

"Carol gave me her permission to use her name publicly."

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April 16, 17

Ms. Christine Elliott
Patient Ombudsman
393 University Ave
Suite 1801
Toronto, ON
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RE:MS. "Carol" COMPLAINT

Dear Ms. Elliott

I would like to once again thank you for taking the time to see me and put me in contact with Ms. Wasserstein.

This is the application on behalf of PATIENT "Carol" whom we spoke of and I had mistakenly thought I'd already sent the completed form.

PATIENT "Carol" is the archetypical example of why PET became the world standard of imaging management for cancer patients, in some cancers as long as almost 20 years ago and in places like Chile. More importantly she represents one of an endless number of examples of patients who have been used as pawns and victims in the Liberal Government's mandate to block PET to avoid paying for it. Here are some of her emails to me, both giving me permission to represent her and the personal impact it is having on her. Keep in mind she had a very difficult time with the radiation therapy, which the PET showed, cannot possibly have worked, and indeed raised the possibility that she never should have had it in the first place.

- PET/CT scanning on average demonstrates that 30% of patients have more disease than their conventional work-up with CT shows, and thus leads to critical changes in treatment options and prognosis.

SOME EMAILS FROM PATIENT "Carol":

Hi Dr Webster,

I give you my consent to discuss my case. Here is the summary I promised to send.

I am a 65 year old retired/casual Registered Nurse of 40 years. Prior to the diagnosis of Cervical/Uterine Cancer, I was active and in good health. Following my treatments of external Radiation and Chemotherapy in Thunder Bay, and Brachytherapy in London, the request for a Pet Scan by Dr 'Oncologist' was submitted mid December.

I have had monthly follow up appointments during the course of my treatments by a Gynecologist/Oncologist from Hamilton. The Doctors in Hamilton recommended a hysterectomy post treatment with a probable Radical Cystectomy. I was informed at that time I would have a small window time frame post treatment to make my decision. I was given two options: The first option was surgery. The second option was no surgery with possible palliative care if the Cancer recurred or metastasized. Big decision to make.

I am not the person to not think, not wonder, not imagine, not obsess or ever give up on anything life has handed me. There is a basic motivated force called fear and because I am afraid, I do not want to pull back from living. My life's path of the unknown is draining me physically and emotionally. I feel it is unfair that what happens in a decision of persons can change the course of a whole life time. That those persons can take over my life and take away the chances and the say of myself. The added stress involved with the wait for a panel's decision is totally unfair. Unknown equals fear and anxiety.

""Carol""

Sent from my iPhone February 10th.

Thank you Dr Dave for your updates and your positivity during this challenging fight for pet scan care

I so appreciate that you feel my concerns and anxieties

Thx ""Carol"" February 15.

Hi Dr Dave

Received a phone call today that my pet scan will be done Thursday .. Not sure whether you knew or not

Will keep in touch with you and have many friends that are interested in writing letters to help other patients to not have to go through what I and many others have

""Carol"" February 21

Hello

I'm sorry that I did not reply earlier . I was trying to hold off until ""Carol"" had met with you .

She shared the results with me yesterday . After all that time waiting for the scan , it is so unfortunate that the news was not better . It does give "Carol" something to base her decisions on now , but also opens up a few more questions .

As her friend , I will continue to help in any way , give her some space as needed , be someone that she vent to , meet for lunch , go cross border shopping for some retail therapy or whatever it takes to keep her in the game .

Life can be so uncertain and definitely unfair at times .

Your participation in her case was extremely helpful , I'm sure .She mentioned many times that it truly felt that she had someone in her corner .

I wish you much success in your ongoing fight for patients and especially for Sudbury .As a Laurentian alumnus, I have a special affection for Sudbury .

Many thanks again

Best regards

Kathy [Friend of "Carol"'s] March 8

Hi Dave

I am doing pretty good

A lot of information to try to process and understand

Hamilton doctors have said no surgery because of the positive pelvic nodes and the sm lung findings and will recheck in 6 wks with mri/ ct scans of the chest and pelvis

I am taking each day as it comes and trying to stay positive . My family and friends are my pillar of strength and sadly have to be my sounding block .

I have requested my chart files and

Cd's and sending them to Rochester mayo clinic for review to their international patient oncology department . They do reviews every two weeks and then respond with their opinions

Pet access has not contacted me with any answers

It would be very helpful and appreciated if you could draft something up for me

It makes me both angry and sad that this could have been avoided to some degree / life is so short and precious and I have do much to live for

Hope all is well with you / you are putting up an amazing struggle for pet access

Take care "Carol" [March 9]

Sent from my iPhone

Hi Dave

Yes it is okay to use my name

I totally agree a pet /ct should be the follow up because of the pelvic / lung findings
but now to get the pet access to see it through my eyes !! Fingers crossed and
praying

Thanks again "Carol" March 12th.

Hi Dave

I had an appnt with Dr 'Oncologist' and Dr Ellit (gyne from Hamilton) today and she
is not receptive to the fact of ordering a pet // said the ct will tell them what
they need to know .. Which is .. have the lymph nodes or lung lesions
increased in size

I along with my daughter questioned them several times thro the meeting about the
pet and how important and beneficial it would be but no go ..

As it stands right now I have been booked for a ct second week of April

If things are unchanged they will repeat scan in 6 wks from then

If there are changes .. My options are chemo or nothing

Chemo drugs discussed using are

1. Carbonating
2. Paclitaxil
3. Bevacizumab

As you see my options are slim but I also want to

Live life to the fullest and without feeling weakened and sick all the time and all
three of these chemo drugs come with major side effects .. Big decisions to
make for myself

So sorry to hear that the CCO can do this to you . (A person who actually cares about
his patients)

I'm truly a believer that health care is not about the patient as far as the government
is concerned

When they use the terms "care beyond compare " or "patient care is our main
focus" Bullshit!!!

Thanks for listening to my rant but I'm so angry with this whole health care rat
race

March 16th.

Hi Dave

Both of them said it but Dr 'Oncologist' was looking quite uncomfortable during our
discussion and even my daughter stated she thought that Dr 'Oncologist'
looked intimidated by Dr Ellit

when the topic was addressed .. Hate to point fingers but totally don't agree with their decision !!

Sorry I did not receive the attachment

"Carol"

March 16th.

Hi Dave

I'm doing okay but definitely not myself ... Had another ct scan last Monday which I don't know the results yet .. See Dr 'Oncologist' on fri 21st for results

Thank you so much for your fight for the pet

"Carol"

Thank you again so much this has been a bumpy ride for sure and had me slowly losing my faith in the healthcare system

"Carol"

April 16th.

SUMMARY:

I have also sent letters to the Cancer Care Imaging Group via Dr. Julian Dobranowski, as well as to the PET Steering Committee through Dr. Ur Mester, asking that they respond to her questions. They have not responded as expected.

I will send these documents to Ms. Wasserstein along with the relevant emails.

The difficulty as you have pointed out is that the very structure of your mandate only allows you go after hospitals and physicians. The problem of course is that as much as they would want to offer her proper diagnostic imaging management, they are being forced by the Ministry of Health to practice incompetent medicine.

Please let me know if there is anything other information you require, or if at some point you would like to meet again to discuss the issues further.

Best Personal Regards

Dave Webster MD FRCP

