Audrey Miller

PSY: So Audrey, how did you get into this work?

AM: Once I graduated with my MSW, I started working with differently abled folks through the Ministry of Community and Social Services. That was 30 years ago. I certified as a rehab counselor, primarily dealing with individuals with catastrophic injuries and acquired disabilities. The kind of work I was doing with that population was certainly transferable to families dealing with aging and disability. So ten years ago, Eldercaring was birthed. This is a work of passion and love for me and I feel very privileged to be able to be invited into people's lives at this point of difficulty. I was able to take those skills and look at the entire family and the client all as very important players in the caregiving team.

PSY: Okay, so this is the Family System approach.

AM: Exactly. So there's a Family System approach and it's about understanding and being able to see the interplay within all those systems. We're not aging in isolation. So much of the time, families don't want to talk about these things. We prepare nine months for birth and it's a very exciting time. Nobody wants to talk about death. Nobody wants to talk about getting older, so we move forward until quite often there's a crisis. Those are the majority of the calls I get — in crisis mode. I'm trying to spread the message to start the process before a crisis occurs. Because when we plan, we have choices. And when we react, we lose the ability to choose, quite often.

PSY: It's a very personal thing you have to do. You have to come in and immediately ask all these painful and difficult questions. Or start the ball rolling towards addressing those painful…

AM: That's true, and what's particularly challenging is that, unlike the practice psychotherapists have, which is usually over an extended period of time, quite often I'm invited in for a one-shot assessment only. So they say: come in, figure out what we need to do and then, thank you very much, goodbye. Part of what we're doing is offering this kind of assessment, which is comprehensive and thorough, but we have to very often think on our feet and have the knowledge to be able to guide. This absolutely requires a professional approach. There are lots of folks out there who looked after their own parents and feel they have something to offer and I'm absolutely sure they do, but the reality is, people don't want, for example, to move twice, if they're looking at a move at all. Quite often we are dealing with folks who are vulnerable, so it's really important that all the care and attention and knowledge be available to help guide the families in a professional and proper manner and not leave anything out.

PSY: You've got basically one session?

AM: It's one session, often. A two-hour initial assessment, where we're in and really rolling up our sleeves and saying okay, let's look at your safety. I may have the opportunity to sit down and meet the older individual, in which case the assessment is hands-on, meaning: I'm looking at the environment. I'm looking at their cognitive issues. I'm doing a brief depression scale. I can only do screening, truly, in the time that I have. There may be a cognitive assessment, such as the mini-mental or there may be a nutritional screen. We're also looking at the caregiver issue. What else is also going on with the family? And then we help the family to address those issues which we can help them address. And in every situation, they are different. We have to be able to assess and think outside the box and then offer different possibilities and tweak them to fit.

PSY: So who starts this process? Who contacts you from this family?

AM: Usually it's the adult child.

PSY: The main caregiver?

AM: It may be the main caregiver. Or the adult child who lives out of town, worried about their parent who's here and going into hospital or coming out and they're not here. I'm a member of The National Association of Professional Care Managers (caremanager.org) out of the States, of course. It's an American model.

PSY: We don't yet have this in Canada?

AM: There's a handful of Canadian members and we belong to the Mid-West chapter, which is absurd — but no, it's not here yet. It will be, as our numbers are growing. As you know, older seniors are the fastest growing group and we're living longer and longer. So we're probably going to see more and more individuals who have a role to play in helping families plan. And there's also a cost-saving requirement because providing care is very expensive financially as well as emotionally, right?

PSY: So you're often seeing the emotional side of things.

AM: And about understanding what the family's needs are and how to work within their budget. I do a fair amount of work with financial advisors and banks and trust companies where they may even hold a power of attorney. Part of my challenge is bringing all that together.

PSY: Within the family unit, if that's who holds those powers?

AM: Exactly. But the reality is, my job is to develop a plan of care for their parent. There are usually conflicts in families and I'm not going to be able to change those situations. So, for example, we might have a family where the parents are in their 90s and daughter is very concerned that Dad is bullying Mum, which has been their pattern I'm sure, for their entire life.

PSY: So this is not a new phenomenon for them, not a geriatric kind of emergence?

AM: Not that I've been told. This has always been their story. So Mum has been in the hospital, had surgery and is now coming home and how is Dad going to deal with assistance or caregivers in the house, which Dad has adamantly refused? So there's a very fine balance in terms of being able to understand what both seniors need and being able to present that.

PSY: Pretty tricky work, I would think. You could easily set one adult off against the other or appear to be taking sides. You have to come in

neutral and also be advocating for the weakest party.

AM: I come in neutral. As a professional. My own mother would push my buttons but your mother won't. That's the distance you have in your job, Sarah, as well. Being able to keep a professional separateness. I can see what their interaction is but I'm not going to dance with them. I'm going to stand back and look at the situation as objectively as possible, understanding their care needs and hearing the voices of those individuals who may not be able to speak for themselves. So Mum is intimidated and has perhaps taken a very submissive role her entire life. That's their pattern. I'm not going to change that. What I can do is make sure her voice is heard.

PSY: Right. Advocate and mediate.

AM: And then try and put that forward. If there are physical and medical needs, there is a medical team in place that helps to support that too.

PSY: Quite complicated.

AM: It can be very complicated — and constantly changing. We are not going to fix all the problems and certainly when they are longstanding relationship problems and conflicts between siblings, as simple as — well, nothing's simple, but there's baggage, and sometimes families don't even know why they aren't speaking any more. It's often the case that families don't speak. Children that are in dispute about what Mum wants or what they think Mum wants. Often money has something to do with it. If we spend money on Mum now, there'll be less for us later. Not everybody has good motives in what they do, so it's being able to understand that. Sometimes we're called in by the courts or by lawyers when they're in dispute, for a professional opinion, because the family can't agree where Mum should go or what Mum needs. I do not get caught up in their fight.

PSY: So it's tricky.

AM: (Laughs) For sure, it's tricky. I'm a social worker by training and several of our Elder Caring counsellors are also social workers, so being able to dialogue and peer-consult is very important. It's not always a clear line of where best to go. We have to be sensitive to the dynamics being put forward. These seniors may have been married for 60 years. We have to respect whatever their pattern is. One of the things I say to adult children regularly is: you may not like your parents' decisions as they probably didn't like all of your decisions when you were a young adult; however, if they are capable, those are their decisions to make.

Credit: Sarah Sheard

PSY: They trump the preferences of the next generation.

AM: Exactly. That's so important. I have to come back to that point. We always assume capacity, as you know. Meaning do they understand the consequences of the action they are about to take? I am not a capacity evaluator. There are other people who …

PSY: …who fly in to do that?

AM: If requested. It's a very complicated area of law. I am presuming capacity unless I'm told otherwise or it's very clear to me that the person is in a delirium or isn't able in this moment in time to understand …

PSY: Because it can fluctuate?

AM: It can. Medication can impact things. There's a whole variety of things ... We're always trying to include the older person in every discussion. Even if they're not capable they still have choices in a number of areas.

PSY: In your seminar last week, you mentioned the alarming statistic that the risk of Alzheimer's doubles every five years after the age of 65.

AM: Yes, exactly.

PSY: Very frightening.

AM: Especially for those of us approaching that magic number and especially if we have a history of Alzheimer's in the family… The majority of senior individuals is still in the community.

PSY: And they prefer to be there.

AM: Absolutely. Most of us want to stay in our own home if at all possible. One thing I often say to families is: try not to make promises because you don't know what's around the corner. I see families turning themselves inside out with the guilt of not being able to do enough or having said, 'Mum, you can always live with me' but now Mum's got a feeding tube and absolutely can't be looked after at home. Incontinence is a minor piece in terms of high needs and fragility and simply not being stable.

PSY: It seems like our society has not really had a close-up look at this the way other cultures have, where it's more accepted that older generations will live with younger generations. All the rituals of death that were probably quite acceptable and normal about a hundred years ago, we're shielded from now.

AM: Especially here in Canada where I think, too, there's a disconnect of families having moved around. Grandparents not necessarily knowing their grandchildren well perhaps, or not living in the same city as their adult children. I agree with you. I'm sure, as baby boomers, we feel powerful. We better be, because we're going to have to change society, to change what our future looks like for ourselves. I mean, it's for our clients but it's for ourselves too. I'm no different from my clients. Same risk factors. I'm sure we're going to see inter-generational families coming together under one roof. I'm starting to hear more about this. Senior-friendly communities, friends coming together … dementia villages, supported by communities. Just because somebody's diagnosed with dementia doesn't mean life's over for them.

PSY: So, seeing some positive models of aging, seems like that's a missing piece.

A.M. It is. And I don't have an ideal model. I have ideas in terms of what I'd like to see. An idea as simple as, who will become our personal support workers?

PSY: It's such an undervalued position, low-paid, low security.

AM: And many Canadian-born individuals have no interest in this work. My hope is that if it can be introduced into the high schools as a possibility for vocation, young people can then

have their field practicum and try it out at a seniors' residence or some other senior organization and be encouraged to enter a community college program. It would address much of our youth unemployment. Culturally, we're such a diverse country. Not being able to find caregivers who speak the same language as the person they're caring for — and understand the cultural issues — this is very, very important.

PSY: Also I'm thinking part of what you are bringing to families is actually D for Death. You are representing the beginning of that conversation, the end of which will be … the end of that person's life.

AM: Could be 20 or 30 years.

PSY: Well, true enough. We're living to our 90s.

AM: You say the D word and in the conversations I have, it's asking those questions about wills, powers of attorney — about Advance Directives, which I think we're behind the times with, in Ontario.

PSY: It's a very icky conversation. There's a lot of phobia around death. It's very sanitized. We just don't see that part of life and we are going to have to, I guess.

AM: We're burying our heads in the sand which is maybe what we like to do. Part of the message, as I said earlier, is to start the conversation gently. Not like, 'Okay, Mum, today I'm having the conversation about your wishes'. It's a gentle conversation, taking the opportunity where it presents itself.

PSY: So are you coaching the caregiver to have that conversation with his or her elder or are you actually conducting that conversation?

AM: In terms of Advance Directives, I'm suggesting and raising it as an issue that needs to be addressed. I am not the person having the conversation about End of Life Steps. That conversation really has to be guided by a doctor who can sit down and explain what's meant by 'Do not Resuscitate' or giving CPR, what a feeding tube is and what it means, whatever's being done, surgically, and if I withhold food what happens to that person and so on. A lot of education has to come from the medical side. There's a religious piece too. Advance Directives are a personal issue — yet, at some point they have to become a little more public, at least to your family, so they know what your wishes are.

PSY: What your preferences are.

AM: And I suggest it get written down. I highlight the need to do it and encourage that it be done. At the end of the day, all we can do is make recommendations. The report or wellness plan is a list of recommendations. What every family decides to do is up to them.

PSY: You provide this set of recommendations.

AM: Yes. Other times, we are rolling up our sleeves and attending the discharge meetings. Today I was touring a retirement residence with a family. We toured our third place where they had lunch, so we can now sit down with pictures and have a look at the three places and I talk about Care being #1. Whatever place will best meet your care needs today, understanding that you have a progressive disease and your care needs are going to increase.

The second C for me is cost, because care is very expensive. Then the third C becomes choice. Where would you like to live, within what geographic location, parameters close to

where you work, close to doctors, to hospitals? So it has to be well thought out.

PSY: How did people ever manage this in the past? I guess they just muddled through somehow …

AM: As we do with most things, right? People can muddle through. People will say to me, 'Why do I need you? I can pick up the care guide or any of these other magazines that list all the retirement residences and go on tours.' Sure you can, but really it's about understanding those three Cs. And you may be able to proceed on your own but you don't want to make a mistake, right? No one wants to have to move twice. And we get those calls from family: 'I just moved my mum into this lovely retirement residence but now they're telling me her care needs are too high and she has to move'. There's only one dining room and seniors don't want to be having a meal with a senior who's wearing a bib or has to be fed. So it's about ensuring dignity and respect.

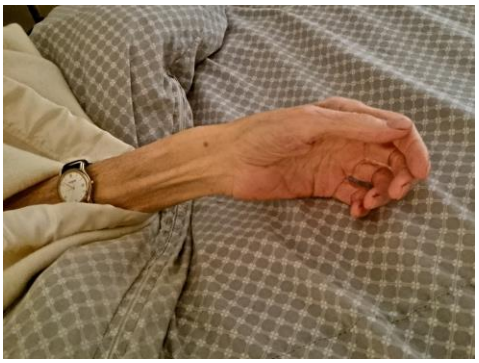
PSY: Very stressful for that senior to have to be moved.

AM: A hundred per cent! So you want to approach this as thoughtfully and as purposefully as possible with the research behind you. Ask the hard questions. Talk to families. What's right for one isn't necessarily right for the next.

PSY: Well, it is interesting how we boomers are going to do it differently. We're going to be smarter —is our theory. We're going to be so together and so organized that there will be as few bumps as we can possibly manage for ourselves.

AM: Let's hope. Let's hope. Because I'm with you. (Laughs)

PSY: Something that doesn't have that flavour of a seniors' residence. A boomer-style place with our friends.



Credit: Sarah Sheard

AM: Exactly! Exactly! Because what do we want at the end of the day? We still want to be able to enjoy our coffee. Or a glass of wine.

PSY: And one another.

A.M: And one another. Exactly.

PSY: Thank you, Audrey.

Audrey has been delivering highly personalized health and wellness solutions to families with geriatric care and rehabilitation issues for over 25 years. As founder and managing director of Elder Caring Inc. (www.eldercaring.ca), Audrey leads a team of highly specialized professional counselors and allied health professionals in helping clients across the country navigate the healthcare and homecare systems, leverage community resources, and plan for present and future stages of care with confidence.

As a Registered Social Worker and a Canadian Certified Life Care Planner, Audrey counsels individuals and families as well as business, including financial institutions and law firms on aging issues and is qualified as an expert witness by the Ontario Superior Court.