

## Caregiving and Palliacco

This month I had the pleasure of speaking with Grant MacKenzie, a board member with Palliacco. Palliacco provides services free of charge to caregivers, people with terminal illnesses and those who have lost loved ones (<http://www.palliacco.org/en/>). Grant spoke about the fantastic programming that Palliacco offers for caregivers in Laurentian region; including respite, accompaniment and support groups.

Here is the full version of our conversation:

Q. What is your position at Palliacco?

A. I'm a board member and I sit on their strategic planning committee and their communication committee.

Q. And how long have you been on their board for?

A. 4 years.

Q. Okay, oh wow, so quite a long time. What led you to become involved with Palliacco?

A. We have an extremely dynamic services coordinator, Louise Lefebvre, and in 2013, she visited me, and because I am a town councilor in Ste Agathe, just asked if I would be interested in sitting on the board, and because she's so dynamic and such a great person, it was a no-brainer. The other thing is that Palliacco originally started in Mont Tremblant but because of the hospital in Ste Agathe, there was a lot of volunteer work done in the Oncology department, and we realized when we looked at the statistics that although it varies from season to season, it was pretty close to 50-50 Mont Tremblant and Ste Agathe. Because there was so much service being given in Ste Agathe, Palliacco sought more representation on the board from Ste Agathe. For a while, I was the only one on the board from the "south". But, following our AGM, we now have 4 members from the southern area.

Q. So is Palliacco really connected with the hospital then or is it more informal?

A. No, it's totally separate. Our Director General, Jean Desnoyers, who I had referred you to, did work for the CSSS which is now the CISSS, and he was in charge of the caregiving wing of the CSSS at the time and extremely competent. He worked closely with Palliacco at the time and has since retired, but 6 months after retirement we were able to hire him on. He has so much experience in the hospital system that he's able to contribute and work within the government system, so if there are any collaborative opportunities out there, he's the guy to navigate the system. Having said that, way back, I don't know if you know Palliacco's history, originally it started off supposedly as a Palliative Care facility and the caregiving wing which is sort of outside the palliative care facility never saw the light of day. So it was 2007 when Palliacco went off on their own

and carried on doing their thing which essentially is the volunteering and caregiving and just seeing people in the oncology department at the hospital.

Q. What do you think are obstacles that prevent caregivers from accessing services?

A. I think that a lot of the caregivers are relatives of the person who has the cancer or some life-threatening disease and they are the people that really need the break. The caregivers that work extremely hard and because its family or very close they are hesitant to accept any help, which is really a shame because in a lot of instances people are getting so close to the end of their life when they do call Palliacco that we don't have the opportunity to contribute as much as we might if they had called us a month earlier. And for that reason, it's our big challenge to try and get the word out to let people know that the services are good services, and just to give respite care to the caregivers.

Q. That's what we are hoping with the article too is that people who may not have heard about Palliacco may through reading the newspaper.

A. I don't know whether it's because we are dealing with end of life that maybe they are a bit hesitant to call us but the sooner they call us the better, that's what we are there for. You know they are going to spend a couple of months possibly, depending on the nature of the illness, and its extremely tiring for the caregivers.

Q. Yes, it's exhausting.

A. Exhausting; that's the word exactly. If we could get out there quicker and really contribute much more to these families that are struggling with this.

Q. How would somebody go about beginning to access services through Palliacco?

A. Just call Palliacco. The number is on the website and Louise Lefebvre is the services coordinator, either her or Jean Desnoyers, or anybody there would be more than happy to talk to them. They have all sorts of services that they give, just to give people a bit of a break. The isolation of having to oversee their ill loved one is tough.

Q. Absolutely, because it does create burnout over time.

A. And the Anglophone population tends not to ask for help, but hopefully this article will give us more visibility and a chance to help out.

Q. We find this to. I don't know if they don't know as much what's available in the community or like you said maybe more shy to call and ask.

A. We had 2 conferences last year in English and we did them in 3 communities; Mont Tremblant, Ste Agathe and Arundel, and we did this 2 years running and it was basically to inform the population of the community services, I think we had invited 4 Korner this year to the one in Ste Agathe. We endeavour to get our message out through these free

conferences with a little snack and drink but we only get about maybe 20 people which is really too bad, because it's an excellent opportunity to become aware. ~~I guess people.~~ Because there's a very short period of time where they are really going to have a need, it's nice if everybody could appreciate that the service is there so they can tell somebody.

Q. And sometimes not wait until it's almost a crisis where they really need the service, kind of put it in place before it gets there.

A. Exactly, the sooner the better.

Q. Can a caregiver call for services even if the person they are caring for isn't involved with Palliacco?

A. Absolutely, we are there for anybody and everybody. There are people that aren't necessarily in a life-threatening situation. There are people that may be struggling with a death of their wife or husband. They are mourning and they just need somebody to talk to and we do that too. We have done a series of video capsules, interviews with people who have had services and people that have given services. (to watch the video testimonials, visit <https://vimeo.com/user7734747/videos> and select the Palliacco video links).

Q. Can anybody access groups, is there an age restriction?

A. No, anybody can, we are there for everybody in the area.

Q. So if you get calls from people outside of the region, are people outside of the region able to access services?

A. Well I would say yes. We are starting to expand into the Pays d'En Haut, which is Ste Adele, further south, but if they are willing to travel, I am sure they could come up and again Louise or Jean would be more than happy to work something out with them.

Q. So what would you say are some of the obstacles that prevent caregivers from accessing services? I mean I know we mentioned not feeling necessarily, not deserve, but you know if it's a family member maybe they just feel it's something they should be doing, but what would you say are some of the barriers?

A. Possible either that they are unaware, but we have an ad in every Main Street, so I think it's just when people have the need that they don't have time to be researching these things. Things are getting near the end and it's a little bit of a crisis, it's just that they haven't sort of locked into this information before hand, which is too bad. I think we are all like that, if we don't have the need then we don't relate to it. I think the other main thing, may be that they are too proud to ask for help. That's tough, you know, we respect that. But they are suffering unnecessarily and anybody we have had, you will see with the capsules, everybody is really, really pleased with the services. Basically, Palliacco listens. Because there is nothing we can say or do that is going to change or solve his or her problems and so it's important that we just be there, welcome their interventions, their comments and their concerns and possibly we can refer them to somebody depending on the needs they have.

Q. And when the caregivers do access services what do you think is the biggest benefit for them?

A. Well it just gives them a chance to recharge their batteries. If they can get away from the 24/7 situation that they are living, have a break and maybe talk to other people that are going through the same thing, and it just gives them a bit of a lift and reenergizes them. It's a very, very demanding situation and it's really just a recharging of their batteries.

Q. If someone wanted to volunteer with Palliaccio, what opportunities would there be for them to get involved with and what process would they have to go through?

A. By calling the office in Tremblant. Honestly, because the Anglophone population are hesitant to ask for help, we have a number of volunteers that we do not have work for yet because the need has not been expressed, but that doesn't mean that it won't be some day and there are any number of things, even if [people] want to get involved in our fundraising. A lot of the volunteers are tied up in the fundraising, especially the *Trek Under the Stars*. It is extremely successful and it's been going on for 5-6 years now.

Q. That sounds so interesting. Because it's really become a part of the community, is the sense that I get.

A. Yes, you can appreciate that we are all looking for the same money. And now there is an attempt at setting up a palliative care unit in Mont Tremblant. You can check that out on the website. It's about a million dollars a year to keep an 8 or 9 bed facility going. And so, they have one major challenge, but so does Palliaccio as we are soliciting the same people. More competition on for the dollars available. So that's our biggest challenge as an organization.

Q. Palliaccio has really grown and built itself since 2012.

A. Yes, they've been very fortunate and this year we expanded [the *Trek Under the Stars*] down to Ste Agathe. Although not as strong yet as in Tremblant, it was a start and I think that it went very well. We were very happy with the total of \$145,000 that we pulled in. It's a fun event and everybody seems to enjoy and we have a couple organizations contributing, like Casse-Desjardins, it all helps.

Q. And it's nice too, because people that want to get involved and help out, maybe don't have the time for an ongoing commitment can get involved for this event.

A. What a person can do, if each person had their own little, network, when the *Trek Under the Stars* comes I write them all and ask if they want to contribute and if everybody did this then there would be a lot of funds coming in.

Q. Right, you might even get some people donating smaller amounts even \$5, but \$5 from everybody, it adds up and then if you have bigger donors as well.

A. It's a challenge and it's ongoing. I guess this is the same problem with all non-profit organizations, is that the staff, instead of doing their jobs, are out pounding the pavement trying to get funding and that is too bad.

Q. Yes, because if there was that basis to pour into the community organizations, it would free up so much fundraising time for agencies and even if they continued with the fundraising to additionally support, I imagine if any organization had that type of support it would help so much.

A. Right.

Q. I know we kind of talked about what made it possible but is there anything specifically that made it possible for Palliacco to rebound and grow to become what it is now?

A. Tim Pepper was in the financial business and had some experience in fundraising, and with the help of Jeannot Larocque who organized the first, *Trek Under the Stars*, things started to take off. Before that, they were really close to the line and their staff took 50% salary cuts just to keep the organization afloat.

Q. So you really had to have people that were dedicated.

A. And we do. We are extremely lucky. The people working with Palliacco are incredible and totally devoted. Even though they are hired staff they are working for next to nothing and are doing a fantastic job.

Q. Well I mean taking a 50% pay cut; you propose that to a lot of people and they wouldn't necessarily go for that so you have to be passionate about what you are doing to stick through that.

To find out more about Palliacco and how to get involved, they can be reached at [819-717-9646](tel:819-717-9646) or <http://www.palliacco.org/en/>.