your own?

ALM: I have one daughter. My ability to conceive was delayed a couple of years from health reasons. I had been on birth control in my twenties and had planned on stopping when I turned thirty. At the same time I was being treated for high cholesterol and for some reason my periods stopped right when I wanted to get pregnant. In a way that is typical in my generation, who tried to have careers and think they could do it all with the kids, so in the sense it wasn't that hugely unusual that I had trouble. I did not want to go through true fertility treatments. I did have a really nice doctor, who would do things to just get the period going thinking it would stimulate a pregnancy. I had it tried for the last time I was gonna do it when I got pregnant with my daughter. Against medical advice I trained

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said pregnancy for summer vacation, which I actually accomplished quite well. It was actually quite a funny memory because news travels fast in small work settings, and my boss came down and I could tell from the look on his face he knew I was pregnant and he was quite happy when I told him not to worry, I'd be back to work in the fall and might need to just tweak my hours down a little bit and take a year off of school. Because by then I was taking phys ed activity classes and I couldn't be in contact sports when I was pregnant.

CM: Did you face any challenges as a working mom?

ALM: Of course I did. In some ways it was easier for me because my husband was working primarily weekends, I didn't have to send my daughter to the baby sitter that much. When I first got pregnant I told my husband I thought I could find a grammy in the neighborhood, and he thought I was a lunatic. Sure enough, I found a grammy not in my neighborhood but the next one over and that worked out very well especially since you [her daughter] didn't have to go every day. But the other challenge of juggling working and family and I was back in school again was if everybody is working Monday to Friday schedule and you clean your house on the weekend, nobody is home during the day, and you come home to a clean house. When you have a family working alternate schedules, its quite different in that you come home to a house that people have been living in all day. And a typical challenge is that most moms carry more of the responsibility than the dads, even though my husband was home doing child care you never hear moms saying that they're babysitting their own kid where you could hear a father say it. I never forgot, ever, that I couldn't make plans without considering who is taking care of the kid, but there were a couple of times where my husband made plans early on just totally forgetting that he is supposed to be home. With his alternate schedule he could use the babysitter for the daytime, whereas I was much more restricted. One of the things that stands out most in my mind of the difficulties of work and kid and husband was a project I did in adapted phys ed. Daughter was still young enough that she needed attention all the time, so the project had been done totally during my daughters naps. I thought I had tucked it away safely, and my husband tossed it out when he was cleaning, and that was very devastating. And I had to redo it, but I didn't have the heart to redo the posters so I typed it out, and I did OK in class but that was one of my mom vivid memories of that.

CM: How have health issues impacted your life?

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ALM: Well, it was pretty ironic, in the sense that just as I was finishing school and I thought I had climbed to the top of my mountain and got rid of the dark cloud over my head of this requirement that I couldn't keep my job until I finished school, I found a lump in my breast that seemed to have grown very quickly. But it had been a very stressful year the year before, with finishing up school and the incredible amount of paperwork involved. The year before when I had been to the doctor I had jokes about it being so easy to give myself breast exams because I had such small breasts. On my way out of the doctors I was thinking if I ever had breast cancer it would certainly be ironic, because I had never really experience having normal sized breasts and that would certainly be a very cruel twist of fate for me to get it. Well sure enough I got it, and I could always sort of tell going through the tests that... Some of the tests would come out negative and I would have to go for one more, and it was so anchored that I knew in my heart it wasn't just a cyst. So I had to go for a mastectomy. And at first I thought, "Well, I can get through this if I don't have to go to chemo after." And then the first news was that I wouldn't have to do chemo, but I was very shortly told no, that wouldn't be the case, they had looked at the slide again and changed the diagnosis and I would have to have chemo. And again, juggling work and family and chemo was a trick too.

CM: And how old was your daughter when all this was happening?

ALM: She was in fifth grade when I was in chemo, and it was only half day...excuse me five years old in kindergarten. So that was a difficult year anyway, because being a half day program, as opposed to preschool being full day, for a working mom it's the most difficult year. I thought I had set up a babysitter where it would be OK, but she was not working out well for a variety of reasons, and then here I am with cancer and her quitting. Fortunately a better babysitter worked out, however I had to leave school and transport you [her daughter]. It worked out only on a fluke that I happened to have a planning period then, so it wasn't like...which I made up, it wasn't like they gave me time off to do this, but at least it got us through that year. When I was on the chemo, it was time that I got sick on the weekends. I got treatment on a Thursday, have a half a day on Friday with some easier activity planned, and again because I lived so close to school I could do it. If I had been driving an hour I probably couldn't have even done that. But however, it meant that I would be sick on the weekend and as chemo goes it gets worse as you go along, so the first couple weren't too bad and it got a little more difficult as it went along. But then by February it was done, thought I was through, but in October I got the flu and on a checkup the doctor had discovered a lymph node had enlarged. For some reason she

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waited a whole month before biopsying it, but it did turn out to be cancerous and at that point they did some scans and I don't want to go into too many details on that because it ended up being a wash, but because of it being my second time, because of being young and healthy, having just finished PE school, I did get referred to a program at Dana Farber that was experimental.

CM: What was that like in Dana Farber?

ALM: It was quite daunting to look at how much was involved in the program because it was going to take nearly six months. Many steps, extremely aggressive. The point of the project was to find the maximum survivable dose of particular drugs, implies they are going to push the envelope pretty far. I had to sign... it was such an intense program I had to sign every page of the document of the proposal to make understand what I knew what I was getting into. They made it perfectly clear that they would take me down to have no immune system and that going... deciding to leave the program partway through would not be an option. It was very terrifying to think of who was going to take care of you [her daughter], that fell into place with your father [George] taking half sick time and landing a babysitter who had changed her college schedule just coincidentally before that happened, but I was back and forth. I didn't go in there for the full time, I would go there for a few days and go home. It was preceded by so called standard treatment at a local hospital, which was pretty difficult in and of itself. But it meant that I left school in February and didn't get out of the hospital until coincidentally the last day of school that year.

CM: Was it difficult going back to work after?

ALM: Yes it was because I was bald and I had to wear a wig and I hated my wig and it hurt. I am a very tactile defensive person so it's hard for me to ignore things and it felt like I had a rubber band on my head, and just a year, two years before that I had returned to work with severe shoulder pain and limited movement so it certainly made work difficult. For the first couple of years after the transplant I survived by not thinking about things, and my energy level was still not close to normal for a couple of years so it impacted a lot of things.

CM: What transplant?

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ALM: Sorry I'll back up on that. My own bone marrow was not affected, so it was called an autologous transplant where they harvested the bone marrow, harvested stem cells prior to two rounds of extremely high dose chemo, so it wasn't really a transplant like getting somebody else's organ, but I am still considered a transplant survivor in that sense.

CM: Do you still feel affected by that experience?

ALM: Not as strongly as the first couple of year. The first couple of years if I heard people talking about how much they are putting into retirement I...one time it made me cry at work while I was trying to do grades I could hear these people and I just, I couldn't think that far ahead. I was just so jealous of them. It forced me to save heavily for my daughter's college because I wasn't sure if I'd be there to pay for it and I saved less for my own retirement because at that time I wasn't expected to have one. So it affected me that way. I think I was more...it was stronger at first, that I would hear people talking about silly things like a bad hair day, and if you've been bald you never have a bad hair day again. If you have hair, it's a pretty good day. A few times people made strange comments to me about "Oh, well, you'd just be happy to be here," whereas they think they are entitled to some other level of activity and happiness, so that was always strange. For a few years you are very afraid to make plans for fear that the cancer is going to come back and its going to be more heartbreaking because you can't live up to your plans. But as time went on, I started to look more towards the future, get less afraid of planning.

CM: What are your views for the future now?

ALM: See my daughter graduate, and not just seeing graduation but helping to get through, because then I'll feel as like a big part of that job is done, so that I can think about my own retirement. But on the same time, I am a member of the sandwich generation with an ailing father, so I know there will be something in my future in terms of dealing with a not just funeral but what's going to happen to the house and making decisions like that.

CM: That must be tough.

ALM: It is tough with dealing with an aging parent. It's tough being far enough away that popping over for a short visit is difficult, but close enough that people expect me to make frequent weekend trips. I'm grateful that he has a strong urge for independence but it's

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very frustrating when somebody's being stubborn in the face of simple things that could make their lives safer.

CM: So your mother is not with you anymore?

ALM: She was quite ill and died seven years ago, and that was also difficult because as was their way, they didn't tell me when she got sick. My dad had been maintaining her at home on a commode as she went from a cold into pneumonia. She had been blind for 20 years and had multiple heart events, multiple surgeries, and when she was in the nursing home, she was not doing very well as far as being totally dependent on care from staff, but thinking she was going to come home and be cared for, and just wasn't being realistic about what her physical state was. So that was extremely stressful, and guilty relief that she passed without having to make some of the difficult decisions that she wasn't going to be able to go home in that state and be maintained, without... she didn't want to consider moving a bedroom downstairs or bathroom bars or anything like that, and just wasn't being realistic about going home when she can't even do a transfer into the bathtub. So I am looking for a possible three or four years left on teacher retirement, as in the case of so many people my age I've seen...not that I've saved that much on my retirement for a couple of reasons, putting away for college, when I was part time there wasn't much extra money, and also I invested, I did a lot of roll over to buy more years in the system, but like a lot of other people, I would choose to retire, if they keep the system going that way, partly because of the health issues, and also because of the expense of the constant recertifications and the nagging fear of possibly of being sued, that if I could retire at 75% or 80% of my salary it wouldn't make sense to put myself out there to get these constant colds and everything that could develop into something worse. And I would probably hope to retire and have some sort of part time job.

CM: What do you think you would do for part time work?

ALM: Either more OT since that is the type of thing that you can do part time, another area that OT can go into is assistive technology. And again, if I was already getting 75% of my salary, I recently found out that at age 62 I can get a little bit of social security from the couple of jobs I had that paid into that. I probably...I might be OK. Some people joke about doing something entirely different, but I don't think I would want to be a store clerk necessarily so I will have to see what happens.

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CM: Well, thank you very much for your time.

ALM: You're welcome, it was my pleasure.

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