

Patient Ombudsman

Wednesday, November 15, 2017

Delivered by Regular Mail

Dr. David Webster

41 Ramsey Lake Road Sudbury

ON

P3E 5J1

Dear Dr. Webster,

Re. Complaint re. Cancer Care Ontario's PET Scan Policy, Case File# 201700672

I am writing further to our discussion earlier today, regarding your complaints about Ontario's approach to funding Positive Emission Tomography (PET) scans and the mandate of the Patient Ombudsman.

Patient Ombudsman's Mandate

As you are aware, the *Excellent Care for All Act, 2010* establishes the authority and powers of the Patient Ombudsman. This legislation provides that she can receive complaints from patients, former patients or caregivers about actions or inactions of a health sector organization that relate to the care and health care experience of a patient or former patient. Health sector organizations are defined in the act as a publicly funded hospitals, long-term care homes, and local health integration networks. With respect to the latter, the Patient Ombudsman may only accept complaints regarding their placement activities and home care coordination functions .

As a recourse of last resort, the Patient Ombudsman's involvement occurs following a complainant's engagement with the internal complaints process of the health sector organization - in other words, after the organization has been given a meaningful opportunity to respond to the complaint. The *Excellent Care for All Act, 2010* also requires the Patient Ombudsman to refer complainants to other persons or bodies who have jurisdiction over a particular complaint. For example, if a complaint relates to the clinical decision-making of a physician or his or her behavior with a patient, our office would make a referral to the College of Physicians and Surgeons of Ontario. If a complaint related to decisions of the Ontario Health Insurance Plan regarding funding, then a referral to the Health Services Appeal and Review Board may be appropriate.

If the complaint falls within the Patient Ombudsman's mandate, the law requires that the Patient Ombudsman work with complainants and health sector organizations to try to resolve concerns. After attempting to facilitate a resolution, if the Patient Ombudsman believes a complaint about a health sector organization should be investigated, the Patient Ombudsman may formally investigate. The Patient Ombudsman may also commence an investigation of the actions or inactions of one or more health sector organizations that relate to the patient care or healthcare experience provided by the organization(s) in any case where the Patient Ombudsman believes the matter should be investigated. Patient Ombudsman investigations are conducted in private in accordance with the legislation. After an investigation, where the Patient Ombudsman finds problems, she may make recommendations to address her concerns. The Patient Ombudsman cannot make orders or overturn decisions of health sector organizations.

The Patient Ombudsman does not have jurisdiction over the Ministry of Health and Long-Term Care, Cancer Care Ontario, the Ontario Health Quality Council and activities of the local health integration networks other those described above. Complaints about these and many other public sector organizations fall within the jurisdiction of the Ontario Ombudsman. As we discussed, the Ontario Ombudsman may also take complaints about the Patient Ombudsman, as she is an employee of the Ontario Health Quality Council and reports to the Ministry of Health and Long Term Care.

Your Complaints to the Patient Ombudsman

You met with the Patient Ombudsman and her Senior Legal Counsel on April 6, 2017, to discuss your concerns. You explained that you disagreed with the Ministry of Health and Long-Term Care's approach to funding PET scans.

Background to PET Scan Funding in Ontario

The Ministry currently funds PET scans as insured services under the Ontario Health Insurance Plan in approximately 15 clinical circumstances. In some other cases, it funds them as an uninsured service. To qualify for funding as an uninsured service, the patient must meet the criteria of one of three programs administered by PET Scans Ontario, a division of Cancer Care Ontario. On its website, PET Scans Ontario describes the criteria for the three uninsured PET programs as follows:

- PET Registry
 - Indications for which PET scanning has been shown to be useful in certain circumstances, but for which the evidence is not sufficiently strong to include it as an insured service
- PET Clinical Trials
 - Indications for which the usefulness of PET scanning is being evaluated
 - Supports PET clinical trials approved by the PET Steering Committee and conducted by the Ontario Clinical Oncology Group (OCOG)
- PET Access Program
 - Indications and circumstances that do not meet eligibility criteria for the insured program, the PET Registry or an active clinical trial, where a panel of experts agree that a PET scan will provide benefit to the patient over other available tests

To obtain an uninsured PET scan, a patient's physician must complete an application to PET Scans Ontario. If a request for a scan under the PET Access Program is refused, there is a reassessment and appeal process available through Cancer Care Ontario, which involves a review of the application by a new panel of experts. Not all applications are granted.

The Ministry has established a group of experts, the PET Steering Committee, to review available evidence and make recommendations about the appropriate use of PET scans, including the criteria for the uninsured programs. The terms of reference, names of members, meeting dates, and minutes are published on-line at <https://www.petscansontario.ca>. Cancer Care Ontario's Program in Evidence-Based Care also works with the PET Steering Committee to gather and publish related research summaries, monitoring reports and guidelines at:

https://www.cancercare.on.ca/toolbox/qualityguidelines/specialized_services/pet_recommendation_reports/.

Your Concerns

You explained that you disagree with the assessments and recommendations of the PET Steering Committee and its underlying methodology. You told us that you believe PET scans should be funded in additional circumstances where they may help physicians better diagnose and treat cancer. You gave examples of other countries that have taken a different approach to PET funding. You also described the experiences of some of your patients, whom you believe underwent excruciating treatments that later PET scans indicated were inappropriate for their conditions. You suggested they may have experienced less pain and suffering and more effective treatments if a PET scan was available at an earlier stage.

You provided our office with detailed documentation of the nature of your concerns and how you have previously raised them, including responses received from the Ontario Ombudsman, the Minister of Health, and the Chair of the PET Steering Committee.

Ontario Ombudsman Investigation

Several years ago, in his 2009-2010 Annual Report, a former Ontario Ombudsman provided an overview of

his investigation of complaints about the evaluation and funding of PET scans by the Ministry of Health and Long-Term Care. In particular, he reported that, in response to the concerns he identified, the Ministry committed to taking steps to make PET scans insured services in certain cases (as they had not been previously) and improving the access process for uninsured PET scans, in particular by making it more transparent and timely. At that time, the Ministry was in the process of developing an accountability agreement with Cancer Care Ontario to administer the access program. The Minister also agreed to make changes to the PET Steering Committee process and that "future technology assessments would be better planned and resourced".

You shared with us a copy of an August 16, 2016, letter from the current Deputy Ontario Ombudsman, responding to your request for a further investigation into PET scan funding. The Deputy Ombudsman confirmed that their prior investigation was "focused on concerns relating to process, rather than the merits of whether the province should be adopting this technology" and that "[i]t is not the role of an Ombudsman to investigate matters of broad public policy." She referred to the changes made by the Ministry in response to the earlier investigation and noted their office had continued to monitor complaints received about the new application process and the Ministry's administration of access to PET scans. In particular, she noted that in 2014-2015, 574 PET scans were approved through Cancer Care Ontario's PET Access Program, with an average approval rating of 72% and a 2-day business turnaround.

Responses from the Minister and Chair of PET Steering Committee

On August 25, 2016, the Minister of Health responded to your concerns about the unavailability of PET scans to Ontario patients by reiterating his commitment to an "evidence-based process to the introduction of high-cost diagnostic imaging services." He noted the province funds scans "where evidence exists that PET scans contribute to improved patient management or outcomes" and

confirmed that the ministry had "accepted a number of recommendations from the expert advisory body."

By letter dated February 2, 2017, the Chair of the PET Steering Committee responded to your letter of concern by detailing the committee's work and noting various recommendations made by the committee to increase patient access to PET scans. He confirmed that the committee "continually reviews the evidence", both from Ontario and in peer-reviewed journals, and engages with experts both within the Cancer Care Ontario framework and externally, such as the Canadian and Ontario Associations of Nuclear Medicine. He concluded by inviting "evidence on indications we haven't yet considered."

Discussion about Individual Patient Cases You Brought to Our Attention

At the conclusion of your discussion on April 6, 2017, the Patient Ombudsman's Senior Legal Counsel clarified that our office only has jurisdiction over complaints about publicly-funded hospitals, long-term care homes and certain placement and service coordination activities of local health integration networks. She and the Patient Ombudsman indicated that if one of your patients had a complaint about their experience at one of these organizations, we would be happy to review it and determine if our office could be of any assistance.

You have since submitted two written complaints to our office, on behalf of two patients you treated. In both cases, the patients' physicians had submitted requests for PET scans to Cancer Care Ontario and received responses through that process. You indicated you disagreed with the application decisions made by the expert panels in Cancer Care Ontario's PET Access Program and the professional judgment of some of the physicians involved in these patients' care. You also suggested that particular treating physicians or physicians involved with Cancer Care Ontario should have answered your patient's questions about her care. Unfortunately, one of those patients passed away very recently. I am very sorry that I did not have an opportunity to speak with you about her concerns before her passing.

As set out above, the Patient Ombudsman does not have jurisdiction over Cancer Care Ontario or complaints

about physician's conduct or treatment decisions. Complaints about Cancer Care Ontario may be addressed to the Ontario Ombudsman. Complaints about clinical decision making on the part of a physician may be addressed to the College of Physicians and Surgeons.

Conclusion

As set out above, the concerns you have brought to our attention fall outside the scope of the Patient Ombudsman's mandate, which is to receive complaints about publicly funded hospitals, long-term care facilities and certain placement and home care coordination functions of local health integration networks.

With respect to your complaints about individual patients you brought forward to our office as a complainant, you may wish to bring any concerns about professional judgment to the attention of the College of Physicians and Surgeons if you have not already done so. Similarly, if you have concerns about Cancer Care Ontario, these should be addressed to the Ontario Ombudsman.

You confirmed during our call today, that your patient and the loved ones of the other patient are not expecting to hear from our office. If you think it would be helpful for our office to communicate directly with them about our mandate and referrals to other organizations , please let us know.

We thank you for sharing your concerns about the funding of PET scans and your efforts to obtain better information to help your patients make difficult treatment decisions. While your complaint does not fall within the Patient Ombudsman's mandate, the information you provided has provided helpful information that will inform our office moving forward.

Finally, as we discussed earlier today, I am very sorry that one of the patients whose case you brought forward to our office passed away before we completed our review and were able to talk to you. It took time for us to carefully review all the documentation and arguments you presented and the relevant legislation. I wish that we could have spoken sooner.

If you have any questions, you are welcome to contact me at (416) 597-5378. Yours

sincerely,



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Counsel

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