

CANADIAN PROSTATE CANCER SUPPORT GROUP

Newmarket, Ontario

Volume 12, Issue 10, June 15th, 2008

**A support group that provides understanding,
hope and information to prostate cancer patients and their families**

Our Support group members are very familiar with Dr. Jerome Green, our speaker for the June 19th meeting, Dr. Green is a Urologist practising out of Southlake Regional Health Centre and he is a regular contributor to our group. He keeps us up to date on what's new in prostate cancer treatment. For the June meeting before the summer break he will be speaking to us about "Testosterone and Hormone Therapy" a subject a lot of us are very concerned about. June is also the month when we select a new executive to run our meetings. We will need at least three new "members at large," [a title we assign to new members until we discover their hidden talents] Several of the current committee will not be available for next year, so come prepared to offer your services. The Job is easy the Pay is great and your fellow exec members are getting old and they need your help.

Meeting Date: June 19th, 2008

**Place: Newmarket Seniors Meeting Place
474 Davis Drive, Newmarket**

Time: 7:00 to 9:00 pm

Speaker: Dr. Jerome Green, Southlake Health Centre

Subject: Testosterone and Hormone Therapy

Canadian Prostate Cancer Support Group,
Newmarket, Ontario. 905-830-0447

a member of the



Canadian Prostate Cancer Network

Assisted by the Canadian Cancer Society
Holland River Unit
Cancer Information Service
1 - 888 - 939 - 3333

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The Newmarket Prostate Cancer Support Group does not recommend products, treatment modalities, medications, or physicians. All information is, however, freely shared.

May speaker notes **Dr. Andrew Matthew,**

Subject: Navigating the Emotional Side of Prostate Cancer



My title for the talk is Navigating the Emotional Side of Prostate Cancer. I find that people go through a whole emotional roller coaster throughout the trajectory of the disease and that can range from various types of anxiety right through to depression. I recognize that people are at very different stages at various times. Some of you may be newly diagnosed, right through to adapting to post treatment side effects and beyond that. There is a relatively large section in the talk that refers to the emotional impact of the side effects and specifically sexually function. The purpose of that is really suggesting that that is something that does play a big role post treatment in terms of adaptation and I think that this will be more or less meaningful to you but a reminder that it will be generally meaningful to people that are newly diagnosed and going through this.

I'll take a look at the experience from a psychological or a psychosocial support perspective right through the disease. Just to give you some idea of the depth of the emotional component in oncology, the Lance Armstrong Foundation did a large survey of 1,000 cancer patients in November, 2004. The results suggested 49% of these patients that had been diagnosed and treated for cancer stated their psychological needs were not met. That either the services were not offered or the physician did not have enough information to help them. As you know, this is often true, certainly down at Princess Margaret Hospital (PMH), where the surgeons that I work with can see upwards of 40 to 50 patients in a day on clinic days, so to ask them to play an integral role in these emotional side effects is probably too much. But to have them have access to people like myself and the unit upstairs and this is also true of other hospitals, we may be able solve this situation. The other thing, and this goes to the point, is that a lot of times the emotional repercussions of the sample we're talking about were still be experienced years after their original treatment. It was probably left untreated at the early stage and it just remained over a longer period of time. The most

prevalent psychosocial complaint at that time was depression. So, what is our role? You can see if you take look at the trajectory of the disease of cancer in general, at the time of diagnosis, we're responsible for acute care. I'm on call generally at the hospital, so when patients are diagnosed and they're having difficulty with it at the time in the clinic, the surgeons will come and get me. I offer very little help at that time, except for the fact that they have contact with me immediately following that day. As you all may have remembered, you can take very little information in on the day you hear the physician say "Cancer". So sometimes knowing that you have access to me or someone else in the hospital becomes more important.

Just a little bit of knowledge about the disease, especially in prostate cancer, can be very helpful just because we are very successful generally in treating prostate cancer. Just to know that is helpful. Then the treatment decision — my favourite is, "I didn't go to medical school for 11 years, why am I making the treatment decision?" and I couldn't agree more as this is quite the task, so we can help in that area. In terms of the actual treatment, the idea is promoting a healthier lifestyle, giving yourself a better opportunity to recover from the disease or from the treatment itself. The side effects the patients experience as a result of treatment, there isn't a cancer and there isn't a treatment that does not have side effects and so a job that we might play in psychosocial oncology is helping people adapt to those changes. And then, in the unfortunate case where the disease may go beyond a treatable stage, then we deal with the acceptance of mortality. But this does not necessarily mean that the patient has been diagnosed with a terminal disease because I think you all remember a time when you first walked into the office and the physician said, "You have cancer.", we almost always equate that with death immediately and then we start working back through it. So, it is the idea of facing one's mortality that can be very difficult. What we really want to do is investigate and maintain a high quality of life. In other words, we want to make sure we're doing our best at managing the psychological impact of the disease all the way through the trajectory but also being careful and not overtreating people and offering them the opportunity to choose their treatments, feel comfortable about their treatments and have confidence in their treatments, so that we have as little impact on their quality of life as possible.

Diagnosis

So looking at that trajectory to keep us organized, there is Diagnosis, followed by interviews and I've done a lot of interviews as part of my research. One patient said, "I was like a deer in the headlights, I didn't hear anything after the word cancer." and another said, "I just felt numb." This goes to the point that, regardless of age, we are generally fairly omnipotent. In other words we always think that we are going to cruise along fine and it is a shame that it happened to

someone else but it will happen to someone else. This can even go through the process, remember, in many ways when the diagnosis occurs, you've already been to your GP, your PSA level went up, you had a DRE, then you went for biopsy. So you've gone through all of this process yet it's still extremely difficult to really experience the diagnosis when you actually hear it from the physician. Then it really hits you.

This is also very important and a lot of what I'll be talking about tonight is that we will be including the partner in almost everything that we're talking about tonight. My interviewer at the time said, "Was there a follow-up visit scheduled right then and there after the diagnostic visit?" The partner said, "No nothing." The interviewer said "No, you just left?" and the partner said, "No, that was it. I came home and I cried for two days." So, we can see that it does definitely have a very significant impact on the partner. The core aspect of this is, not only has the patient been diagnosed, but so have those who care for him or her. The diagnosis usually creates shock, disbelief, denial, numbing, confusion, isolation, depression, anxiety, anger, hostility (both at God and doctors, even though sometimes doctors think they're God) and fear. I bring this list up because, in the area of psychiatry and psychology, we have a diagnostic manual just like a physician would for physical illness and these symptoms fit a category called post-traumatic distress disorder, (PTSD). PTSD is the development of these characteristic symptoms following an event which exposed a person to actual or threatened death, including being diagnosed with a life threatening illness. That makes a little sense, because, if you look at the diagnostic categories of PTSD, this is where some individuals life is under a lot of stress already They might be having marital problems or other traumas that are going on and then you add the diagnosis of cancer into that mix and it heightens their reaction. So this would be a more extreme form of a reaction to diagnosis but the criteria are intense response, fear, helplessness, anxiety when you recieved the diagnosis of prostate cancer, I'm sure most of you felt some of those. You may re-experience, such as dreams but also be reactive to triggers. I know very much, even now, wherever you were treated, if you drive by that hospital it brings back very vivid memories of your experience of treatment and diagnosis, like numbing, feeling detached or estranged from other people, that is the isolation of cancer that a lot of people experience that they don't know how to talk to other people about it.

Descriptive symptoms are difficulty falling asleep or staying asleep, irritability, outbursts of anger, difficulty concentrating; a big one in prostate cancer and other cancers is hypervigilance, that refers to the idea that now, whenever you get an ache in your back or a pain in your side, the thought is no longer an innocent thought of sleeping funny but that it might be the return of cancer. The less severe forms of this, we have acute anxiety disorder and adjustment disorder, so these are the anxiety based difficulties. Acute care, as I said, connection to the hospital; knowledge and initial understanding of the disease; challenging any distorted thinking; a simple one is, I've just been diagnosed with cancer, cancer means death, I'm going to die and I'm going to die soon; Stress man-

agement; meditation, relaxation training; another big one is the gathering of resources, an example could be social support. In many ways a lot of people have a tendency to withdraw rather than utilize the resources that are around them. They don't ask for support and, in fact, that makes it much more difficult for the patient and the partner to go through the experience but, more than that, those people that care about you most are left out and are unable to help you, which would also help them deal with someone who's close to them who has been diagnosed. Obviously the impact on the family as well as the impact on the couple is an additional stressor. This is especially true of couples who are having a bit of a rough time at the time of diagnosis. Any of the difficulties that happen often rise to the surface because they become overwhelmed with the experience of the diagnosis.

The benefit is, in PTSD, the idea is to process the experience, let it pass through you a little bit without avoiding it and then integrating it as part of your experience of living, in order to help maintain a sense of self esteem and confidence in your physical and mental self, engagement in family and social activities and the ability to experience feelings related to the illness without persistent anxiety and depression. You know, it's phenomenal to watch the natural adaptation of the human being anyway. When they're diagnosed, I will say to a patient, I will bet you in three days time you will feel better than you do now and call me if you don't and call me if you want to come in anyway. What happens is, you do get the deer in the headlights, it's a shock reaction and it takes some time, and even three days is not a whole lot of time but it takes some time to process it enough so that you start to become proactive. You say, "O.K., this has happened to me now, what do I do?" But, in the office when you get diagnosed you're not able to make that original step.

The other thing is cancer diagnosis, of course, does not free you from responsibilities. The idea is that you don't get a free pass when you get diagnosed with cancer, so everything else that you were responsible for up until that point: your marriage, your income, parenting, parenting adult children, any employment, anything along those lines, you still carry that responsibility for a period of time. You may get what I call the lasagna period and that is the period where you get a lasagna at your front door to help you over the first two weeks but those lasagnas dry up and then you're asked to return to your responsibilities again. That can be a difficult experience as well but also, obviously very helpful, because it gets you back into your routine and back into your role.

Decisions

In terms of decisions, one patient said that the hardest part was getting to know where to get information and then knowing when to quit. This is the lost in the forest for the trees example. One person said that their experience was that they had a lot of information but the missing piece was how to assimilate that information and integrate it into your own reality. How do you emotionally and psychologically deal with it, how do you cope with it? I think it's even more than emotionally and psychologically deal with it but how do you organize it so that it's meaningful to you. Because there's so

much information out there and you've got your own diagnosis, your own experience with its own Gleason Score, its volume, its stage and so, you read a lot of information but you don't know how that specifically relates to you. That is where a program where you can see someone in the healthcare system that helps you through this process and decision making and helps you to assimilate that kind of information is good. The idea is that everybody needs what they call a critical mass of information about each of the treatments. You just need to feel that you know enough about each of the treatments that you can make a rational decision about it. The best advice is, start with the basics. Know all the diagnostic features of your cancer and then that will often times rule out some treatment options and then you look at the options left over and you look at their side effects. Interestingly enough, the reason why you're given the choice is that, really the survival rates for all of the treatments are nearly the same. So then we're looking at the side effects but even those side effects, in the long term - two years out - are also almost indistinguishable. So then, you're really looking at what you're most comfortable doing, whether it's going into an operating theatre or, for instance, going in to the hospital for radiation every morning for a number of days. A couple's approach is team up together. The idea is that you've both been diagnosed. One carries it physically but, as a couple, in reality you've both been diagnosed. The challenge is to confront the disease together and not leave it up to any one person. I find often that dividing the task according to your abilities and strengths is helpful. My wife has the most incredible ability to organize things and with a wonderful time line. I stink at that. My wife's desk looks like a hurricane went through and I have a little bit of obsessive compulsive disorder, so I make every pile stand up straight. So, the idea is, if I could organize the information coming in and she could make sure that we were going to the right appointments and that we had access to things, there's a combined way in which we could support each other in challenging the cancer.

The other thing about treatment decision making is this, there is no wrong answer. That really is the case. Our treatments are the best we can get to this point and they're basically of equal value. You are not alone so that means that if you are not getting enough information directly from your primary physician because they're seeing 50 patients in a day, your GP can be extremely helpful, or ask for some more supportive service from the other team members and you'll be sent to someone like myself or other support staff. The other thing is that this is choice not chance. You've got a lot of options that are available for you. We do not have medical guidelines like other cancers and say, "If you're here, this is what you're going to get." The reason for that is that these treatments are basically of equal value. So it's not a chance decision, it's a choice decision. You actually have some choice in how you want to approach your disease. There's a lot of science that goes into the decision aids we use to help people. I find that talking to a non-biased healthcare provider is often very helpful in terms of this. I often say to my patients, go ask your surgeon or your radiation oncologist, if I was your

brother what would you do and see how they answer (don't ever tell them I told you that though).

Risk distortions: help clear up any distortions about risk. That's quite common, you can migrate up in your risks in that anxiety base. Personal value: this goes to the point are you making the treatment decision that matches your personal values in life? Feel supported in your decision making. Move through a decision analysis approach where you have decision modes to help keep your mind clear, then, you're automatically participating in your own health care, so there are some psychological benefits. We increase knowledge and confidence and hopefully reduce some anxiety and it integrates significant others and families in the decision making.

Treatment and recovery: the main thing is don't forget you're being treated for cancer. What's happening nowadays is there's this feeling, "Oh, you've been diagnosed with prostate cancer. Well, if there's any cancer you're going to be diagnosed with, prostate cancer's the best." Which is true in many ways but it's no fun getting diagnosed with any kind of cancer. The fact is, your life will change regardless of anything. Regardless of whatever success the treatment has, you will have side effects, you will have faced mortality for the first time in your life, even though they tell you you are not facing it. It will alter your life and the problem is, the expectation is, that we say, "Come on, get treated, right now your surgery's two and on half hours, you're walking the day after surgery, you're out of the hospital within three days. So we actually approach it like it's an in and out service, you're done, thank you very much and people think, My Gosh, this is great and I'll be golfing in a month. But, obviously, anybody who's actually gone through the experience knows that that's not really the case and it can be a real blow to people after the fact. Couples who are most successful recognize this and make space in their lives to be able to cope with it through diagnosis and treatment.

Adaptation to side effects: As we know, the two main side effects are urinary incontinence and sexual dysfunction. The good news about urinary incontinence is that, in general, about 90% of men will return to a level of continence that does not interfere with their quality of life within about three months of treatment.

In terms of **sexual dysfunction:** sexuality is life long. The unfortunate thing is after surgery, long term erectile dysfunction is 40 to 75%. That is one crazy span. Why are we not doing better? That's because there are a lot of methodological issues, how old you are when you measure your erectile functioning, so if you're a scientist and you're measuring at six months out or one year out or eighteen months out, or twenty-four months out, you're going to get different levels. But, I can tell you when we accrued all this information and we took a look at meta-analyses, long term erectile dysfunction, you're probably looking far more into 75% range. The good news is we've got a lot of pro-erectile agents and devices, from oral meds. like Viagra, suppositories, vacuum devices, etc. but the problem is, while they have rates of success they have low rates of continued use. People are stopping using them even when they are effective. Specific to

prostate cancer patients, a large study said only 30 - 40% of men remain sexually active one to five years post surgery, despite use of two or more aids. These are not people just sitting back and saying I've lost my sexual functioning, I'm going to cope with it or I'm too embarrassed to do anything about it, these are what we call the health monitors, they're seeking assistance and they are still not being very successful. This wouldn't be such a concern and the reason I bring it up here and I bring it up wherever I go, is that it's obviously an interest of mine but it also creates a substantial amount of distress in patients post treatment. When we take a look, 60% of patients report moderate to severe distress related to sexual dysfunction. When psychologists get excited about things, if I could say 50% of patients reported mild to moderate, this would be that I could get the Nobel Prize in the area. The idea that we're at 60% of moderate to severe, it's a huge impact on patient quality of life. One quality of life study reported, they asked patients one year post surgery, "What was the single greatest impact on your quality of life?" 12% said fear of cancer returning, 40% said sexual dysfunction and its impact on themselves individually and as a couple. The other thing is the stress is especially elevated in younger men, particularly considering that we are diagnosing men at a younger age. Partners experience greater distress as well. We don't know a lot about distress so we want to figure that out a bit in order to help patients. I did a study where I followed 25 couples. I interviewed them as a couple and I had them interviewed separately by colleagues of mine. We did it post treatment, three to six months post treatment, 12 to 15 months post treatment and 21 to 24 months post treatment. That's three interviews per couple at three different times. Here is some information from those first set of interviews. With each finding, I provide a quote.

Patient's difficulty with acceptance of erectile dysfunction: I've been working on myself in other ways to compensate for the fact that I don't have the same feeling of manhood and I think I have always made a big association to my manhood in erection, so without it, it's like there's something lost, there's something gone, there's something missing? We're terrible about talking about sex in North America. We generally have never had it modeled by our parents or by people we know, so we don't even know very well how to go about it in many ways. So patients often retreat inwardly. This means they really are isolating themselves. We feel it is part of our manhood, we're threatened by it and in many ways we don't want to bring it up or make note of it to our partner and so, often times, we won't disclose our concerns to our partners as well. When we deal with other problems in our lives, a lot of other problems, different traumas, we have our usual support networks, our partner, our close same sex friend, couples, but in this case we don't do it. That really means that our usual support network is gone. That is where the hospital, the healthcare team really needs to pick up the slack and help patients feel more comfortable receiving the support and being offered information on how to collect support back from their usual support group. The patient says, "I keep the problems to myself, I don't want to involve anybody else and I

realize it is wrong, especially with my partner, especially when you have somebody who is very close to you, that really cares about you." So this patient even knows that he's holding back and knows that it's probably hurting his partner but he doesn't know what to do about it. When I did all these interviews, and I did a whole bunch of pilot interviews before this, 9.9 times out of ten, the partners are far less concerned about the actual erectile dysfunction. They are far more concerned about their partner's response to that erectile dysfunction and that emotional retreat, that patient retreat inwardly. As this partner said [this is a 63 year old woman,] "There is a series of emotions that you go through, I feel sad, I feel rejected, I feel angry and pissed off, I'm too young for this. Now we both have to just let go a bit. It makes me unhappy to think that this is where we'll be heading."

Couples **communication** breaks down. Both are withdrawing, one's retreating inwardly, one's having no success at getting anything and they also have a tendency to retreat. This leads to communication breakdown. It's not any more just about cancer. It's about a lot more, including intimacy. We had a couple in the group that had very severe trauma. They lost a child, a teenager, several years before and they were able to communicate and process and make it through that trauma remarkably well. We noted that there were a lot of couples that had excellent communication skills about a number of different things but we also noted that even patients, including the one I just talked about, they just didn't have the tools and skills available to talk about this. One patient said, "I think what was frustrating for my wife was that I wasn't showing any interest and she, I think, tried to with me but didn't seem to be getting anywhere, so we just got to a point of non-discussion, non-contact and it effected our intimacy. So in spite of these generally excellent communication skills, they had a difficult time talking about this.

Naturalness and Spontaneity: Sooner or later the pro-erectile agents and devices are generally going to be introduced. They're usually introduced in the hospital: here's a bag, take it home, give it a whirl. It doesn't have any instructions, what to expect. Patients obviously have difficulty with the loss of naturalness and spontaneity. One patient said it beautifully, "What do you do? Do you say, O.K. dear, I'm going to take a tablet now, so in six hours time maybe we should go to bed." That's not exactly romantic is it. I didn't know whether I should just take one and hope for the opportunity. It doesn't say anything on the box." So, incorporating the emotional side is very difficult.

Expectation can lead to regret. This is what I talked about earlier on that the general expectation relates to prostate cancer but even worse is the expectation that they are going to back to normal, their regular old sex life, everything will be fine. That is never the case. Even if the pro-erectile device is successful, it is different. Patients need to know that there are going to be changes in their sex life and the more they know that, the better able they are to process it and cope with it and move forward. One patient said to me, "At times I feel frustrated, a little bit angry about it and I really wonder if I made the right decision in having the surgery or should I

have taken whatever number of years I had and had more normal functioning in the shorter term." His wife was sitting beside him and she looked at me and said, "See, that's why I just want to smack him upside the head."

Adaptation: Resuming sexual activity. It's very important to get that back going, whether it's intercourse or non-intercourse sexual activity, it's a drastic change. Usually after years of a very usual routine, and I mean routine in a nice way, not in a boring way. This is what they're used to. This partner said, "I didn't think it would matter to me but it matters. Before the operation he was ready to have intercourse more often than I was, so sometimes it was easy to just let him take the lead role and I could just accommodate, basically without getting involved and I would ultimately enjoy it. But now, I have to be more involved. I have to be more engaged. I couldn't be distant. I was quite sad that our sex life was changed. That's what I felt, it was like a mourning." That's because the way you participate now in your sex lives changes and it can be very difficult to integrate that into your regular sexual activity. So, if you can see this, it hits anxiety, it hits depression and it also hits a couple's relationship very hard and it can have a snowball effect. What can result is that patients and their partners stop having a sex life altogether, finding it too difficult to navigate and we do know that sexual activity, whether it's intercourse or non-intercourse is very closely related to intimacy and it can also threaten the intimacy of the couple. Another patient said, "I don't feel like it's as natural. Touching used to be a big thing with us. I was very spontaneous in all that. Now I feel uncomfortable, I don't know what it means. If I say, I love you, what does it mean" I'm not sure any more. You get into a pattern of ships passing in the night and it just makes it difficult. We have just drifted a long way apart."

Additional Presenting Problems: I bring this up because there's androgen deprivation therapy, some people are on hormone therapy, this adds a whole new aspect. There's loss of libido, body feminization, a qualitative analysis which was similar to my study said that they also experience much of what I've just discussed but with the loss of libido it can be very difficult and some men are quite a bit younger but because they have an aggressive disease, they're treated with hormone therapy. A young patient in another study said about passion, "Initially I still hoped that I could at least fantasize about sex, but everything, even my erotic dreams have vanished, everything in me became numb, my penis, my lust for women, my drive to masturbate, nothing excites me any more, without sex my world has grown boring, grey and mechanical. I lost the capacity to enjoy trips and music, even the fragrance of spring." So you can see that even in this area you could basically slide towards the experience of depression. In terms of intimacy, another patient stated, "The problems were solved when one day I moved into another room, I have my own bathroom and I take care of my own affairs without involving my wife. It isn't the way I thought things would turn out. We discuss practical matters without drifting into feelings and when friends and family visit, we put on the performance of intimacy and union." That is a true struggle with androgen deprivation therapy and I haven't even started

in that arena and there's very little research in that arena and it's a very difficult experience. We need more psychosocial approach plus we need surgeons, we need health care professionals, special health counsellors, we need very sensitive, informed nurses to manage the disease as a whole and the person as a whole rather than just focusing on the tumour.

In the final section we deal with the **acceptance** of mortality. In this area, we look at a few things. When you first hear the word cancer, you immediately think about death and our omnipotence, our feeling that it's going to happen to someone else generally goes away and, for the first time, we could be faced with our own mortality. So the sense of lack of control, one of the ways in which we generally deal with this we call problem focused coping. Facing mortality is where previously well adjusted men are feeling distress post-diagnosis and treatment of a very serious illness. It heightens the sense that life is finite. We often think that we're going to go on and on and on. We think that's there's an endless possibilities of achieving our aspirations because we always think that I can do this tomorrow and then there's a realization that there's not always going to be a tomorrow. We generally use emotion focused coping for that. In terms of fear of recurrence and the problems coping it's quite simple. The idea is that Western medical treatment doesn't leave a lot of room for patient involvement. You come in, you're told what's going to occur, it's like getting onto a plane and trusting the pilot. There's nothing you can do, you can't fly that plane so you walk into the doctor's office and say, "You take care of it." But, in reality there are a lot of things that you can do that may support your well being. One alternative is the self help approach which are health behaviour changes like nutrition and exercise, or guided self help approaches like stress management. This is where you're tipping the balance. The idea is getting healthy momentum. You take a look at your body healing system. Let's see if you can get your immune system functioning. Just because it failed to keep the prostate cancer in check, doesn't mean your immune system isn't working. It just struggled and that makes some sense because we're not supposed to be around after we're 45. We've got this prostate that's living up to 75, 85 years of age. There is evidence to suggest that 30% of 30 year olds have prostate cancer, 40% of 40 year olds, 50% of 50 years, 100% of 100 year olds are going to have prostate cancer. In many ways it doesn't matter whether you live two weeks, two years, 10 years or 20 years, you're always going to be taken at some point in the middle of something. People really think, O.K., I've been given two years to live, I might as well not start anything because I won't finish it. Well, when does anybody put up their hand and say, "O.K., I'm done everything. Thanks, take me now." It doesn't happen. Don't let the cancer steal this time away from you. If you spend 90% of your time fighting the cancer for whatever years you have left, then you've already given those years to that cancer, so you're solving nothing. Take time to smell the roses. Past thought equals depression, future thoughts equal anxiety. That's why there's the importance of the here and now because it's the only time you're actually experiencing anything, it's also the only time you actually have control over, so it's very important. *Develop that healthy momentum.*