Local physician Denise Marshall is in Montreal this week to present to a summit of her peers and medical professionals from across Canada on the local palliative care program. The Niagara West Share Care Model has been chosen by national organization Canadian Partnership Against Cancer (CPAC) as a Canadian “choice model” for end-of-life health care.

Dr. Denise Marshall is entrenched at McMaster University, having schooled, trained and now serving on staff teaching at the Faculty of Health Sciences. Originally trained as a family physician, Dr. Marshall specialized in palliative care and has worked at the Henderson General Hospital (now Hamilton Health Sciences), St. Joseph’s General Hospital and, since 1996, at the West Lincoln Memorial Hospital (WLMH) in Grimsby. She has served as the Director for the McMaster University’s Division of Palliative Care, is a Full-Time Professor, and today she serves as Assistant Dean for Faculty Development. As you will read, Denise Marshall passionately believes the foundation of our health care system lies with primary care – and she considers herself a “family practice trained, palliative care physician.”

Dr. Marshall was interviewed in her office at WLMH, early in January 2010.

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**Question** - The Niagara West Shared Care Model has been selected by the national group The Canadian Partnership Against Cancer for special recognition. Can you tell us about this?

**Dr. Denise Marshall** - My understanding is that the Canadian Partnership Against Cancer (CPAC), which is a national health organization, is interested in understanding whether there are models of excellence across our country that should be held up and shared and, hopefully, replicated. CPAC has gone through a thorough process of identifying priority needs in our country. They then hired a firm to do fact-finding and investigative work on potential innovative models of care across the country.

We came to their attention through a publication about the Share Care Model. We had published the essence of the model in Canadian Family Physicians in late 2008. We were subsequently hooked up with this multi-staged process of detailing the model, interviewing me, gathering information, fact-finding, and then there was a discernment process by the organization. They had a precept template of different aspects of cancer care; so they were looking at models, everything from pre-detection to end-of-life care. After that discernment and vetting, they notified us to let us know that the Niagara West Shared Care Model had emerged as an innovative model of choice for end-of-life care.

The CPAC organization’s intent (in providing this national recognition) is to ensure that the medical community is communicating and connecting Provinces, other organizations, policy planners and systems people, so that we’re not all recreating the wheel and can learn from one another. The event in Montreal is to showcase innovation and our model has been chosen as one of them. The hope is that there will be some traction nationally from the discussion.

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Q - The selection process for the CPAC recognition was peer-reviewed. Can you tell us about the peer review involved with the article that was published in the Canadian Family Physicians?

DM - Ideally, you always look for externally-funded, peered-review outcomes and there was no better place for something like our model than to be reviewed in the Canadian Family Physicians, the official journal for the College of Family Physicians of Canada. The model is based on, first and foremost, supporting primary care. It revolves around how you can support family doctors who are doing full-spectrum practice, including end-of-life care. So, we felt the Journal’s coast-to-coast audience of Canadian family doctors was ideal. We are very proud to have a peer-review in the Canadian Family Physicians.

This article focused on the model’s program description. It was a brief write up that described what the model is about, with an emphasis on “What does this have to say for family doctors?”

We had reams of data, looking at many aspects of it; such as patient and provider satisfaction, what do patients and families think about the model of care, symptoms severity, bereavement data… There are virtually no bereavement councilors on end-of-life care teams anywhere. The literature suggested bereavement counseling is important so it was great to have data so that we can analyze it and write it up. So, we have a databank that we could probably mine endlessly. However many articles we can publish is really now left up to how much time we can devote to it.

Q - Now you have the task of going to Montreal and attempting to synthesize all of this data and to tell the story of the model. You will be making a presentation to your peers and what more will occur at the CPAC conference?

DM - I was invited to make a presentation to approximately 4,500 delegates. This is not the first time we have had a chance to make a presentation about the Niagara West Share Care Model to a large audience. But this is probably the best-positioned audience to affect system-change. The delegates come from across the Nation. There will be policy planners, people who are in leadership roles of power and influence, those who can affect change.

Being recognized as one of the national choice models of care speaks volume with this audience. I particularly like the way the CPAC selection process was done. It was unsolicited. Nothing about this recognition was generated from us. We were sought and analyzed, dissected, and what emerged from the CPAC process that there is some merit to what our shared care model accomplishes. Other presentations we have made were driven by us; we submitted abstracts, posters, and offers to do workshops and presentations. In this case, a national organization has come to us and that is what is distinctly different about this presentation opportunity.

Q - It’s tremendous. So, can you explain in a few sentences what the shared care concept is?

DM - It really is quite simple. In fact, it is so simple it is intuitive to clinicians who have always known, whether implicitly or explicitly, that the best way to provide care is through relationships with one another. In essence, it is identifying people in palliative care, who have enhanced expertise, who are positioned to work along side primary care providers whose role with patients and families is to be the first point of contact. The model positions experts along side primary care
providers in a way that enables them to have interactions and relationships to attend to what the patient needs. The outcome of this web of interaction, what the patient sees is that their care was provided seamlessly.

The role of the expert clinicians in this model, the idea of sharing care, means that there is a negotiation taking place all the time. The negotiation is highly individualized: this patient, this family, this doctor, and these needs. It’s a highly customized interaction and the sharing care part behooves the experts to be responsive. How the experts respond to that unique patient-family doctor problem is highly customized to what they need and want. There’s no cookie-cutter algorithm that goes with this; you don’t pre-suppose much of anything. The experts are there to understand in each unique case what is needed and then to respond.

Q - So, the experts on the shared care team who would be interacting with the patient may vary in number and in personnel depending on the needs of the patient?

DM - Each team has a set number of people. However, who is involved for what, at any given time point in time is different every time. There is enough international literature that identifies the core expert palliative care providers who might be needed on a shared care model like this. Generally, you will have a physician, a nurse, some kind of counselor role, and then it is nice to have other experts as well. How involved any one of us is depends on the case. In responding to the patient’s different needs, you have a constantly emerging relationship that has to be determined as you go.

Q - The model pivots on the palliative care nurse and, so, can this role be best described as a “traffic cop” or a “quarterback?”

DM - The popular term that is used in healthcare these days is a “navigator.” So, the term “nurse navigator” has emerged. The idea is that there’s one person with the finger on the pulse of what is happening at a high level and at a grassroots level for the primary care providers’ case load – for the people with whom you have been entrusted with care. Part of having the Ontario Ministry of Health grant between 2004 and 2006 was to develop this role, to pilot how this team works with a dedicated nurse navigator. The literature suggests that this model would not only be cost-efficient but way more effective than to strictly depend on the physician. The physician is a more expensive resource and doesn’t necessarily have the right skills set to coordinate all the experts. So, the nurse navigator is the lead as a connecter who knows who to call, for what, when. It’s a lot of lateral thinking.

Q - So the patient and the family are getting their information through their family doctor, and the idea is that the family doctor is getting information form the sharing of the team?

DM - For the patient, the family doctor is the first point of contact. So are the bedside nurses, either here with a patient in the hospital or the community nurse with the patient at home. The communications between those of us involved with the patient’s care, from the expert team to the patient is customized person by person. Information might flow through the family doctor; it might be the community nurse. So, there is a high-level sort that needs to happen – and it might be more than the family doctor.
Q - This model began in 1996 at the West Lincoln Memorial Hospital. Can you tell us something about those early days?

DM - To say this was an organic evolution is an understatement. None of this was laid out or planned. It just emerged. It’s the complexity theory at its best, really.

I was a physician living here in Grimsby but working elsewhere. Somewhere along the way I got hospital privileges here at WLMH to do the occasional consult. So, some of the family doctors here knew of me. What happened in 1996 is that I had my third child and left my medical director position at St. Joe’s. Some of the physicians at the WLMH contacted me to consider doing more consults. So, I started to do more consults and very quickly a team concept started to emerge around me. The nature of palliative care is team based: really, I am only the physician. As a physician, when you are meeting with patients, you are uncovering a host of needs – physical, emotional, spiritual – and you are expected to assess those needs. Well, I may not necessarily be the best person to address the needs. Once I was doing more consults, it became apparent that I needed more resources around me.

So, with this occurring, I realized that I didn’t want to do consults alone and without a team, and address just the one dimension of the person before me. I looked to see if we could gather a team together at the WLMH and in the community. In Grimsby there existed a pretty good homecare program, a local volunteer program, and several nurses in this hospital with experience in palliative care roles. Conversations started to happen where we asked, “Could those involved with palliative care in our community start to intentionally plan around patient care to help the family doctors out?” That was the start of what eventually became team meetings.

The nurse that stepped forward basically did it as a volunteer. She said that she’d act as the nursing liaison for about a year – four hours a week. I volunteered similar hours. No one was paid to do this. We just started to organize around the idea of how to support the family doctors and the patients. We cobbled together an organizational structure. As we did this, our sense was that this organization was a helpful thing in providing a service. The doctors were happy. More referrals started coming in and, so, it grew. We gathered statistics for about a year and then I asked for funding for a nursing role.

I gave a presentation to the WLMH Board and it was quite compelling given what we were providing and the little cost it would take to keep the organization going. The Board initiated funding and the program started off quite small. It has grown in baby steps – a few nursing hours, a couple of admin hours. We set up a trust fund through the hospital because we found that patients were grateful for care and wanted to give money to the hospital. That allowed us to return some of that funding into education, to grow skills and to offset some of the costs for patients who couldn’t afford medication. So, things like this just started to happen.

Once we got a little bit of funding we were able to establish a part-time team and a little office here at WLMH. During those years it was completely funded by West Lincoln Memorial Hospital. At the time, if I were to paraphrase the Board, they said, “This is exactly what a community hospital does – to care for its community. It is more than what happens in our building.” The Board was well aware at the beginning that they were investing not just in clinicians who would be walking around in the hospital walls. They were investing in clinicians who would be going to wherever the patient needed them to be – knowing full well that this is what constitutes good patient care.
In the end it does help do something for the hospital budget; like it helps keep people out of the emergency room, helps get patients out of acute care beds when that is not what they need. So there are real outcomes that hospitals need to look at. But with the WLMH Board, very definitely, it was more than that; a group of community-minded people deciding this is what community hospitals do.

It was the Hospital Board and local folks involved in palliative care who stepped forward. These were all community-folk who, for the large part, were volunteering their time. It was an intersection of people who decided, “We are going to make this happen.” There were a great group of people thinking about this…

**Q - And how has this program evolved from those earlier years?**

**DM -** Within a couple of years we very quickly became overwhelmed. You couldn’t manage the program on four hours of nursing time. I then had to ask for 8, 12, 20 hours and each time I had to go back to the Hospital for more funding. Between 1997 and 2004, we grew the nursing hours and secretarial hours and we had money from our trust fund to help offset our counseling. This was all within the West Lincoln Memorial Hospital.

Nothing changed until 2004 when, through a research group I set up at McMaster, we got funding from the Ministry of Health to fund our team more fully. At the time, we were funded as “a demonstration project.” We got money to move from our cobbled together, part-time team from WLMH. For the next two years we got money to increase our nursing hours to full-time, hire a research assistant, a psycho-spiritual counselor, and a bereavement person – and then we had extra money for things like shift nursing hours for patients receiving care at home or money for medication for people who couldn’t afford it.

We ran the program for two years and then we reported back to the Ontario Ministry of Health. From the start, our hypothesis was that if we got more nursing hours, with a full time nurse, we would have an efficiently run team. We think that the nurse navigator is what a community needs. The Ministry invested in us and, at the end of that period, it was apparent that this was a successful shared care model. And, near the end of 2006, we then began talking to the local Community Care Access Centre (CCAC) to pay for a full time nurse navigator, a counselor, a bereavement person. That is when the partnership emerged to keep the essence of the program going for west Niagara. And, again, it was the community-minded people at the CCAC, who saw this program and realized that our community needed it. The CCAC supported us and made it work, even though there was no specific funding for the activity. And, now, we are attempting to move this model system-wide, across our local LHIN… in several LHINs in Ontario, they are funding palliative care teams based on ours, directly or with Aging at Home funds, or channeling funding through their CCAC.

The shared care model, as it is applied with the West Niagara Palliative Care Team, is a good model when looking at the ideas of integration. It’s the notion of integrating “just enough” specialty support to not only sustain primary care but helps it get better and better and become more and more capable. The winners in the end are the patients and the front-line people. This is not complicated and it’s not expensive. It’s really talking about relationships. To me, it is the quintessential exemplar of integration.
Q - You have made many presentations on the West Niagara Shared Care Model. What kind of reactions are you getting from your peers, the physicians, and from nurses?

DM - It depends on the culture and roles that those folks are in. I think those who are working in a health care environment where it’s become siloed, where you don’t feel you are working in a collaborative system, can’t imagine how this model might work. The model hinges on, “We’re all in this together.” So, I get reactions from some people, “Well, that would never work here. I don’t know what is happening over there – I just am doing my thing here.” I get that from folks who are working in an environment that won’t allow them to see that this is possible.

I get a range of reactions. There are people in between, who say, “Could that work? There’s something to that.” And then there are people who say, “Yes! We can do that!” I think it really depends on what their experience is of anything that is similar.

Q - Is it possible that there may be an urban-rural split in understanding and accepting this model? For instance, in a facility like WLMH where many of the professionals work closely and daily with one another- when you compare that to larger institutions – does this factor into how people react to the possibility of the shared care model?

DM - That is one of the factors we are looking at. At a provincial level, that is one issue that we chew on a lot. We hypothesize that there could be a cultural split between whether there’s been a culture that allows physicians and nurses and professionals to work collaboratively. For example in Toronto, some major palliative care programs there made a conscious decision in the 1990s that they were going to go with more of a “take over care” model. That’s almost the opposite of a shared care model. In that model, palliative care specialists move in a take over and the family doctor is not involved in the care of the patient. That was an intentional decision to handle the numbers in the GTA. Now, a decade later, they’re re-visiting that decision, and we are all in dialogue together. They are finding that a “take over care” model is hard to sustain because of the large and increasing numbers of patients and heavy expectations thus placed on the Palliative Care Physician. So, now they’re looking at other models with the questions of how to re-engage family doctors. Provincially, there are a lot of issues that we hypothesize about the split that we haven’t studied yet.

It just makes intuitive sense that in communities where you have always stayed in some more intimate collaboration with other care providers that it is more likely that shared care will work. Again, that relationship foundation is there.

“Can this model of care work in larger communities?” That’s a good question. For example, what about all the other communities, somewhere in between small town, and Toronto in size and scope, – like, for example, Hamilton? Historically, Hamilton has had a very strong family practice culture, but the tertiary care environment is necessarily growing and it’s important, and as that happens the role of family doctor has changed. Yet, there’s enough will, interest and capacity that we’re investing in developing shared care palliative care teams in Hamilton. They won’t be identical to the model in west Niagara, but the overall concept is the same: “How do we keep the family doctor involved in the care of the patients so that they’re happy and the patients are happy – and that there are specialists who provide the second level of support?” So, there is a team established in Hamilton now and second and third teams starting up over the next few years. St. Catharines is
another interesting area where family doctors, in large part, have very limited scopes of practice now, mostly office based, with little involvement with the hospital, or house calls etc. So, the challenge is to how to get family doctors re-engaged in end-of-life care. We’ve started a shared care team there in September so we are piloting, and will patiently hope that one family doctor at a time, this team ends up being a great support to them and their patients.

So, the success of the shared care model is something that doesn’t happen overnight. It might take a decade – and it will happen with relationship building, doctor by doctor, maybe neighbourhood by neighbourhood. I am talking about something that has to percolate and be organically driven. It’s a change of culture over a decade - a cultural shift. That’s what we need to have confidence in. So, the interesting question is, “Are we prepared as a society to understand and support that integration and culture shift is a slow and organic process?”

Q - So, coming back to what is happening in Montreal later this month. This is why the recognition and presentation of the Niagara West Shared Care Model is so important. You are able to share your experiences with colleagues and policy makers from across Canada. With the boomer generation aging, and all the fiscal challenges our health care sector faces, how do you see the share care model of palliative care evolving in the next decade and 20 years?

DM - Well, the first thing to say is that the shared care model we’re proposing is not expensive. With the right support, at the right level, there is no reason why you couldn’t have this model across the Province and across the country in the next ten years. It would be part of a provincial model that would need to dovetail with other aspects of the full palliative care system, like tertiary care. But this could form the integral part of how palliative care happens at the community level. It wouldn’t require a lot of new money – just organization. So, I can see that we could have a more comprehensive network of palliative care support across the system if we decide to make it so. The palliative shared care consult team component would be an integral part in a larger system design…

I believe this shared care model is possible in almost every circumstance – even if family doctors, clinicians and nurses have not experienced this kind of collaboration in the past or for a long time!. People need to move outside the lens of their experience to date and see this model for what it can accomplish. The medical community needs to tap into their hope for what our Canadian system can be. Tommy Douglas’ dream was to have a seamless, integrated, community-based, equitable access health care system. So, today’s reality is something short of this vision. But, if we can tap into peoples’ understanding of what Medicare was founded on and the aspirations of what our health care system can be, then we might just create an approach to care where we can actually get equitable, quality care that meets our individual needs.

The share care model isn’t fancy and it isn’t expensive. It is possible. In this Province, I think we are on the cusp of understanding that we need to move forward with this. I am cautiously optimistic that we have a critical mass of people in policy and government, and within the health care sector that could make this happen.