

# Tips on getting the best care from your primary care provider

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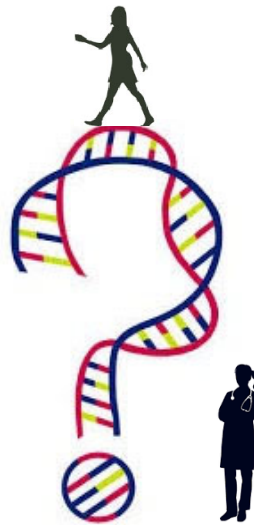
*8<sup>th</sup> Lynch Syndrome Education Night  
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Mount Sinai Hospital*



# Getting the best care from your primary care provider

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- General tips about working with your primary care provider
- What's unique about Lynch syndrome?
- How to handle some situations that may have happened to you

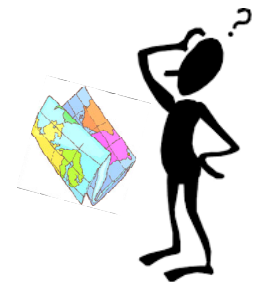


# General tips on getting the best care from your primary care provider

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## 1. Set an agenda

- Create a list of topics you want to address
- Introduce them at the start of the visit
- Prioritize
  - Ask the most important one first
- “I have some medical problems, fears or worries I’d like to discuss”
- Visit is only 10-15 min



# General tips on getting the best care from your primary care provider

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## 2. Be honest about your worries and concerns

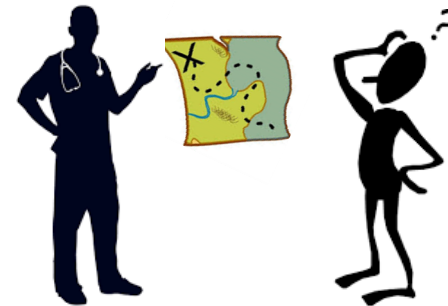
- Providing detailed information helps your primary care provider get the full picture of your overall well-being and factors that might contribute to your health
- Might include things about lifestyle, relationships at home or work
- It's okay to say "I'm not sure you really heard how concerned I am about this"
  - Gives your provider a chance to revisit the issue more deeply and/or explain their reason for reassuring you

# General tips on getting the best care from your primary care provider

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## 3. Ask questions

- Be sure you understand – repeat back, revisit the issue, ask them to draw a picture
- Write down information
- Consider bringing a friend or family member with you
- Learn how to access your medical records
- Remember that nurses and pharmacists and dieticians are also good sources of information



# General tips on getting the best care from your primary care provider

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## 4. Work together with your primary care provider

- Partner with your provider about investigations, treatments – for the best outcome
- Share your worries about side effects, ask questions about other options
- If you need more time to talk about something, tell your provider – perhaps see if you can schedule another appointment to continue your talk
- Go into the appointment expecting that your primary care provider is going to help you

# General tips on getting the best care from your primary care provider

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- Have a record of your health history
- Make a list of all your medications (strength, how often)
  - Include vitamins and supplements

***Bring them with you to every medical appointment***



# Lynch syndrome

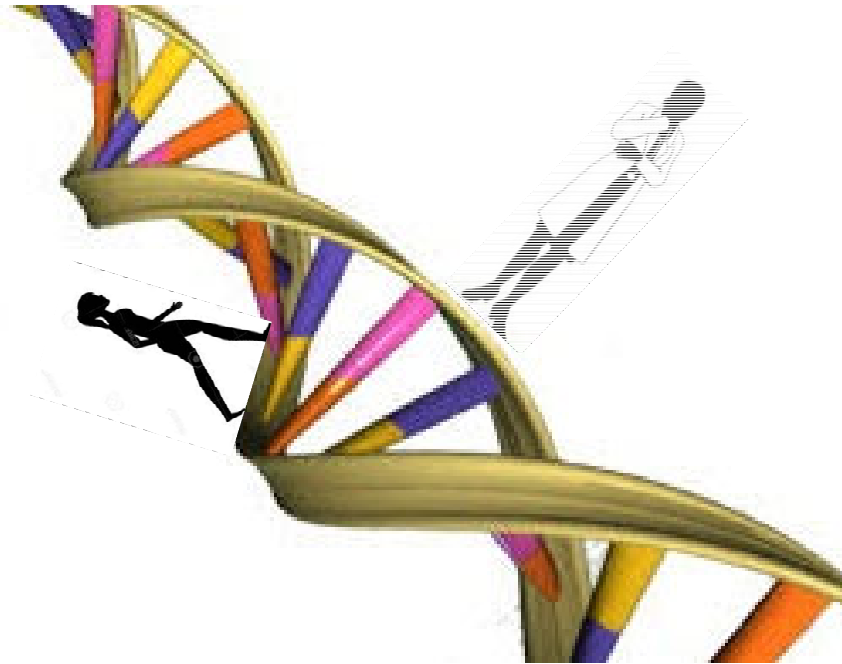
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- What's the same about Lynch Syndrome?
  - Primary care provider has a vital role
    - Making appropriate referrals to specialists
    - Coordinating care
    - Assisting you to obtain the support you need
    - Recommending other preventive care strategies (screening, immunization)
- What's different about Lynch Syndrome?
  - Rare
  - Many patients have spent many hours studying the medical literature
    - compelled to become experts



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# Scenarios you may have faced...



# Scenario 1: You'd like a screening urine test every 6 months – your primary care provider refuses

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- Primary care providers make decisions based on medical training, experience and knowledge/evidence
- May seem unfair/arbitrary

*What to do?*

- Come prepared with 20 pages of internet print out from patient groups advocating that you should insist your provider order this test
- Have a calm, informative discussion

**NOT RECOMMENDED**



# Screening recommendations

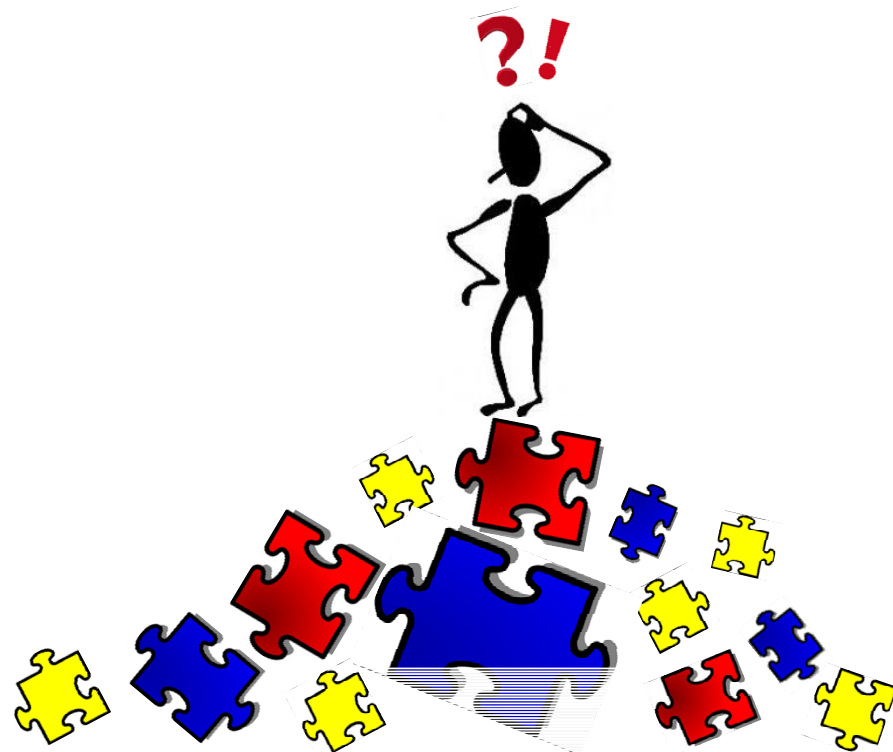
<b>Urinary tract cancers (renal pelvis, ureter, bladder)</b>	<b>For MSH2 positive families and those with familial clustering:</b>  <b>Consider: Non-invasive: Urine cytology and microhematuria or</b>  <b>Invasive: Cystoscopy - consult uro-oncologist</b>	<b>Annually</b> (using 2 separate samples)	<b>Begin at age 35</b> (or dependent on age of onset in the family)	<b>Evidence is lacking - balance of benefits and harms cannot be determined</b>
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## *Remember*

- More tests not always better
- One test can lead to another – anxiety, discomfort, infection, allergy
- Limited health care \$



## Scenario 2: You have a symptom that might be associated with LS but your provider says “it is nothing to worry about”

- Primary care providers may not have knowledge of Lynch Syndrome and its associated cancers

*What to do?*

- Book the test & reassure yourself

**NOT RECOMMENDED**

- You need to be an expert on your own condition ✓

- Have an informative discussion that certain cancers are associated with Lynch Syndrome ✓

- Express your worries and that you would like testing and/or referral ✓

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## *Remember*

- Most primary care providers want to help with your care




<b>Endometrium</b>	<p><b>Patient awareness of gyn. cancer symptoms so they can be investigated thoroughly</b></p> <p><b>Prophylactic TAH-BSO to be discussed after child-bearing is complete</b></p>			<b>Strongly recommended</b>
	<p><b>Pelvic and transvaginal ultrasound</b></p> <p><b>Endometrial biopsy</b></p>	<b>Annually</b>	<p><b>Begin at age 30-35 (or 10 years younger than any endometrial ca &lt; age 35 in the family)</b></p>	<b>Evidence is lacking, the balance of benefits and harms have not been determined (Offer in research setting)</b>

## Scenario 3: You'd like a second opinion – your primary care provider refuses

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- Physicians/Nurse Practitioners are gatekeepers – need a referral to see a specialist

*What to do?*

- Call the specialist you want and book an appointment
- Discuss your concerns 
- You feel your request is reasonable, why do they think a second opinion isn't necessary
- Have a dialogue – your provider may have good reasons

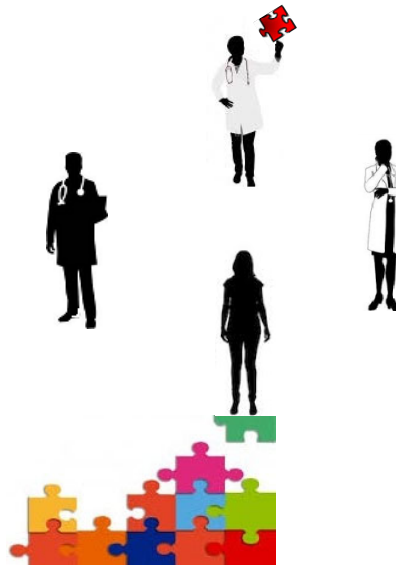
**NOT RECOMMENDED**



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## *Remember*

- If you reach a standoff – perhaps not the right primary care provider
- Consider:
  - Walk-in clinic
  - Health Care Connect (1-800-445-1822)



# Scenario 4: You'd like your provider's opinion about a complementary medicine you are taking to prevent cancer

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## Complementary and Alternative medicines

- a group of diverse medical and health care systems, practices and products that are not presently considered to be part of conventional medicine
- *Complementary*: if combined with traditional treatment
  - medication to enhance healing after surgery
- *Alternative*: if replacing traditional treatment
  - treating cancer rather than chemotherapy

## Scenario 4: You'd like your provider's opinion about a complementary medicine you are taking to prevent cancer

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*What to do?*

- Stop your treatment because of side effects and try an alternative medicine **REALLY NOT RECOMMENDED**
- Bring all the bottles of CAM you are taking and ask if they are safe/effective ✓
- Let your provider know you are thinking about a complementary treatment and want to be sure it won't interfere with your regular medications ✓

## Scenario 4: You'd like your provider's opinion about a complementary medicine you are taking to prevent cancer

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### *Remember*

- Your primary care provider will likely not be familiar with these medications; they may offer to look them up and get back to you
  - NCCIH web site <https://nccih.nih.gov/>
- Further considerations:
  - Talk to your pharmacist
    - dietary supplements can interact with other medicines
  - If you are considering CAM for side effects or symptoms, ask your provider if there are 'mainstream' medications that might work

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