



Workplace Issues for Caregivers

This program provides key insights into the challenges that caregivers face in providing care to patients with Alzheimer's Disease while maintaining employment. Available support programs, resources and importance of connecting with the community of caregivers are all provided during the program.

JON MERRIL: So to start out with this program will focus on the role of the care giver and their interactions with the work place. And a lot of care givers are employed in the work place and that creates some unique I guess benefits and tensions. And can you speak a little bit in broad strokes sort of about some of the issues that care givers or may be, could even be the boss if you will, what issues do they face when they're starting to become a care giver?

DONNA WAGNER: Okay we are estimating now nationally that about sixty percent of the people that are doing family care giving are working either full or part time. And most of those are working full time. So beginning to care for a family member who has Alzheimer's for example can be a big challenge because not only do people have to try to balance their work and their family responsibilities, if they have children for example their relationship with their spouse or friend, but they also now have to add to the mix the ongoing care responsibility. So it presents a lot of let's say complicated logistics for many family care givers. They're not all negative, the implications of those logistics, but some of them are. And we've been talking a lot around the country in the past few years about this issue because family care givers who are employed are, their care giving responsibility is spilling over into the workplace and so it kind of increases the stakeholder group in the care giving itself. For example if they're working, their employers have a stake in having them effectively balancing work and family issues as well as their family members.

JON MERRIL: Can you give some examples of, in the work place, you know some of the issues and you know I guess the hot spots that someone that someone that's a care giver faces in the workplace?

DONNA WAGNER: Okay, if you're working and you begin to take care of a family member there are some common things that we are seeing around the country that cut across all kinds of care situations, not just Alzheimer's but all kinds of care. And those include the need to make workplace accommodations that range from changing your work schedule, coming in late, leaving early, needing to do some care arrangements while you're at work, missing days of work, and for the care giver who care at a distance. And there's about seven million Americans and most of those are employed full time who are caring for a family member who is a distance of an hour or more away. Those people generally are required to take full day off work and have an increased likelihood, although all caregivers have this likelihood, of having unplanned absences. So all of these things kind of add up to a problem for the workplace. And in the sense that coworkers kind of have to pick up the slack when they're missing, when they're gone. Many of the supervisors are not sympathetic to care giving employees and a lot of care givers who are working are let's say reticent to talk about their care giving responsibilities at work because they feel that it's not welcome. And so there's an attitudinal issue, there is an actual time issue, there's also for many people, we're finding they have to take a leave of absence in order to manage the care. About ten percent of the working care givers take an unpaid leave to manage the care of the family members. And so this can add to their own financial issues and this is particularly true in the case of someone with Alzheimer's. If you're caring for an Alzheimer's person there are limited financial supports for you that might be in



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place for other types of illnesses or disability issues. So the care giving family member is not only doing hands on care but also often paying for services that are needed. And sometimes they just can't get the services they need and end up taking leave.

JON MERRIL: And you mentioned different supports that may be available to different diseases you know as a care giver. Can you give a little bit of a, why is there a differential between someone that's caring for someone that's caring for someone with Alzheimer's versus someone that's caring for someone with cancer? Are there actually different state, federal, local programs or- ?

DONNA WAGNER: Well I think the difference between someone caring for someone with Alzheimer's and other conditions and we'll just look at late life conditions is that Medicare will cover a lot of the expenses related with for example with recovery from a surgery or from an illness and that kind of thing but they will not cover the ongoing long term care needs of someone who isn't getting better. If you're caring for an Alzheimer's person and they happen to fall down and break a hip, Medicare will cover that but they will not cover the routine daily expenses. So this places a very high burden on family members and I think the, of looking at what families pay out of pocket for long term care I mean they are a primary payer for long term care, but for an Alzheimer's person they are paying a significant amount of money. The last statistics I saw were that family members are paying an average of sixteen thousand dollars a year for the ongoing care of a person with Alzheimer's. And this is the kind of day to day things they might need. For example if they're working they might need to put their parent into an adult day care center to supervise their activities and help them during the day. While they're at work some of the people who are working decide to bring their older loved one into their home and they may decide to hire someone during the day to be with that person. So there's all kinds of care arrangements that are not only difficult to manage but are costly as well that may not be present in your standard kind of older person illness frailty disability issue.

JON MERRIL: And I'd image there's probably a lot of challenges too if someone doesn't have that financial resource. Then are people tiring early to become care givers or is that kind of changing the landscape if you will of decisions that are supposed to be the golden years?

DONNA WAGNER: Well yes. And of course it historically has hit women the hardest because they've been in the past the primary care giver who has been the one in the family who kind of takes lead. They don't then continue to accrue credit towards social security, that kind of thing. So care giving for many people is a gift that keeps on giving. And it gives again after they themselves grow older and find that they're facing less income in late life. And one estimate that was done suggests that a family care giver actually can lose as much on average as six hundred and sixty thousand dollars in lost wages or retirement benefits as a result of their care giving. So it is a big financial issue. And I think that a lot of people when they're thinking of family care giving, they think only of needing to go over and be with their person, bring them food, do their grocery shopping, help them around the house, that kind of thing. They forget that there's often a financial exchange as well. And about forty percent of family care givers are actually spending out of pocket money, either purchasing services for the older person or buying them goods and services that they need for their home, that kind of thing.

JON MERRIL: It sounds very challenging. Are there any tips that you can give to people who are you know faced you know with the care giving responsibility to you know lessen the load?

DONNA WAGNER: Well one of the things that continues to surprise us when we look at working care givers is that many of these people never expected to be a care giver. And even though they have older parents or they see that one of their parents has been diagnosed with say an Alzheimer's diagnosis, they this idea that either Medicare or Medicaid or some sort of governmental program is in place or community support services is in place. And they really have a hard time understanding that it really is going to fall on them. And the best predictor of having the most complicated work family crisis is not expecting to be a care giver. And I kind of wonder myself when I look at these answers that people are giving me like well who did they think was going to do it? I think the answer is that most people just assume that there is something out in the community that is going to be there for their parent when their parent needs something. And that's really not the case. So I guess if you're looking at what would really help care givers, one thing is really just more information about what it is to grow old in America today and how that process is supported. And basically eighty percent of the long term care that's being provided to people in America today is being provided by family and friends. It is not provided by nurse or a doctor or a professional home health aid. And that balance of care is actually continuing to shift. We actually saw a new study that just came out that showed the use of formal services, services that we pay for that professionals provide to us, is declining even further and that older people are basically compensating for that decline by increased reliance on family members and on technology. And the technology that they're primarily relying on is low tech things. Like they won't have a home

health aid come and give them a shower, they'll have one of those little stools for the bath tub to put in or they'll get a grab bar or that kind of thing. And so we're really looking at a kind of situation where families are being asked to more than they were asked to do in the past. So I guess I feel like we should be maybe on a national level doing a little more to inform people about what it's like and what is going to happen and what is going to be expected. I'm still seeing a lot of people that come into this care giving situation shocked and saying, "What, I have to do this? Isn't there someone else that can do this?" And then there's other people who come into a care giving situation feeling like it is my job to do everything because I am the daughter or I am the son and my mother took care of me and I'm going to take care of her. And the kind of person that comes in with that attitude or a belief system about what their role is often finds that there are some things that they just can not continue to do and do their job as well. For example I had in a study that I just finished a young man whose father had Alzheimer's disease and he also had some physical illness as well and he developed cancer. And so the son had to be with him to help him through all the cancer treatments and he was missing a lot of work. And at first the coworkers and the supervisor were supportive and reassuring and saying, take your vacation days and take your sick days and you know we'll manage without you. But as the treatments and his illness continued to progress and he continued missed work people became less supportive. And finally his supervisor said to him you can't just keep leaving this, you can't just keep leaving work, this isn't going to work for you because you're not going to have a job. You have to make a choice. And so the man who was trying to care for his father stopped going with his dad to his treatments and tried to make arrangements for someone else to go but the father was basically saying, I'll just put it off, I won't go, you know I'm not going to go if you don't go. So when I spoke to him he was in a real dilemma like okay I have to have a job, I have to have my career in order to live my life but I'm being asked to make choices that actually are hurting my father. So there's a lot of very complicated issues and he was not at all anticipating this would happen and he really needed more information, I guess I would say, to help him. I think there are solutions for people but I think they're hard to find. Now in the workplace what we're seeing and we've been seeing this for a while is programs that are developed explicitly to help care givers that are working. And these programs unfortunately are primarily found in the large companies, they're eldercare workplace programs. And they will give employees information about services in the community. Some companies actually provide some financial help to their employees to cover cost of services, that kind of thing. And then most recently and I think most promisingly is the new trend that started around two thousand of actually having a geriatric care manager on site, either on site or on contract to help employees who need ideas about strategies and services. So this is a really, I think very positive thing because if an employee, I mean when you're doing elder care you really are doing, if you've seen one older family and one older person you've seen one older family and one older person. So one size does not fit everyone in the elder care world. So geriatric care manager can sit down with the employee and talk about their situation and design specially tailored responses for them that would be not possible probably if that professional was not there with them. So I think there are some promising things but the fact is that at the end of the day it's really a family that's going to have to make the decisions on how things are going to be managed. And no one can help or take away the emotional issues involved with helping a parent. So, sorry I'm going on too long.

JON MERRIL: No, it's fine, it's good. In terms of you know the different levels of someone in an office whether they're white collar, blue collar, red collar, do you think it makes a difference whether someone is in more of a support role or more of a leadership role? Does that impact their ability to be a care giver?

DONNA WAGNER: Whether or not the employee is the boss or has a functional job does make difference. Because if you're a white collar person and you're sitting at a desk all day and you have a computer, you have a resource for your care giving and it's not hard for you to take a couple seconds and look something up about if you need to know about a service or make a phone call. If you're a blue collar worker and you're working not at a desk but at a construction site for example, you don't have that luxury. You have to do it on your lunch hour or you have to do it in the evening, you have to do it on the weekend. And also your presence at the workplace is important for the actual job to get done. It's a little easier for the people that are white collar to kind of sneak away. There are, there is a difference in job category, but there's also a difference in the type of job you have, the type of company you work for. For example I've surveyed a lot of employees and a lot of different companies and the one company I felt was the worst company to work for was a company in the publishing world. And I don't know why that was but everyone there was really upset about the situation. Even though they had a workplace program, none of the supervisors were supportive of it. And they were actually criticizing anybody who came forth and said that they had a care giving issue. And so the culture, the type of job, that kind of thing. In the mid nineteen eighties, Fortune magazine did a survey of Fortune 500 CEOs about elder care. And one of the questions that they ask all of these CEOs was: Would you have a problem doing your own job if you had to care for your mother or father? And more than half of the CEOs reported that they didn't really feel like they could really carry out their own job if they were care giving. And that was a really I guess pivotal study in the development of workplace elder care because these were influential people, people who really had the ear of all of the business community and they said that they couldn't do their job. And so it really made the difference of how willing other companies were to spend the money to start an elder care program. Now if you're the CEO of a large company, IBM for example, it's probably easier for you to do this because you can hire people, you can take a few days off, you can, you have more resources than someone who's actually working in the mailroom of IBM. But I think it's hard on everybody and it depends on the company. Some of the small companies for example that don't have any programs in place and we have to

remember that most American workers work for a small company that does not have a program in place. They don't really have a choice. So they have flexibility. They'll say to Joe, "Joe, I know that you've got this problem with your dad. So just go ahead and take what ever time you need and then come back." And they do it on an informal basis. Sometimes it involves money, sometimes it doesn't. But it might be a little more comfortable for Joe than for example a large company. A few years ago we did a study on men who are care givers. And this is another interesting area because in the past care giving has been seen as a woman's issue. But we've been noticing among the working care givers that there are an increasing number of men who are reporting that they are the primary care giver for their parent. And so we wanted to know what difference did it make? Were men at work difference than women at work in terms of care giving? And we did find there were some very important differences. Men for example were much less willing than women to talk about their care giving responsibility at work. I think they feel that you know it's going to be held against them or they'll be looked down upon or they'll be repercussions about revealing their responsibility because they think that maybe people, maybe their supervisor will think that they care more about their family than their job, that kind of stuff. Or maybe it's just the old macho thing, I don't know. But that was probably the key difference. And of course that is a difference that means that even if a company has programs in place, it's unlikely that men who are not even going to reveal that they have this issue or are worried about revealing it are going to use those programs. So I think you know we've talked about, in the world of work and family we've talked about the fact that men don't use maternity leave and women do because it's not considered to be you know what men do. And I think we're seeing the same kinds of things when it comes to elder care. Am I going too far off field here?

JON MERRIL: No, no, no. The one thing I'm wondering you know for this internet audience, for the people that will be coming to the website. If you were to construct or contribute to something that will alleviate the shock and would offer more support, I mean obviously as you mentioned fewer people work for these large companies that have these additional services and supports. But for the majority of people that are working in the small companies that may have access to the website that we're putting together with Copper Ridge, what types of resources do you think we could make available that would make a difference? Even if we you know, either creating them to know about or resources that you know you mentioned people going on the internet and finding particular services. But are there things that you know strike you that are some burning needs that we could address and then, in one category and then you know in the other category would be just link or resources that either hard copy or internet based that you know everybody should know about that's you know based with care giving responsibilities?

DONNA WAGNER: Well I think one thing is just information about how widespread care giving is because I think it is helpful to people to know that they're not alone. And still many family care givers feel that they're in a small group. So that's one thing, that education piece about how big that boat is and it's huge. The solutions are complicated but I'm thinking there's two different sets that I've seen that are really important. And one of those, the first thing when a family care giver realizes that they're going to have to get involved in helping the parent is, the first thing they want to do is they want to find out a lot of information about the disease and what the prognosis is and how things are. And there is a lot of information about that but there's also a lot of bad information. So having a good reliable source of information that for example you're doing Alzheimer's so the Alzheimer Association has done an excellent job of doing two things. One, the Alzheimer support you know the groups I think are really great for care givers particularly if you can get them in there early. And so getting information to them about that is a resource. And then the other is just practical hands on and scientific information about the disease itself and what options are available for services. So I guess that would be one of them. Then the other thing is one of the big problems that people in the care giving research field have been battling around for many years is this problem with care givers and the health system because most physicians and nurses and health care providers do not recognize the critical role that family health care givers are playing in the health care team. And many care givers will come and say, "I don't feel valued. I don't feel like I'm part of that team. I feel like I'm being told to do things I don't know how to do." And so that technical training, you know how do you do some of these things? There used to be a great site in Canada that I don't think is there any more. But it was a care giving site and they actually had a demonstrate, they animation used to demonstrate things like turning someone so that you don't injure yourself or giving someone a bath or you know doing some of these basic kinds of things that you know care givers are having to do all the time. So it's helping people think about strategies for affectively communicating with health care professionals. And also visa versa also having health care professionals be more informed and aware of the importance of the family care giver. My you my mother-in-law was just in the hospital with it turned out to just be gall bladder problems. But you know she's eighty-four, she has her gall bladder out, and the next day they call up and say she's ready to go home. Well she isn't ready to go home. And you know the doctor was able to intervene but you know this idea that well who is in charge of her care? And how come she is being told that she has to go home the day after this happened. So there's a lot of issues and family members have problems like you know my sister-in-law who is her primary care giver was like you I can't really call and complain about that. Why not? You know so I guess you know consumer tips with the health care and then information to the health care provider would be two things that I think would be really good.

JON MERRIL: That's great. And along those lines you know just to wrap up you know the message about care giving and you know

empowering people to know more about resources, are there any you know sort of thoughts in summary that you could provide that kind of button up you know the concepts and essentially point people in the right direction?

DONNA WAGNER: This would be kind of a recap of the whole thing?

JON MERRIL: Yeah, just a real brief, maybe just a few themes that you mentioned. You know, the shock. I mean the things that I heard were you know you mentioned that people haven't prepared for the issue of care giving, that the supports aren't necessarily there in the work place. You know I guess it's what could they do? You probably addressed most of it. But just any little thought if you will. A metaphor, anything at the end just to kind of tie it.

DONNA WAGNER: Okay. People who are new care givers, who've just begun to take care of a parent have a lot of work to do. And some of that work has to be done at work and some of that work has to be done at home. And I think a lot of resources out there just to- I should start over. Do you think this was the wrong direction to go?

JON MERRIL: No I think that was great.

DONNA WAGNER: Okay, so new care givers who also have jobs have to recognize the fact that they have two jobs. And the best thing that they can do for themselves and their family is to figure out ways to take shortcuts to get the information that they need and the support that they need to do all their jobs well and to keep all the balls in the air. And one of the things that's really important is to, if you can, talk to other people who have gone through care giving themselves on a personal level and find out what they've done, what's worked for them. The other thing that's really important is to find out what your employer thinks about, what policies are for care giving or taking time off. Some employers for example will tell you that you can not use your sick days to take care of a family member. Other employers will say that's fine, vacation days are fine, personal days are fine. But it's up to you to figure out what's good, what's going to work, what isn't. And it's also up to you to manage the information, find the information that you need about making the right choices in the health care arena. Doing the right thing, being the right health care advocate for your parent when they need you the most. And this is a hard job. It's one of the hardest jobs you can ever do but most care givers say at the end of the day that they were happy that they did it, that it made them closer to their parent, that they felt that they had done something that even though it was difficult it was of the most rewarding things that they'd ever done in their life. So don't lose heart because there is light at the end of the tunnel and there's lots of people out there to help you.

JON MERRIL: That's great. And the very last thing is if you could just state your name and professional affiliations that'd be great.

DONNA WAGNER: Okay. My name is Donna Wagner. I am a professor of gerontology and I direct the Center for Productive Aging at Towson University in Towson, Maryland.