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



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QUOTE OR QUESTION FROM PATIENT/PARENT

“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”

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

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

Who

- All sibs
- Avoids feelings of inferiority with sibs, distrust in parents

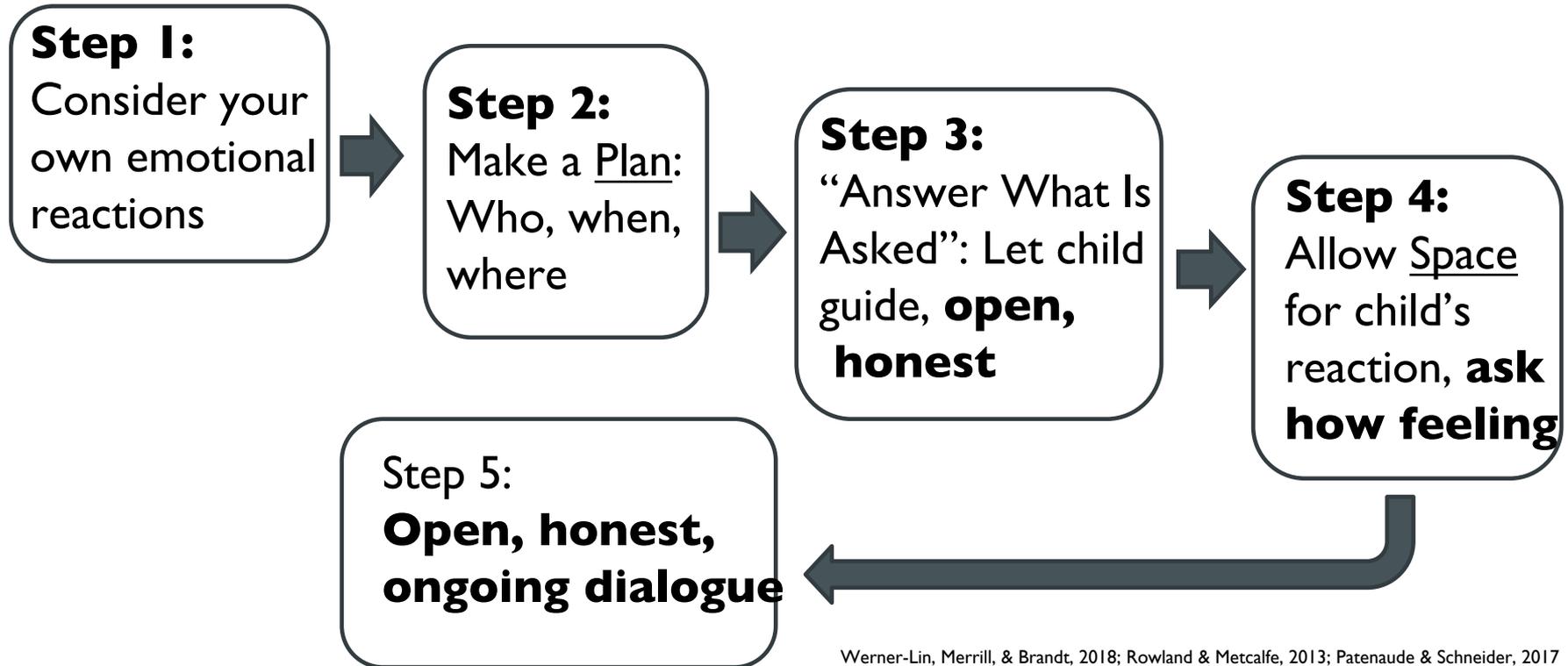
When

- Begin early age, developmentally appropriate
- Deliver gradually over time
 - Less shocking, easier to handle
- Critical life junctures
 - cancer diagnosis, screening
- Genetics/health in school
- Child asks questions
- Unplanned, ongoing, empower to look for opportunities

Where

- Family meeting
- Car rides, shopping

CONVERSATIONS ABOUT GENETIC RISK: MODEL FOR PARENTS



EXAMPLES FROM LFS FAMILIES (VALDEZ ET AL. 2018)

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..."

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."

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."

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

CHILD COGNITIVE DEVELOPMENT AND GENETICS

LANGUAGE

Preschool (~2-4y)

Magical Thinking

Play and fantasy

Concrete physical information

No abstract thinking

Information/Language

Minimal information

Use books/pictures

Simple concepts

“You’re not sick, we go to doctors when we are healthy, doctors are giving Mommy medicine to feel better”

“Do you look like Mom or Dad?”

“Can you curl your tongue?”

CHILD COGNITIVE DEVELOPMENT AND GENETICS

LANGUAGE

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.”

CHILD COGNITIVE DEVELOPMENT AND GENETICS

LANGUAGE

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.”

CHILD COGNITIVE DEVELOPMENT AND GENETICS

LANGUAGE

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.

EXAMPLE FROM LFS FAMILY – ENCOURAGING INDEPENDENCE

“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

TAKE AWAY

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

EXAMPLE FROM LFS FAMILY (VALDEZ ET AL. 2018)

“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.”

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