

**Online International Breast Cancer Rehabilitation Summit 2016 for health professionals
Presenter: Alene Nitzky (A) with Denise Stewart (D)**

D: Alene is a registered nurse and trained in Oncology. And is the founder of Cancer Harbors. "Getting well after cancer takes a lot of work- more than what anyone told me" is on your website. I like this - this is very true.

A: Hi I am a registered nurse, a health coach and cancer exercise trainer. I did not actually start my career in health coaching - I was in natural resources and studied the health benefits of leisure. I ended up teaching in University in exercise science and leisure and recreation. Then I started a personal training business and working with older people who had chronic health conditions. They told me that they were frustrated with finding solutions to their quality of life issues until they started to use exercise and be more active. As I was working with these people I thought that if I had a medical background then I would be able to do a lot better job. So I ended up going to nursing school. After nursing school I ended up in oncology and infusion for many years and while I was doing that I was hearing a similar thing from the oncology patients - that after treatment they were really having a hard time at getting their quality of life back. So at that time I realised it was time to put it all together - my background with leisure, nursing, oncology and be able to service quality of life issues with cancer patients. There really were not many people doing that. I have also been a runner , an ultramarathon/endurance runner for over 25 yrs and so gave me great perspective about how much work it requires to achieve a goal.

D: Did you go straight into your work as Cancer Harbors?

A: I started off doing private health coaching and there were people who had been through cancer treatment. I saw that there were common threads and so developed a program - and this is what Cancer Harbors grew out of.

D: What did you think must be included in the program?

A: Cancer Harbours is a comprehensive support system for both the person after cancer and their caregivers too. It has educational resources and it helps to build skills around self care and improved quality of life. It provides guidance and support face to face, feedback and resources for both reading and videos and face to face discussion and coaching. It addresses many health needs, it help improves health literacy and being a better consumer of health products, information and services. It helps people understand ways to reduce their risk and actually apply in their lives - this is the risk of cancer recurrence and also other health problems. We can build their skills in confidence and advocacy.

D: So you were running a face to face coaching program and now Cancer Harbors in an internet based service?

A: Yes it is - there is information online and I use a computer /video platform to interact with people.

D: Alene you really attend to the needs of the caregivers- this is an unusual thing to see online.

A: When it comes down to it caregivers are least as stressed as the patient. They may not undergoing the cancer treatment themselves but they have so many stressors - they need self

care , they need to refresh themselves. They don't get the respite or their health needs addressed when the pt goes to the Doctor. So helping the caregiver know more about cancer and cancer recovery, health literacy and advocacy - not only can they help the pt - they can help themselves as well. You have to treat them as a unit -not just a patient or caregiver - both separately- they are a unit and need to be treated together.

D: I am fascinated about the caregiver- what services do they say they want?

A: They want to understand about the information they are given or read. They see research findings in the media. But they are reported prematurely before the evidence is conclusive and then the next week they will hear something that contradicts that information from the week before. They do not know what to believe and how to interpret it. So I can help them look at these things with a more critical eye. Also to help them know what questions to ask. Such as when making a purchase of a product that makes claims to help people with cancer. You need to ask questions and think critically about these kind of matters.

D: When you are talking about this type of service- what sort of timeframe are you talking about after cancer that there is a need for this kind of service?

A: I find there is a need about several months after they complete their treatment. I think what happens is that they complete treatment and think that even though they do not feel OK - they will get better later on. Then a few months down the road - they may have a few symptoms resolved but they may be still fatigued and may have some other ongoing effects. And they don't know when they will feel better and so they get to this point and not know what is going on- is the cancer back- and they do not want to bother their doctors. So they are worried and they do not know who to reach out to.

So it can be anytime after treatment- but I find it is when they have been out of treatment for 6-12 months - sometimes 2 years, and they are still struggling and they do not know where to go.

D: In Australia we are just looking at survivorship care plans and in different countries they do different things -what is happening in your area about this? How long does a care plan last for?

A: That is a good question because what is happening here is we are trying to get consistency in what people receive. It is a follow up screening plan more than anything, it is not a comprehensive care plan- it does not have behavioural interventions. It will tell them to come back and see your doctor every 3,6,or 12 months and then it goes for 5 years. In this time they transition back to the primary health care doctor - and check with the oncologist at these intervals or when needed.

The problem is that we are giving people this survivorship care plan - which is just a screening plan, but they are not helping people with the behaviours and the risk reduction. The doctor may say - yes you have a risk of recurrence - here are some things that you need to watch out for and then eat healthy foods, you should exercise and wear sunscreen etc - but there is no

guidance to implement these practices into their life. If a person has never done that before or if they are suffering with fatigue or cognitive problems then it is hard for them. So that is what Cancer Harbors does - it fits in right there- it helps with the behavioural interventions and address the practical implications of recovery. So what can happen is that they leave their doctors with their survivorship care plan and then not DO anything to improve their health. And then when they check in with their doctor in 6 months - then nothing has changed - so they are not making any improvements or reducing their risk and not feeling better. So Cancer Harbors is a complement to a survivorship care plan - it is not a substitute for it or medical advice but it is important to be there in addition to the traditional survivorship care plan. That is how it is going in the US.

D: If the person gets a survivor plan - this should be looked at - not accepted as a detailed and supported recovery and health plan- we should ask questions about what is on the plan - so we can work from there.

A: Yes the oncologists and the medical team most likely does not have the resources or the skills to address behavioural issues or provide a lifestyle plan - and that is OK if they don't - but they do need to be referring outside to a complementary provider who can provide that kind of service for the patient.. This task gets skipped over- if it was done, the patients would be happier, the providers would have an easier time because the patients would be more compliant and then have better outcomes. It would be great to have that interaction between the physician, the patient and the complementary provider-- that communication would be great. We can all work together- however the physician needs to make the referral.

D: The physicians and oncologists are possibly overwhelmed and have not got the time or head space for this task. I am hoping that the patient navigators, breast care nurses may be the ones that can take on this task.

A: In the US we have these nurses and they are there when the pt is going through the treatment- but it is down the road when the person is outside of the hospital that there needs to be something- because it doesn't just end right - when they are healed up from surgery. The work comes afterwards with the fatigue and fibrotic changes.

D: Alene you have been doing this for some time now- how do you get the word out there to make people aware of this need for the "work".

A: It has been a challenge - I reach out to non profit organizations. I have tried to reach out to physicians- however that is a real challenge. In the US we really need some changes in the healthcare system because of the way the health care gets reimbursed - it does not extend to the complementary providers. This step of referring and medical fund reimbursement is not being addressed - there is no one taking responsibility for helping the patient get this type of service that they need to get well and be healthy.

D: One of the points here is that the patient listens to their Doctor and surgeon and they may be frightened - not all of them - to go outside of their care and advice . That is why it would only take a sentence - a short conversation by the breast surgeon or oncologist to open up this need to use this type of service for their ongoing care.

A; That is so true. It would make things so much easier for the physician too- as sometimes the patient is afraid to take up too much of the doctors time - they know that the doctor is busy and so they may not feel like they can ask questions. So if there is someone outside of the doctors surgery who can at least field some of those questions and then advise the patient eg “ this is something to worry about - go to your doctor” or “ this is something that can be cared for in the community” This is what is needed to help the patient sort these things. I think the doctors do need to take some time to know “us” so that they can trust us and know that we have the patient’s best interest at heart. We are not giving out shoddy advice.

D: The other point is that there are so many different health professionals that can be a part of the patient/ caregiver team: mastectomy fitter, massage therapist, Reiki, hypnotist etc - the patient is not in the hospital long enough to receive these many health professionals and at the right time.

A: Right- when we make the cancer after care all about the medical interventions- we are doing a disservice to the patient. We need to get (the patient) out into the community and getting the support they need there. We can not keep them as patients - they need to move back into a “normal” life. Regarding the team- it is the health care providers working with the person after cancer and their caregiver/ family - it is all about teamwork . It is a relationship in this team- not a one way transaction - where the doctor says to.. and the patient does it. It is not a consumer product - this is a relationship. So working together as a team is in the best interest of the patient.

One of the other challenges is with the patients in order for the patient to benefit people really do need to do the work! At Cancer Harbors they need to get engaged in the program and do the activities and put some time into the work. It doesn't require a lot of time and effort but it does require some. So you can not be a passive recipient of these resources. So if they take responsibility and do this work then they will get great benefits. But it is not entertainment -it is not something that you sit back and watch - not like a Youtube video and watch it and you are done. They have to get out and do the exercises and the activities. So that is another challenge- to get the patient to realise that yes they have been through cancer and that was horrible- but if they really want to get back to functioning as well as possible it is going to take more work!

D: Can you give us an idea of what your program would involve?

A: The program is divided into 6 different parts. So we start with post treatment recovery and fatigue and we talk about how to expect tough times and how to progress forward. We talk about physical activity nutrition and weight control.c We talk about self care and restorative activities - making sure the environment at work and home is conducive to healing. We look at

mental and emotional health, communication skills, health literacy and advocacy. Finding new activities that they may be interested in. Also personal growth, cognition and occupational needs. We talk about goal setting and reframing priorities looking at before and after treatment - priorities may not be the same.

So really just to help people move forward and set appropriate goals. People may still hope that they will go back to how they were before- but things are usually different. So it is important to set new goals and not be disappointed by not achieving old goals. So to feel good about what they are doing now.

D: Alene what is on the horizon for Cancer Harbors?

A: I am working with a non profit organization here that works with breast cancer survivors and they are providing this Cancer Harbors service to their clients for 6 months after treatment. I would like to put these materials into a book and so this is my next project.

Also I am looking for researchers who may be interested in studying this and running a trial on this program. As I really do think if you paired this with a survivorship care plan you would get better results than compared to just the survivorship care plan.

I would also like to develop this as a prehabilitation program -so to prepare people. So we know that $\frac{1}{3}$ - $\frac{1}{2}$ of people are going to get cancer at some point in their life and so the more prepared you can be and knowledgeable that you are before something happens the better the experience and outcome will be. I would like to get people before they get the diagnosis.

D; Thank you ALENE!