LFSA ASK A GC WEBINAR SERIES: TALKING TO KIDS ABOUT LFS

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“My daughter is going to ask me why she has to have an MRI…”
“My son asked me why he has more doctor’s visits than his sister…”
“My daughter asked me if she is going to get cancer some day like me…”
“My son asked me if we got the results from his (genetic) test…”

“…What/how do I tell them?”
DISCLOSURE OF GENETIC RISK TO CHILDREN

Teenagers and young adults want parents to disclose at an early age

Parents want to disclose, but find it very challenging

Anxiety, guilt, fear, want to preserve “normal childhood”

Rowland & Metcalfe, 2013; Valdez et al., 2018; Patenaude & Schneider, 2017
DISCLOSURE OF GENETIC RISK TO CHILDREN

Benefits of disclosure

• Reduces parental and child anxiety
• Empowers autonomy for health needs, prepare for future
• Enhances coping strategies, emotional well being, adaptation, self-identity
• Increases understanding of family medical needs
• Increases family cohesion

Harms of non-disclosure

• Parents: increases anxiety, conflict
• Kids: misunderstanding, confusion, self blame, fear worse, lose trust in parent, later anger, frustration
• Weakens family cohesion

Rowland & Metcalfe, 2013; Valdez et al., 2018; Patenaude & Schneider, 2017
CONVERSATIONS ABOUT GENETIC RISK: MODEL FOR PARENTS

**Step 1:** Consider your own emotional reactions

**Step 2:** Make a Plan: Who, when, where
**CONVERSATIONS ABOUT GENETIC RISK: MODEL FOR PARENTS**

<table>
<thead>
<tr>
<th>Who</th>
<th>When</th>
<th>Where</th>
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</thead>
<tbody>
<tr>
<td>All sibs</td>
<td>• Begin early age, developmentally appropriate</td>
<td>• Family meeting</td>
</tr>
<tr>
<td>Avoids feelings of inferiority with sibs, distrust in parents</td>
<td>• Deliver gradually over time</td>
<td>• Car rides, shopping</td>
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<tr>
<td></td>
<td>• Less shocking, easier to handle</td>
<td></td>
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<tr>
<td></td>
<td>• Critical life junctures</td>
<td></td>
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<tr>
<td></td>
<td>• cancer diagnosis, screening</td>
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</tr>
<tr>
<td></td>
<td>• Genetics/health in school</td>
<td></td>
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<tr>
<td></td>
<td>• Child asks questions</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Unplanned, ongoing, empower to look for opportunities</td>
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</tbody>
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CONVERSATIONS ABOUT GENETIC RISK: MODEL FOR PARENTS

Step 1: Consider your own emotional reactions

Step 2: Make a Plan: Who, when, where

Step 3: “Answer What Is Asked”: Let child guide, open, honest

Step 4: Allow Space for child’s reaction, ask how feeling

Step 5: Open, honest, ongoing dialogue

Werner-Lin, Merrill, & Brandt, 2018; Rowland & Metcalfe, 2013; Patenaude & Schneider, 2017
Consider Own Emotional Reactions

“It’s tough for the parents too and to try and negotiate and make sure you're on the same page with things…”

Answer What Is Asked

“We've tried to be pretty open with the kids, though age appropriate, we don't want to scare them or tell them information that they really—we didn't think that they could handle.”

Allow Space for Child’s Reaction

“We've approached it to their level; they seem to go pretty well. They would usually listen pretty intently and then every once in a while, they'd have a few questions and we also found out some of their anxieties through the process.”

Ongoing Dialogue

“We've kinda made it an ongoing process so it wouldn't be a, you know, a shock at the end when they do get the information. So, we kinda tried to take a graduated approach where, you know, they get a little bit at a time.”
TIPS

● Draw from previous experiences
  ○ Other difficult conversations, build on what they already know

● Let your child(ren)’s questions and reactions guide you
  ○ Determine what they already know, what they want/need to know, what support they need

● Normalize
  ○ Relate/compare to other family members, ex: “From time to time you’ll get some additional tests that don’t hurt at all – similar to what dad gets.”
TIPS

● Frame the information in a positive way
  ○ “We’re doing the testing/taking you to a new doctor to keep you healthy”

● Take your time
  ○ May need to have multiple conversations/re-explain concepts

● Team approach with medical providers
  ○ Tell them your plan to communicate results/information, can ask them to avoid certain words/phrases, ask them to help explain or for advice to help you explain

<table>
<thead>
<tr>
<th>Preschool (~2-4y)</th>
<th>Information/Language</th>
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</thead>
<tbody>
<tr>
<td>Magical Thinking</td>
<td>Minimal information</td>
</tr>
<tr>
<td>Play and fantasy</td>
<td>Use books/pictures</td>
</tr>
<tr>
<td>Concrete physical information</td>
<td>Simple concepts</td>
</tr>
<tr>
<td>No abstract thinking</td>
<td>“You’re not sick, we go to doctors when we are healthy, doctors are giving Mommy medicine to feel better”</td>
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<tr>
<td></td>
<td>“Do you look like Mom or Dad?”</td>
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<td></td>
<td>“Can you curl your tongue?”</td>
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Cherry, 2014; Werner-Lin, Merrill, & Brandt, 2018; Brand, Schienda, & Kamihara
**Elementary School (~5-10y)**

- Thinking more logically, but can be rigid
- Begin to think abstractly, hypothetically
- Learn through visual clues

**Information/Language**

**Simple genetics concepts**

- **Genes**: “Instructions that tell our bodies how to grow. Your hair color, eye color.” “Genes are like words, made of 100's DNA letters.”
- **Inheritance**: “Do you look like Mom or Dad? A little of both? In what ways?”
  - “Why do you think that is? You get half your genes from your Mom and half from your Dad.”
- **Purpose of testing**: “To keep you healthy.”
- **If asked about cancer**: “Cancer is a sickness. It is not contagious, doctors give medicine to treat cancer.”

Cherry, 2014; Werner-Lin, Merrill, & Brandt, 2018; Brand, Schienda, & Kamihara
Middle School (~11-13y)

- Majority concrete thinking
- Begin abstract thinking
- Reasoning and deduction
- Able to assent to genetic testing

Information/Language

More complex genetics concepts, building upon earlier concepts

Genes: “Can have a spelling mistake called a mutation. It prevents the gene from working correctly. Genetic testing is like a spell check machine, looking for misspellings in the gene.”

Inheritance: “You have a 50% chance to have the same mutation as your Mom. And a 50% chance you won’t. It’s like flipping a coin.”

Interpretation: “If you have the same mutation, it does not mean you have cancer. It does not mean you will get cancer. (Use family member as example. It is different for everyone, Grandpa has the mutation but never had cancer.) Your chance to get cancer is very very low right now.”

Cherry, 2014; Werner-Lin, Merrill, & Brandt, 2018; Brand, Schienda, & Kamihara
High School (~14-18y)

Increase in logic, deductive reasoning
Abstract thinking
Genetic concepts may be taught in school
Identity formation
Independence from parents

Information/Language

Complex Genetic Concepts
Can describe cancer risk and management in more detail
Ask about their thoughts on pros/cons testing
Ask to imagine how they might feel if test comes back positive
Doesn’t change who they are, goals, dreams, etc.

Cherry, 2014; Werner-Lin, Merrill, & Brandt, 2018; Brand, Schienda, & Kamihara
“Right now, we left it open if he has any questions to ask, go right ahead. We also promote when he goes to Doctor, if at any point he has any questions to ask them.”

“Definitely when they get to be teenage, which is around the corner with my son... preparing them for their adult lives, when this is something they're gonna have to take care of.”
CAN MY CHILD JUST HAVE A BLOOD DRAW?

Yea?

• Don’t want to worry child
• Respects parental autonomy
• Testing benefit outweighs risks of nondisclosure
• In certain circumstances? Age dependent?
• Only if parents absolutely won’t disclose?

Nay?

• Assent necessary
• Risk trust relationships with providers/parents
• Transparency, respecting child as a person
• Worry that parents won’t share results with child
• Child worried anyway?
• Parents underestimate child’s maturity to make decisions
• Disclosure improves compliance with tx plan
• No distress with testing, anxiety relieved with communication

Bester et al., 2018
There are ways to talk about LFS & cancer with children of all ages. There is no one right way or time. You know your child best.

Provide information and emotional support to the developmental age level of the child.

Conversations with children:
- Open
- Honest
- Ongoing
"We've taken the power in our own hands.

We're going all the time to get you tested,

to make sure as soon as the day comes...

we'll know and we'll do what we need to do."


