# **Navigating Second Opinions**

Why



How

#### Presentation to the Lymphoma Support Group of Ottawa May 4, 2021

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(Disclaimer: this presentation neither provides medical advice nor endorses a service)

### Not my opinion!

A <u>perspective</u> that brings together:

- Conversations with 13 clinicians/allied health professionals:
  - 3 BMT Hematology physicians
  - A specialist in each of Internal Medicine, Urology, Orthopedics, Hematology & Pediatric Oncology
  - 3 GPs (one at a community health centre)
  - 2 Social Workers.
- Input from two LSGO patients who have obtained second opinions
- Input from the Ministry of Health of Ontario
- Web literature review/offering review
- Chats with intake staff at US entities offering second opinions
- My personal experience

# **Three Questions**



1. Have you <u>considered</u> getting a second opinion?

2. Why would someone want a second opinion?

3. Why would someone <u>not</u> get a second opinion?

# Do I have a right to a second opinion?

#### <u>Canada</u>

- "Respect the patient's reasonable request for a second opinion from a recognized medical expert" (CMA Code of Ethics & Professionalism)
- "There is no limit on the number of consultations a patient can receive from different physicians. A physician can refer a patient for a consultation with another physician if the physician feels that it is medically necessary for the patient to receive a second opinion. A physician can also refer a patient for a consultation if another opinion is requested by the patient or patient's representative. A consultation with another physician to receive a second opinion would be insured by OHIP." (Email from the Ministry of Health 30 April 2021)

#### <u>USA</u>

- "Physicians can best contribute to a mutually respectful alliance with patients .... by respecting patients' rights. These include the right: (g) to obtain a second opinion.... Assure the patient that he or she may seek a second opinion." (AMA Code of Medical Ethics)
  - Referrals not required in many cases.
  - Many insurance plans require second opinions for medically-necessary surgical procedures and cancer treatment. Medicare B will pay for second and third opinions (when necessary).
- Yes, with the caveat that, in Ontario, family physicians and specialists are gate keepers for second opinions in system.



- Life-threatening emergency situations
   There may be multiple opinions in the ER (e.g., PE)
- Acute situations (e.g., burst appendix)
- Minor issues

• Everyday healthcare

# Maybe a second opinion?



**Examples** 

- Surgery / invasive procedure
- Diagnosis of serious diseases and chronic conditions, e.g., heart issue, diabetes or cancer, subtypes
- Disease/situation that is stressing to life by affecting health and physical abilities in the long term, e.g., MS, accident
- Unexplained medical issue
- Continuing/worsening symptoms
- Risky treatments
- Solo practice/small hospital vs. academic hospital



If you are comfortable with the diagnosis and treatment proposed, you don't have to ask for a second opinion.

## Why Get a Second Opinion?

- ✓ Obtain the best possible health outcome and quality of life (for you).
- ✓ A second opinion can improve quality of life, provide treatment or care options, or avoid a mistaken diagnosis.
- $\checkmark$  Get peace of mind
  - $\checkmark\,$  Be confident and trust that it is the best decision for you.
  - ✓ Avoid the regret of "I should have".
- $\checkmark\,$  Find a sense of control in a time of uncertainty
  - ✓ Decrease fear & anxiety

#### "If you feel you need it, it is not trivial."

### "Behind the Scenes" Second Opinions

- GPs' differential diagnoses --- a list of possibilities for the diagnosis based on presenting symptoms. "The art of family practice includes watching how conditions respond and pursuing further investigation (e.g., tests, specialist referrals)"
  - Refer with as accurate a diagnosis and with as specific a reason as possible.
  - GP tenacity: to send the patient for more tests or another specialty opinion if a specialist sends a patient back because the symptoms are unrelated to the specialty.
- Tumour boards and Multidisciplinary Cancer Conference (MCC) --- look at a case from different perspectives to decide the best treatment approach.
  - Gives multiple second opinions instantly to clinicians.
- Sharing impression with colleagues --- pathologists and radiologists
- BMT disease groups --- new cases rounds; discussions may produce changes.



These validate the <u>clinician's</u> diagnosis and treatment, but may not provide answers for <u>your</u> questions.

## Things to keep in mind

- Patients give Informed Consent.
  - A clinician explains an intervention to a patient before the patient agrees to it.
    - Patient can ask questions and accept/refuse the intervention.
  - Includes:
    - Patient's ability to make a decision
    - Explanation of information needed to make a decision
    - Patient's understanding of the medical information
    - Patient's voluntary decision to get treatment.
  - Components:
    - Diagnosis; name & purpose of proposed treatment; benefits & risks of the proposed treatment; alternatives and their benefits & risks.
- There are always alternatives. Patient cannot give informed consent without knowing them.
- Informed Consent is **not** something to take lightly!



A patient giving Informed Consent "buys in" to the treatment—its upside and its downside. Clinicians need it to proceed.



## Things to keep in mind (cont'd)

- Specialists tend to propose their treatments
  - Surgeons: surgery (e.g., mastectomy, prostatectomy)
  - Radiation oncologists: radiation therapy
  - Medical oncologists: drug therapy.
- Hospitals typically offer treatments that its clinicians know.
  - Clinicians rarely support treatments from elsewhere.
- Different centres have different ways of viewing the world.





Patients and physicians can put up barriers to the patient's optimal treatment. Examples:

- Patients:
  - reluctance to ask for a second opinion to not offend or anger the doctor and risk getting less care
  - projection that the doctor will interpret the request as a lack of trust or confidence
  - discomfort with questioning people in positions of authority.
- Physicians:
  - mindset that similarly educated/trained colleagues should have same conclusion.
  - discomfort and/or inexperience with someone without medical knowledge/training questioning their recommendations.

#### These notions are changing.



- A second opinion helps the patient with decision-making.
- It is an opportunity for the doctor to validate the diagnosis and proposed treatment option.

# **COVID 19 and Second Opinions**

- Doctors still give them even in COVID world!
- In system referrals may take longer resources stretched & backlogs
  - Also, US appointment lead time may be increasing as hospitals resume pre-covid activity levels.
- Telephone consultations now norm
  - Not the best if you need a physical assessment
- Zoom makes it easier to get a second opinion
  - A good way to have "face to face" contact
  - "zoom-type" meetings popular in US.
- Meetings still require records and images
  - Sometimes you can upload these.

# Why do I want a second opinion?

#### **Examples**



- Unsure about a diagnosis
  - Do you have a pathology report? Is it definitive? Do you understand it? Is there imaging to support a diagnosis?
- Unclear about how well a test or treatment may work
  - Has the doctor explained it? Have you done your own research?
- Need information about other treatment options
  - Did the doctor tell you how he/she arrived at the proposed option? Say what other options were considered? If options ruled out, why?
- Don't understand something
  - Have you asked your doctor to explain it?
- FEAR (of the treatment, dying, affect on family, affect on quality of life)
- Don't trust the doctor/don't like the bad news/looking for the answer I want to hear

#### **Communication Matters**

- A medical second opinion vs. a second conversation with your doctor.
  - Examples:
    - not resonating with my preferences and values
    - my family wants a second opinion
    - not able to afford an aspect of the treatment
    - how it will affect my family.
- Verbalize what you are seeking to answer, whether to your doctor, or a second opinion entity
  - Clarify your "ask" into specific questions.
- The conversation doesn't end when you say, "I'm getting a second opinion.
  - Check back in when have gathered the information and discuss.

# "Know Before You Go"

#### What is my:

- comfort level with being assertive?
- timeframe for making a decision?
- budget?
- available physical and mental energy/stamina?

#### <u>What:</u>

- do I want to know?
- kind of second opinion do I want?
- calibre of second opinion do I want?

#### <u> Who:</u>

• can help me?



Ask your doctor about the risks and consequences on your health status/treatability of delaying a treatment decision





You will have work to do.



- Honesty is the best policy --- don't blindside.
- When asking about second opinions be polite and respectful.
- Practice your conversation—your "ask" and why.
- Ask whether your case was presented to a tumour board or multi-discipline case conference.
- Perhaps ask your doctor for the name of another expert, someone <u>not</u> closely connected.
- Inform your GP they are a key partner throughout.
- Your GP can be a "sounding board" for the proposed diagnosis and treatment, eliminating or confirming the need for a second opinion.

"Ask" Broad Area	Potential Pathway	Opinion Cost (Approx.)
Pathology Report		
	Call the pathologist on your report	FOC
	<ul> <li>Ask your clinician/GP to find a pathologist who can give a second opinion</li> </ul>	FOC
	<ul> <li>Request the Chief of Pathology at the hospital to look at the report.</li> </ul>	FOC
<ul> <li>"weird pathologies/diagnositic difficulties"</li> </ul>	<ul> <li>Ask your clinician/GP to send a request to the National Institutes of Health Hematopathology Section.</li> </ul>	FOC
	<ul> <li>Request a Pathology second opinion consultation from MD Anderson Cancer Center, TX</li> </ul>	\$272 - \$3000 USD

"Ask" Broad Area	Potential Pathway	Opinion Cost (Approx.)
Radiology (Imaging)		
	<ul> <li>Ask your clinician/GP to find a radiologist who can give a second opinion</li> </ul>	FOC
	<ul> <li>Ask your clinician/GP for a second reading and opinion on CT/MRI scans from Second Radiology, TO</li> </ul>	FOC
	<ul> <li>Request an imaging second opinion report (CT, MRI, Nuclear, PET/CT, US, Xray) from Second Opinions</li> </ul>	A la carte from \$99 - \$299 USD
Hematology		
	<ul> <li>Request a hematology second opinion (written report or phone call) from Second Opinions</li> </ul>	A la carte from \$219 - \$599 USD

"Ask" Broad Area	Potential Pathway	Opinion Cost (Approx.)
Diagnosis/Treatment Recommendations		
	<ul> <li>Ask your specialist for a second opinion consultation with a specialist at Princess Margaret Hospital (TO)</li> </ul>	FOC + Travel & Accom. (if in person visit)
	<ul> <li>Request a second opinion consultation at Memorial Sloan Kettering Cancer Center (NYC)</li> </ul>	> \$4,000 USD + Travel & Accom.
	<ul> <li>Request a Remote Second Opinion (pathology review, radiology review and video or written consult) from Memorial Sloan Kettering Cancer Center (NYC). Available as package or a la carte.</li> </ul>	\$ 4,000 USD, +/- (\$ 2,750 USD for standalone written report)

"Ask" Broad Area	Potential Pathway	Opinion Cost (Approx.)
	<ul> <li>Request a remote second opinion with a written report and phone call from the UChicagoMedicine.</li> </ul>	Start at \$750 US (additional fees for cases requiring radiology or pathology review)
	<ul> <li>Request an in-person second opinion consultation at The Mayo Clinic in Rochester, MN</li> </ul>	<b>\$ 7,000 USD, +/-</b> (plus Travel & Accom.)
	<ul> <li>Request a virtual second opinion consultation at The Mayo Clinic</li> </ul>	\$500 – \$1,000 USD
	<ul> <li>Order an online written second opinion from Stanford Medicine.</li> </ul>	\$ 700 (USD) (additional fees (est.) \$500 USD if deemed necessary to consult with pathology/radiology experts)

"Ask" Broad Area	Potential Pathway	Opinion Cost (Approx.)
	<ul> <li>Speak directly with a licensed physician/oncology navigator to answer your questions and discuss possible treatment options or clinical trials from your phone, tablet or computer.</li> </ul>	\$50 for Initial assessment (may be covered by insurance). + Fees for consultations
	<ul> <li>Request an in-person second opinion with a full evaluation (diagnostic tests, bloodwood, pathology, consultation) over a 7 day period from MD Anderson Cancer Center, TX.</li> </ul>	\$50,100 (USD)

"Ask" Broad Area	Potential Pathway	Opinion Cost (Approx.)
	<ul> <li>Request a second opinion written report to confirm diagnosis and treatment options based on a review of medical records by a Canadian doctor from Medical Second Opinion.</li> </ul>	Must have insurance coverage from an MSO partner insurance company.
	<ul> <li>Get an Expert Medical Opinion on your condition with their analysis and recommendations from Best Doctors.</li> </ul>	Available to Sun Life clients enrolled in a Personal Health Insurance Plan.

### Considerations



- Advice without the responsibility of care for the patient
- Treatment recommendations that are not available in your area/country
- The US medical system: "options at all costs"
- The opining physician may never have met you
- Who is actually giving the opinion
- Opportunities for asking questions

### > What people/information sources do you trust?

### **Personal Experience**

Phase/Event	Concern/Ask		Second Opinion Action
2000 Pre-Diagnosis - Symptoms getting worse for 2 ½ years.	Bad and worsening symptoms. I need a diagnosis.	1.	Self-analyzed symptoms on Web MD => HD.
		2.	Re-requested a referral to a RA specialist.
April 2002 Post Chemo – CT Scan shows Suspected Relapse	Asymptomatic. Recommendation for High Dose Chemo & Stem Cell TP. Is the lymph node change a true relapse?	1.	Requested a PET scan to determine if anomaly is scar tissue
			Impression: increased uptake in the mediastinum suggestive of HD.
		2.	Requested a second opinion at Princess Margaret Hospital in TO.
			Recommendation: 1) Repeat CT scan; 2) if progression, get a biopsy to confirm; 3) SCT may be warranted if systemic; 4) consult with a radiologist on local therapy

### **Personal Experience**

Phase/Event	Concern/Ask	Second Opinion Action
		3. Self-referred for a second opinion at MSKC in NYC.
		Recommendation: 1) Agreed SCT is right option; 2) Repeat CT scan; 3) if progression, get a biopsy to confirm.
		<ol> <li>Requested referral to radiologist re: radiological therapy.</li> </ol>
		Recommendation: not a good option if systemic disease. Radx may affect efficacy of later SCT.
		5. Requested CT scan to check for disease progression. Impression: no sign of active disease

### **Personal Experience**

Phase/Event	Concern/Ask	Second Opinion Action
Mid-2004 CT scans and physical exam show lymph node enlargement	Asymptomatic Confirm that it is a disease recurrence	<ol> <li>Requested a lymph node biopsy to confirm HD.</li> <li>Impression: "Consistent with classical HD"</li> </ol>
		2. Called pathologist to discuss.
		Recommendation: send slides to NIH Hematopathology group for a second look.
		<ul> <li>3. Asked GP to send request to NIH for a review.</li> <li>&gt; Impression: Diagnosis of HD.</li> </ul>
July 2004		4. Requested a second opinion at PMH
		Recommendation: SCT indicated. Due to very slow progression, an option is to wait until symptomatic or nodes get larger.
Late August 2004	Significant blood clots in supraclavicular veins with left arm enlargement.	TIME FOR SCT!

Second opinions are very personal.

This is your life.



#### These are your decisions.

#### Thank you and stay safe!