

Local Supports: The Personal & Beyond

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Good morning!

If you ladies think that you can escape from men by hiding up here in Nova Scotia for a few days, you are wrong: I'm here, and so are a handful of other gentlemen.

Breast cancer touches everybody – including men: Husbands, brothers, fathers, sons, sweethearts and lovers. So it's only fair that some of us get to raise our voices...

Men are strong and men are weak, men can be a nuisance and a pain in the ass, but we can also be an asset, helpful and supportive. We don't understand a thing, yet, we are presidents and prime ministers and the first ones to the moon. Men can take up a lot of space, but we can also feel small and invisible.

I have been it all, I have felt it all.

For the last 30 years, I have been travelling the world as a reporter, covering wars and strifes and earthquakes and disasters. I have seen some ugly things in my job, and I have dealt with it all. If things got too nasty, I could always leave, and try to forget... But then, all of a sudden i december 1996, the biggest disaster ever struck in my own backyard: My wife was diagnosed with breast cancer. I faced a catastrophe I could not turn my back on, so I prepared the only weapons I knew: The pen and the paper!

Armed with these weapons, I embarked on my life's journey: From the day she got her diagnosis, until she passed away in my arms 15 months later, I put down my thoughts and feelings, day by day, on any little piece of paper I could find: It all ended up in this book, titeled "Charlemans Wagon", after the constellation. You people call it "The big dipper" or "The great bear", we scandinavians have named it "Charlemans Wagon", because it looks like a big, huge wagon on the night sky...

- When I am gone, I'll seat myself in that wagon, my wife said to me with a tired smile just before dying.
- That's the one you always point at when we stand together under the starry sky, and that's the one you can see no matter where you are in the world. Then I'll know that you see me. And when it finally is your turn, I'll come down to pick you up in my wagon... I received thousands of letters and calls after that first book, all kinds of people seemed to grasp the idea of a place to go to. I collected a few of them in this second book. One late evening, I heard a tiny little voice on the phone:
- My dad's crying all the time. May I please tell him that my mom can have a

seat in your wife's wagon? You see, my daddy and I want to see her on the night sky...

- Yes, of course, I said. - The wagon is big enough for them both, billions of miles long. And I am sure my Elisabeth appreciates the company of your mammy. That wagon is big enough for everybody...

But back to earth: There is, as we all know, no such thing as a golden recipe on how the ideal relationship between the woman with breast cancer and the world around her should be. She may wish and hope and pray for a whole lot of basic needs to be fulfilled,- such as love and friendship and support, inner strength and good medical care.

But when the rainy days come, in my opinion, it boils down to a couple of key words:

LOVE - that someone is there for you, comforting you and helping you - and GOOD, PERSONAL COMMUNICATION, signalling respect, support and understanding between fellow human beings. Between doctor and patient, between patient and those close to her, and - not to forget - the good talk between doctor and family.

If family - or next-of-kin - is not involved, the road to recovery may be a long and hard and lonely one.

Having a cancer is not only a question about diagnosis, about life and death and high tech treatment. It is just as much a condition, a state of mind, an experience. Which means that trying to understand the patient's fear and pain - is at least as important as all those latin words...

Breast cancer comes without a warning, without discrimination. Anyone can get it, even men. The richest, the most gifted and celebrated women of our time get breast cancer, and so do the poorest, the most secluded. Many of them have shared their stories, trying to raise the awareness. And they all deserve credit for that. You are doing the same thing, right here, right now. And I commend YOU for that...

The WORD "cancer" is scary for most of us,- GETTING it knocks you flat out. I still remember how my wife went into a big, black void, and stayed there for a long time. And with her being there - in that void - it was more important than ever before that we, the ones closest to her, had the will - and actually helped her carry some of her burdens.

Local support and care depends on tradition and culture, on religion or ethnic background, on lifestyle and living arrangements, and on the quality of the local welfare system. But whoever you are, wherever you live, whatever your age, the wellbeing of the woman, and her sense of security and support, will to a great extent depend on the people she trusted BEFORE the rain set in. That these people are willing to help fight the battle...

Some breast cancer women don't want to reveal the bad news to their loved ones. Perhaps based on a desperate attempt to spare them the pain and fear often connected to the word cancer, or simply based on the fact that in some

communities, breast cancer may be associated with shame and guilt.

Women in these communities have told me that they cannot even tell their male companion about their diagnosis. As women often are the primary caregivers, many of them feel unable to burden the family with their disease, often suffering in silence, and not receiving any form of support from family members at all.

At a breast cancer conference in Portugal a couple of years ago, I met a great lady - and a strong activist - from Nigeria. She was one of the lucky ones, she told me, having a husband and a family who listened to her and supported her, comforted her and gave her the courage to fight on...

- But there are villages in my country where they still consider breast cancer to be "evil", she said.
- Where men regard women with breast cancer as "witches", and where they fight "the evil" by pouring burning tar on their breasts...

And there are other barriers based on culture: We have for example thousands of immigrants from far away and orthodox muslim societies in my own country. Many of these women are kept isolated from the norwegian community by their conservative, male family members, and are consequently denied access to the local social life and welfare network. And also frequently denied access to the most powerful tool we have between people, the possibility to learn a new language, and thus communicate.

As a result, they will forever be kept ignorant of the new society they live in, and be barred from existing local support systems when those rainy days come.

A few years ago I watched a movie called "A walk in the Clouds". The film legend Anthony Quinn was playing an old and wise - but very sick - mexican grandpa on a winery in California. Every day he would walk among his grapes, being annoyed, thinking about the many rules of life:

- They will not let me smoke my beloved cigars, he complained,- and I am not allowed to eat chocolate any more.
- And when they offer me a brandy every now and then, they will only give me a SMALL glass! Then he sighed, and said to himself: - What the hell do the doctor and my family know about the needs of my SOUL ?

The old man was thinking about the COMPLETE compassion, the complete care,- not only what the doctor had to say about his ailing health, or what the family wanted him to do or not to do.

He was thinking about the existential pain. How THAT pain could be nursed and plastred. Not only with an operation or chemo therapy or radiation, but with understanding and comfort and friendship and love and compassion.

Or with a "large glass of brandy", as he put it.

You ladies here know more about the needs of the soul - or the existential pain - than most other people. You also know that losing a breast may feel like losing an important part of yourself, a part of your own identity.

In addition to the fear and the pain and the sorrow...

Breast cancer stole my beautiful wife away more than seven years ago. And I can assure you all that there were times when also I - as a husband - missed that "large glass of brandy". When all communication from the doctor or the nurse or the local community was one way only to both of us - without empathy, and in latin words. And when I was not seen, not even by those I trusted before the rain set in. And when you are invisible, you feel small. And when you feel small, you may not be able to help, or to comfort the one who really needs you...

I see myself as a person with a strong back and a good network of friends and advisers. And as a professional journalist, I am well trained in confronting authorities and asking questions. But I felt just as small as everyone else, then: My wife`s illness had become OUR illness. Her fear had become OUR fear. Her pain was MY pain!

From the book "Charlemans Wagon" - **March 1st, 1997:**

"Your hair was falling out in big clumps throughout the night, and that was harder than you had thought. You were so sure that you were psychologically prepared for this, and may be you were. But to see hair everywhere, in the sheets, in the sink, in the shower and on the floor made you lose heart.

I heard you sitting alone in the bathroom, crying, and I went in to you to comfort you. But I didn't understand what you needed, what words you wanted to hear. The more I tried to comfort you, to help you and to give advice in my practical, masculine way, the worse it got.

You finally screamed at me and sobbed inconsolably.

We ended up beside each other in bed. I was silent, and caressed your hand. You were crying, and then got suddenly silent. You just lay there and looked at me, surprised, and I asked you what you were thinking about.

- I was thinking about the fact that it must be pretty hard on you too, you replied.
- To try to relate to my illness, to my mind, to my reactions and to my sorrow..."

Close family and next-of-kins ARE often in the same boat as the patient. We feel the pain together, we long for brighter and better days together. We are in this together...

Only by experiencing the rainy days together, is it possible for those close to you to listen, to touch and to comfort – and to SEE: To see the distress and the sorrow. To see the fear – and to see the needs.

But equally important: It takes at least two to create pleasant moments of love and laughter and normality.

I often use the word next-of-kin instead of family or husband, because it isn't necessarily a person in the close family that the doctor or the local network

should relate to. Normally, "the family" are parents, a spouse or a son or a daughter.

But not always: In our modern and emancipated world, with different lifestyles and different living arrangements, the traditional family structure has changed a lot. So the "family" could be a close friend, a colleague at work, a trusted neighbour or a cohabitant – gay or straight.

So "family" is the person - or the persons - whom the ill wants to represent her, and support her and her matters during that difficult period...

Except for the little things in the daily family life, I had NO prior knowledge in that noble art of being a next-of-kin. A family NEVER have prior training in being next-of-kins. That role comes along unexpectedly - always. A little puncture doesn't let the air out of us, it SUCKS the air out, and leave us paralyzed behind. And who will take care of the patient - a loved one - when the health system or the doctor or the local community lack capacity or compassion, and I feel like a flat tire...

So it is important that also the next-of-kin is taken care of in the middle of that cancer hurricane. Because he - or she - is an important tool for the doctor and the society in that crucial work of getting the patient back on her feet.

Yes, the patient is sick and scared, but hopefully being taken care of. The patient is in a way "in the eye of the hurricane", where everything is quiet.

But I – the spouse – or the next-of-kin - is often out there somewhere, lost in space, where nobody sees me, and where that cancer storm is ravaging, tearing hopes and prayers and bright days and family life to pieces.

And in the middle of it all, the joy of living and the hope for a future free of fear is bubbling deep within both patient and companion. That lust of life must the doctor and the nurse and people in the local community help to surface through good communication, by being fellow human beings.

Don't take the dreams away, don't take the hope away. Do not forget "that large glass of brandy"...

Finally, I would like to philosophize a moment about the privacy between the patient and her beloved one, her sweetheart: A man is not always able to communicate his love and support, because he, too, is full of fear and pain, both for himself and for his woman. Perhaps is he afraid to hurt her, or maybe he is just like most men, simply having trouble talking about feelings. And perhaps SHE wants to hide from him, to conceal herself behind an appearance that she is no longer satisfied with, or pleased with.

Maybe she wants to be inaccessible, unapproachable to her sweetheart because she is ashamed of no longer having "the perfect body", or because she doesn't feel sexy anymore.

And then – what could have been warm and tender and close, what could have welded two lovers even closer together, has instead become a silent, unclimable wall between them.

A life shared between a man and a woman, between two equal souls, is not easy, even when both are feeling happy and well. Outsiders can only imagine how

difficult it can be when one of them is ill...

I have found a new love now, with her own losses. Come rain, come shine,- we have promised to see and listen and be there for each other whatever happens to us in the future. These are the qualities that count in the long run, and I believe that caring like this matters.

Like I write in my diary, **january 2nd, 1997:**

.....today You have seen your scar for the very first time, Elisabeth. You asked to see it when they changed your bandage this morning. Where you before had a soft and beautiful breast, a bloody scar cried out at you, from the middle of your chest to way back under your arm.

And you have tears in your eyes when I come to visit. I grab your hand and squeeze it, to comfort you:

- It was not your right breast I fell in love with down in Italy 25 years ago, I say helplessly.
- It was You...