MRKH & Friends: The Journey of Disclosure with MRKH

October 4th, 2020

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GLOBAL MRKH

SUMAAVI

MRKH & Friends: The Journey of Disclosure with MRKH

Sunday, October 4, 2020
1:45 pm to 4:30 pm

Time (EDT)	Session
1:30	Participants login to waiting room
1:45	Waiting room opens
2:00	**Welcome** — Amy C. Lossie, PhD and Christina Ruth Martin, co-founders Beautiful You MRKH Foundation
2:05	**Agenda** — Erinn C. Webb, MA, RDT, Emcee
2:10	**Who's at the Table?** — Erinn C. Webb and Susan Carroll, PhD
2:35	**Rima's MRKH Mockumentary** — Rima Zigaitis and Friends
2:45	**Disclosure: More than One Perspective (AKA Badia's Bubbles)** — Badia Atcherson and Erinn C. Webb
3:15	**Sharing our Stories** — Erinn C. Webb
3:30	**Five Facets of Disclosure** — Sunni Anne Ball
4:00	**Wrap up** — Amy C. Lossie
4:10	After Hours Hangout with the Presenters
4:30	Adjourn

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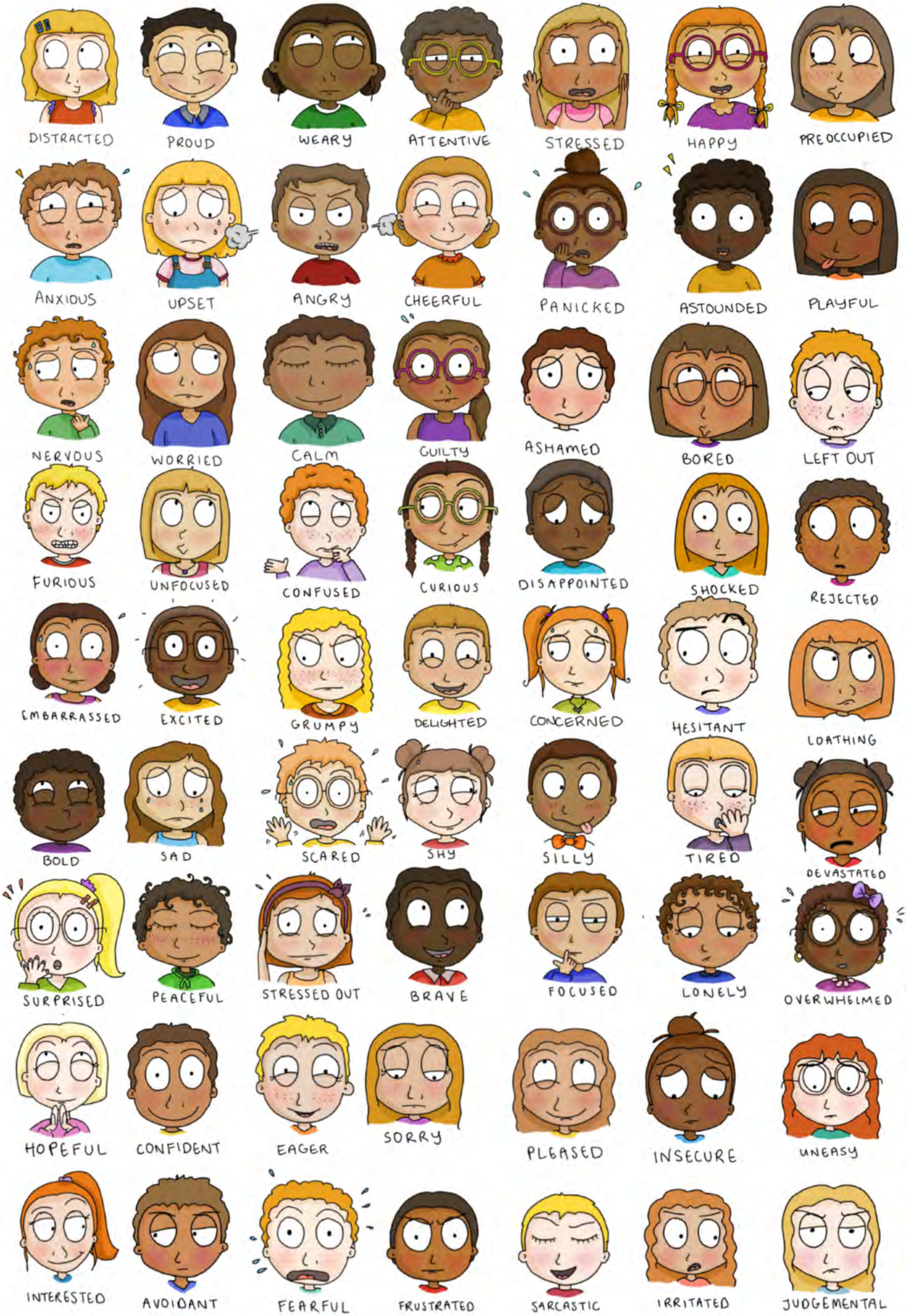
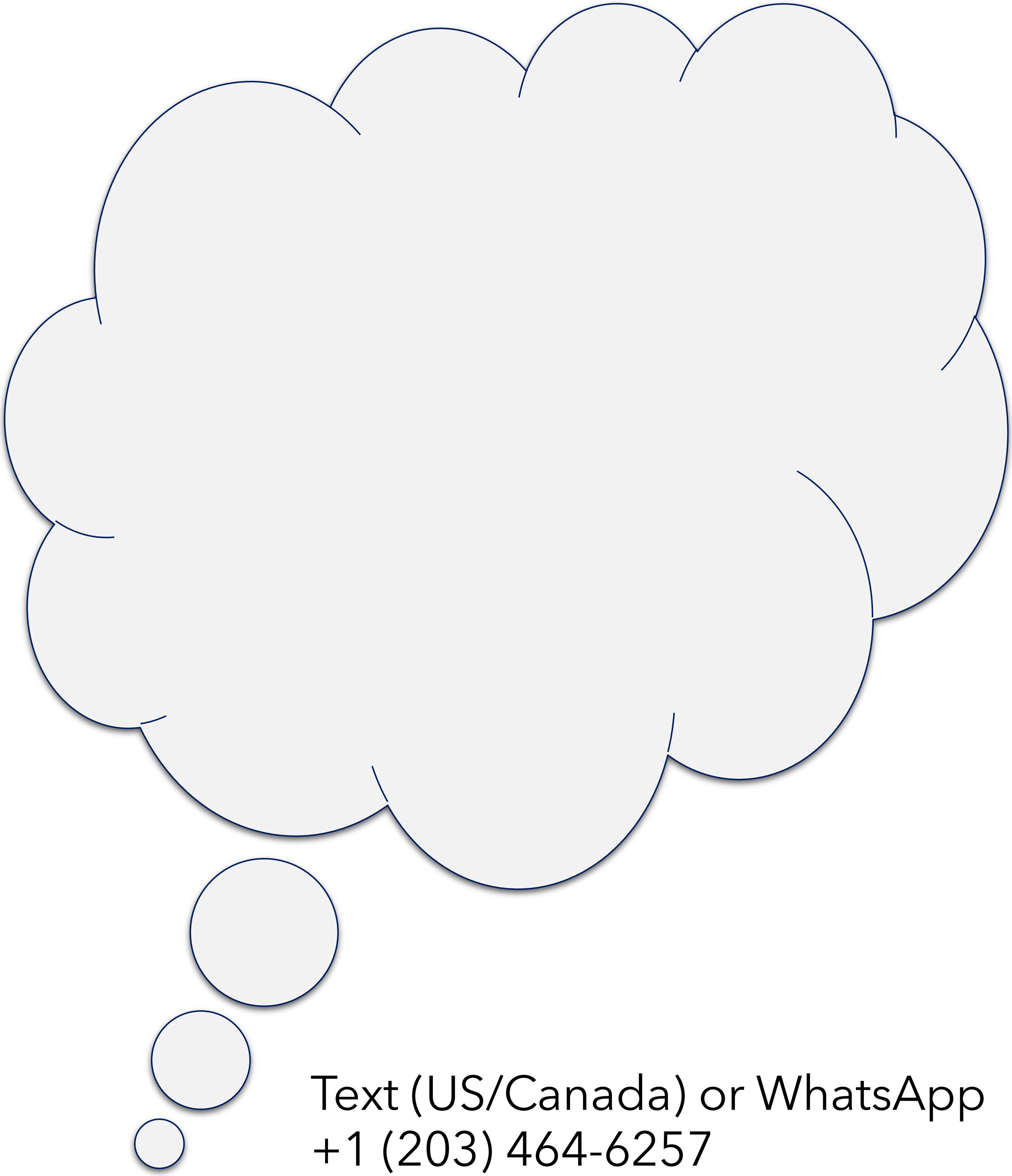


THE JOURNEY TO WELLNESS JUMBO FEELINGS CHART - @journey_to_wellness_

What part of YOU is at the table right now?



Text (US/Canada) or WhatsApp
+1 (203) 464-6257

What worry do you have about you or someone close to you disclosing MRKH?

What do you want to tell that worry from another part of you? What do you want to say to yourself about that worry?

Transitioning to Adult Gynecology Care

A Guide For Young Women With MRKH

Boston Children's Hospital
Until every child is well

Center for Young Women's Health
Division of Gynecology

Talking to Your Partner About MRKH

Most young women with MRKH will at some point find themselves faced with the decision of whether, when, and how to tell a romantic partner about their MRKH. The decision to tell your partner about your diagnosis is entirely your own, and there is no set rule which fits for all women, in all circumstances. Sharing anything intimate with a partner should be based on trust, communication, caring, and the possibility of a future together, but not all romantic and sexual encounters will have all of these components. It is up to you to use your good judgment to determine whether this is the right thing to do, and when.

To tell or not to tell?

Whether or not you tell your partner will depend on a number of factors. First and foremost, it is important that your partner can be trusted with your personal information and has demonstrated that he or she is generally supportive of you on an emotional level. Sharing this information may cause you to feel vulnerable and you'll want to know that your partner will be respectful of your feelings. If you are in a relationship with someone with whom you may consider raising a child with in the future, you might choose to have a conversation sooner rather than later about your MRKH so that you can talk about your fertility options. Finally, if you and your partner are considering a sexual relationship, and you have not chosen to create a vagina yet (either with dilation or surgery), it will be important for your partner to be aware of your anatomy so that he or she does not accidentally cause you pain or discomfort. If you have created a vagina, remember that your partner will not feel anything different, so you will have the choice whether or not to discuss your diagnosis.

When is the right time?

While there is no right or wrong time to have this conversation, you may want to consider the level of trust and intimacy that you and your partner have developed before deciding to share your diagnosis. Some women may choose to share this information early on in a relationship because it feels too difficult to keep it to themselves, while other women may choose to wait months or even years before they feel ready to share this very personal information. Only you can decide when you feel comfortable telling your partner about your MRKH, and you are the best judge of when your partner is ready to hear it. As much as your MRKH impacts you, it will also be important to recognize that it will impact your partner too, and they may need some time to adjust to what you have told them. They also may have a lot of questions about what you have shared, so consider telling them at a time when you feel you are ready to answer any questions that may come up.

How do I do it?

Again, the best way to share this information with your partner depends on you and your level of comfort. Some women may choose to share everything about their MRKH right up front, while others may choose to gradually disclose more information over time. For example, if you haven't created a vagina via dilation or surgery, you may wish to tell your partner that you were born with an incomplete vagina early on but then wait before you discuss the impact of your diagnosis on your future fertility. Alternatively, some women may feel more comfortable sharing that they have an absent uterus but wish to wait before telling their partner that they were born with an incomplete vagina. Keep in mind that if you have not had treatment, a sexual partner may need to know this information to avoid unintentionally causing you pain. If you think it would be helpful, you might consider printing information about MRKH (from our website www.youngwomenshealth.org) for your partner to read.

Finally, remember that you are not alone in this. It can be extremely helpful to talk with other women who have MRKH to hear about when and how they have had similar conversations with their partners. Your health care team is also available to answer any questions you might have or help you talk through your decision. In the end, the most important aspect of this decision is that you feel comfortable and confident having this conversation with your partner. Keep in mind that sexuality is only one part of a well-rounded and healthy relationship, and sharing this information with your partner can lead to a richer, deeper, and more intimate connection where you both can be open to talking about your feelings, desires, and needs. Your partner will likely feel honored that you trusted them enough to share this information, and you will probably breathe a sigh of relief at no longer feeling like this is something you have to keep secret.

What if it doesn't go well?

While these guidelines can help make the process of sharing your diagnosis with a partner go more smoothly, it can be difficult to predict how this conversation will unfold. There may be some situations where, despite your best efforts, the discussion does not go as planned. Remember that your partner's initial reaction is coming from a place of surprise and maybe even shock, and the feelings and thoughts they express right away may not be the same as those they experience after they've had some time to process the information. After all, you have had time to prepare exactly what you want to say to your partner but they have not had any time to prepare their response, so it's important to give them some time and space to take in what you've shared with them and organize their thoughts about it. It takes a certain level of maturity for an adult to understand and process medical information. Unfortunately you may come in contact with some people who are judgmental or have not had experience dealing with medical issues and therefore their reaction may not be supportive or fair. If you find that your partner makes you feel bad or is not able to be supportive of you and your MRKH, know that you are worthy of far more than what that partner has to offer. You deserve to be with a partner who loves you and accepts you for who you are in every respect and you WILL find that person. In the meantime, you have access to a community of women who share your diagnosis and who will be there for you as you process feelings about MRKH at different points in your life.

Getting Through an MRKH Diagnosis: *Starting the Conversation*

For Parents - Take a breath; decisions can wait.

How can you foster an environment that gives your child or the child you care for some control of their diagnosis? What have other parents and caregivers done? How can I find that information?

One example from a remarkable Dad is that he lets his child control who knows about the diagnosis. He comes from a large family and no one outside of his wife knows because his child does not want their grandparents, aunts and uncles to know.

Your Ideas:

STARTING A CONVERSATION

Consider the questions listed below:

1. **How can you start a conversation with your child?**
   One example is to use this as a way to start the conversation. Sometimes, those who are affected with MRKH are not comfortable talking about MRKH with their parents, but they are much more comfortable writing down their thoughts and feelings.

2. **Have you asked them what they want?**

3. Have you tried multiple methods—writing, in person, different days?
   What may lead to a slammed door one day may be met with a willingness to talk on another day. Keep trying, even when met with anger. Let them know that your door is always open. Let them know that you love them, no matter what. Anger directed at you is typical. Try not to show anger towards any emotion that they show or fail to show you. It's difficult to put an expectation on how exactly to navigate this sensitive and transformative time in their life. Also, this may take time—weeks, months. It may not be something they are ready to discuss. Remember, this diagnosis is traumatic for both of you, but it is important to remember to focus on what they are feeling during these discussions. What is their time frame for discussion?

4. Do you want to broach the subject weekly? Bi-weekly? Monthly? What works for you?

5. What are your fears?

6. What do you need help with as your navigate this with your family?

7. If you are married or have a partner, what do you need from them?

8. How can they help?

9. Can you identify a safe place to ask questions and get the help you need?

Other thoughts:

Getting Through an MRKH Diagnosis: Starting the Conversation

FOR THOSE DIAGNOSED WITH MRKH:

Take the time you need. You do not need to make a decision right now. Expect to be angry, sad, shocked, depressed, confused.

1. **What are your thoughts, feelings about MRKH? Do you want to share this information with your parents? Why or why not?**

   Write them down; whatever they are
   Are you angry? Sad? Feeling isolated or alone? Happy? In shock? Feel that you lack control of your body? Depressed? Withdrawn? Do you want to lash out at anyone? Who? Why?

2. **Who do you want to know about MRKH?**
   - Siblings and/or step-siblings
   - Your friends
   - Aunts and Uncles
   - Grandparents
   - Your parent's friends
   - Clergy/pastors

   It's perfectly acceptable to say no to all or to say yes to some and no to others. This should be your decision, and if you let your parents know your thoughts, feelings and decisions, they can best represent your wishes.

3. What decisions do you think you should be able to make?

4. What decisions do you want input from your parents?

5. What do you think you need to help you through this diagnosis?

Full Privacy to Full Disclosure

Disclosing your MRKH diagnosis is a personal decision. How, when, or why you disclose your MRKH diagnosis to someone depends on so many factors. It may depend on where you are in your MRKH journey, how you feel about disclosing, the situation you are currently in, who you are talking to, your background, and so much more. There is no 'right way' or 'wrong way' to tell someone about your MRKH diagnosis. In fact, you don't have to tell anyone at all.

Remember: It is your decision. Only disclose the information you are comfortable sharing and when the time is right for you.

Directions: How to Prepare for Possible Situations and Responses that are Right for You

- Review a few sample responses below.
- Then use the worksheet at the end to help prepare yourself for various situations.

Situation	Full Privacy	Moderate Privacy	Full Disclosure
Do you have a tampon or sanitary pad that I can use?	No, I don't. I'm sorry.	No, I'm not on my period right now. No, but I bet [*insert name*] does. Yes, I do. Here you go. (Some MRKHers have choose to carry such items.)	No, I don't. I don't have periods. I don't have a uterus, so I don't get periods.
What kind of birth control or protection do you use? Are you on the pill?	Let's talk about that later. I have to go right now. I'm not comfortable talking about that. I'd rather not talk about that.	No, I'm not on the pill. I'm not ready to be intimate with anyone right now. I'm waiting until marriage to be intimate or have sex.	I don't use birth control because I can't get pregnant. I do use condoms to prevent to prevent sexually transmitted infections (STIs).

		I think condoms are an appropriate birth control. I always use a condom and/or dental Dam to prevent sexually transmitted infections (STIs).	I have MRKH so that means I don't have a uterus and I can't get pregnant. So I don't use birth control.
When are you going to have a baby?	I'm not comfortable with this conversation. I'm not having this conversation right now. That's private. That can be a really hurtful question. I didn't know you were so interested in my sex life.	I/we haven't decided whether we want children or not. I'm not/we're not ready. It's not the right time for me/us right now. It's complicated. Whenever God decides it's time for me/us. When I decide, I'll be sure to let you know.	I don't want to have children. I am/we are currently [*fill in the blank with what you are actually doing*] Explain what MRKH and what your options are to be a parent if that is what you wish.

Things to Consider in Different Situations

Baby Showers and Pregnancy announcements:

- Baby showers and pregnancy announcements can often be difficult or painful
- It's okay to decline the invitation and not attend.
- It's okay to be happy and sad at the same time. And then to take time to be alone.
- Attend but don't participate in the games "I'll let someone else win the prizes."
- Send a gift, but don't attend the actual event.
- Focus on the celebration and love you have for the other person.

- Remember this day is not about you. It's difficult to hold two conflicting emotions so by focusing on the positive emotions for the other person, it will help you step away from your sadness.

Parenthood/Motherhood/Fertility Options:

- Not being considerate of other people's situations (Note: This can happen within MRKH communities, too)
    - Remember not everyone has the same family goals as you.
    - There will be awkward questions and moments, even within our community.
- Talking about your children too much
    - This is sometimes a problem within the community, forgetting about other’s situations during our own happiness.
    - Judging other people's choices in fertility, parenthood, etc.
- Personal choice in what is right for you and or for available for you:
    - Uterine transplant
    - Gestational Carrier
    - Adoption
    - No children by choice

Getting Through an MRKH Disclosure: Your Response Toolkit

Going to the Doctor

Response Examples for Disclosure with Various Healthcare Professionals

Remember: Remember not every healthcare professional needs to know about your MRKH diagnosis. Use your own judgement and consider if any procedures will be performed.

Question you may be asked by many healthcare professionals:

- When was your last period?
- Could you be pregnant?

Type of Doctor or Healthcare Professional	Full Privacy	Moderate Privacy	Full Disclosure
Primary Care Physician	Can you tell me why you need to know that? You don't really need to know that information for my treatment today.	I'd be happy to write that down on the chart/form for you. I'll only talk about that with my doctor. I'm happy to tell my nurse. Please make a note in my file or chart so I don't have to answer this every time.	I have Mullerian Agenesis (Note: Medical professionals are likely to understand this terminology more so than MRKH). Its ICD Code Q51.0. Please look it up. (This code is likely only valid in the States.)
Dentist	You don't really need to know that information for my treatment today.	I've had a hysterectomy.	I have Mullerian Agenesis. Its ICD Code Q51.0. Please look it up.
Psychologist/Therapist	Unless you are seeing a mental health professional in part because of an MRKH diagnosis there is no reason to disclose.	Again, unless it directly pertains to your treatment/therapy there is no reason to disclose.	I have Mullerian Agenesis, (you may have to explain what this is to your psychologist or therapist).

		If topic of family preparation/building comes up consider the following response: I/we haven't decided whether I/we want children or not. I am not/we're not ready. It's not the right time for me/us right now. It's complicated. Whenever God decides for me/us.	Upon sharing you may be asked how you feel about your MRKH diagnosis. Also, how you have dealt with the diagnosis overall. Be prepared to discuss the topic. If you are uncomfortable at any point, remember you con revert to full privacy.
Chiropractor	There is practically no reason a chiropractor would need to know about your MRKH diagnosis I don't get them.	I'll only talk about that with my doctor. Can you tell me why you need to know that? You don't really need to know that information for my treatment today. Is that necessary information for my treatment today?	Its ICD Code Q51.0. Please look it up. (This code may only work for the States.) I have Mullerian Agenesis (Note: Medical professionals are likely to understand this terminology more so than MRKH).
Emergency Room/Walk-in Clinic	I don't get them.	I'll only talk about that with my doctor. Can you tell me why you need to know that? You don't really need to know	Its ICD Code Q51.0. Please look it up. (This code may only work for the States.) I have Mullerian Agenesis (Note:

		that information for my treatment today. Is that necessary information for my treatment today? I'm happy to talk to my nurse about that.	Medical professionals are likely to understand this than MRKH).

Your Personal Response Worksheet

Ask yourself, "What would I say?" Thinking through the situations in advance is one helpful way to prepare for each situation. Consider how you would answer if you were maintaining full privacy, moderate privacy, or ready for full disclosure.

Directions: Use the space below to write down your own responses.

1) Do you have a tampon or sanitary pad I can use?

Full Privacy	Moderate Privacy	Full Disclosure
Write your responses here		

2) What kind of birth control or protection do you use? Are you on the pill?

Full Privacy	Moderate Privacy	Full Disclosure
Write your responses here		

3) Are you trying to get pregnant or when are you going to have a baby?

Full Privacy	Moderate Privacy	Full Disclosure
Write your responses here		

4) Baby Showers

Full Privacy	Moderate Privacy	Full Disclosure

Getting Through an MRKH Disclosure: Your Response Toolkit

Write your responses here		

Getting Through an MRKH Disclosure: Your Response Toolkit

5) At the doctor's office:

Primary Care Physician asks, "When was your last period? Is there a possibility you are pregnant?"

Full Privacy	Moderate Privacy	Full Disclosure
Write your responses here		

6) Chiropractor

Full Privacy	Moderate Privacy	Full Disclosure
Write your responses here		

7) Psychologist/Therapist

Full Privacy	Moderate Privacy	Full Disclosure
Write your responses here		

8) Dentist

Full Privacy	Moderate Privacy	Full Disclosure
Write your responses here		

9) Other situations; ____________________

Full Privacy	Moderate Privacy	Full Disclosure

Getting Through an MRKH Disclosure: Your Response Toolkit

Write your responses here		

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Beautiful You MRKH Foundation, Inc.

Beautiful, just as you are

Creating a supportive community that partners with health care professionals to empower all people with MRKH to feel beautiful, just as they are

What is MRKH?

Mayer-Rokitansky-Küster-Hauser (MRKH) Syndrome is a congenital condition characterized by under-development of the female - bodied reproductive tract, with a prevalence of 1 in 5000.

Typically, people born with MRKH have functional ovaries and develop breasts and other secondary sex characteristics. The majority find out they have MRKH due to a lack of a period.

MRKH Type I affects the Müllerian tissues (fallopian tubes, uterus, cervix, upper portion of the vaginal canal, and). In some, the uterus develops an endometrial lining that grows during their hormonal cycles. This can be painful and lead to endometriosis.

MRKH Type II/MURCS can affect kidney, heart, ear, and vertebral systems. Some have heart defects and hearing loss.

Klippel-Feil & Ehlers-Danlos Syndromes are also seen in people with MRKH. These musculoskeletal syndromes can be accompanied by distinct facial and skeletal features, connective tissue problems, and pain.

Mental Health and Wellbeing

MRKH can be a difficult diagnosis. People often experience shock, feelings of loneliness, and isolation. It is common to question gender identity and to have feelings of anger and sadness.

People often seek mental health care when their friends start building families. This can be an isolating and lonely time for people with MRKH. Many have found mental health care to be an important part of their healing process.

Sexualiy

Many have a shortened vagina that can lead to painful attempts at intercourse. The choice to or not to lengthen the vagina is a personal one that is best decided by the person who has MRKH. Some choose to create a vaginal canal shortly after diagnosis; some wait until they are much older; and some choose to not undergo any treatment.

Dilation is recommended as a low-risk, first line of treatment by the American College of Gynecology. The person with MRKH gradually stretches the lower portion of the vaginal canal using plastic or silicone dilators. This should be done under the care of a physician, who can teach the individual optimal methods and techniques.

There are multiple surgical methods that can be used to create a vagina, and there is no consensus on what method is best. Each surgeon typically focuses on one type of surgery, and most must dilate after surgery to avoid complications.

Family Building

The options to build a family vary depending on where you live, your religious and cultural values, and your personal preferences. As people with MRKH typically have functional ovaries, it is possible to have biological children through in vitro fertilization using a gestational carrier or a uterus transplant. Many have chosen to adopt or foster adopt. Some create a savings account to help with these costs.

Living Your Best Life

Accepting MRKH is often a grieving process. It's rarely linear, and MRKH can pop up in your head when you least expect it, even when you thought you've accepted it. There are many in the MRKH Community who lead happy and fulfilling lives – with and without children. We wouldn't trade MRKH for anything.

Visit us at:

www.beautifulyoumrkh.org
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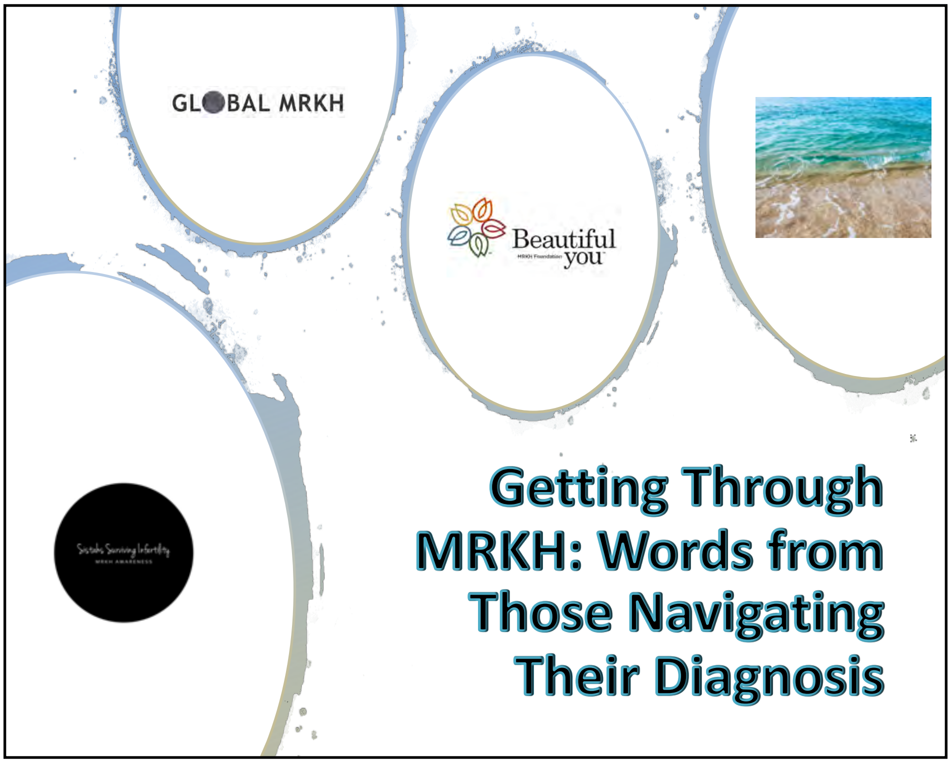

Getting Through MRKH: Words from Those Navigating Their Diagnosis

MRKH Perspectives

The following are the experiences and struggles that others diagnosed with MRKH have gone through. Remember throughout this journey of diagnosis and disclosure you are not alone.

MRKH Perspectives

I would add the cost of surrogacy and or adoption. We normally do not have families who save funds or do not have the ability to get bank loans of large amounts needed to embark on a journey to having a child. I think just like educating parents to save for a college fund, finding out your daughter has mrkh parents should start an off fund to help once the child is older and decides on a path for them.

Lack of support, emotionally and financially is huge in our community

In the black communities, we are afraid to speak about MRKH. People having babies has caused us to keep our feelings and thoughts to ourselves. Let us face it, the black community deal with a lot of teenage pregnancy. People are surprised when they meet someone over 23, with no children

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MRKH Perspectives

RUSSIAN

MRKH related. Anonymous please. Answer. My culture/ethnicity (Russian culture). People start to raise questions as to why you're not pregnant by like 25 or married and not pregnant. Infertility = you're not a woman. Also means, you failed at your most basic function as a human being on this planet. Out of any of my russian friends/family only my mom and grandmother know. Out of the American friends/family, all of my in-laws know and few close friends. I don't think I could ever come out about it for the fear that my mom and grandmother will feel ashamed/ embarrassed, even if I am personally ready, even if this is MY decision and MY body. Culturally, I cannot let my family feel embarrassed for me

Hi friend. Thank you so much for sharing this with us. I will keep you anonymous. 💛💛💛 sending you love.

ECUADORIAN

condition. I told him everything. From me not getting my periods to explain the little scars on my pelvis.

He accepted me the way I am. And we are committed to each other in a serious relationship. We plan on starting the IVF journey next year. And I am not afraid to share my experiences with MRKH (if it is brought up). However, I haven't fully opened up to some family members like my grandparents or uncles cousins because I am not ready yet. I'm not sure how they will react and I don't want to cause stress on my grandparents. They are old school and this might be too much for them to cope with. My mom, dad and brothers know about my journey with MRKH and they are my best support system. When my family makes comments about my future kids/ family like "You will be a great mom" or "Nicole is next in line to give grandchildren" (Ecuadorian sayings) it gets to me. But I do respond back with comments like those and say "If it is God's will then let it be"

I am comfortable with sharing my name 👍

SRI LANKAN

embarrassing and can be alienating since it's so hard to talk about this with normal girls or even family and friends. Either it's weird or they take pity, both of which really suck. But what can you really expect? Then it's the fact that in my culture I have to keep it a secret, because only the cursed or only had people can't have children. It's like a punishment from God, and bad luck for any family she'll marry into. So I personally had to keep it a secret for so many years and it was so painful. Then when I told friends they'd tell me I was so lucky that I didn't have to worry about periods or painful pregnancies . Or brush it off saying you have so many options now, nothing to worry about. The feeling of not being understood is painful.

Then having to tell your significant other of this whole lack of "womanhood" and feeling sad and guilty - at least I did - but it's because I felt like it was one of those basic requirements for marriage and without it I was depriving the relationship of a basic joy. There are too many emotional battles in this. Often times I feel like people can't understand how all of it feels and

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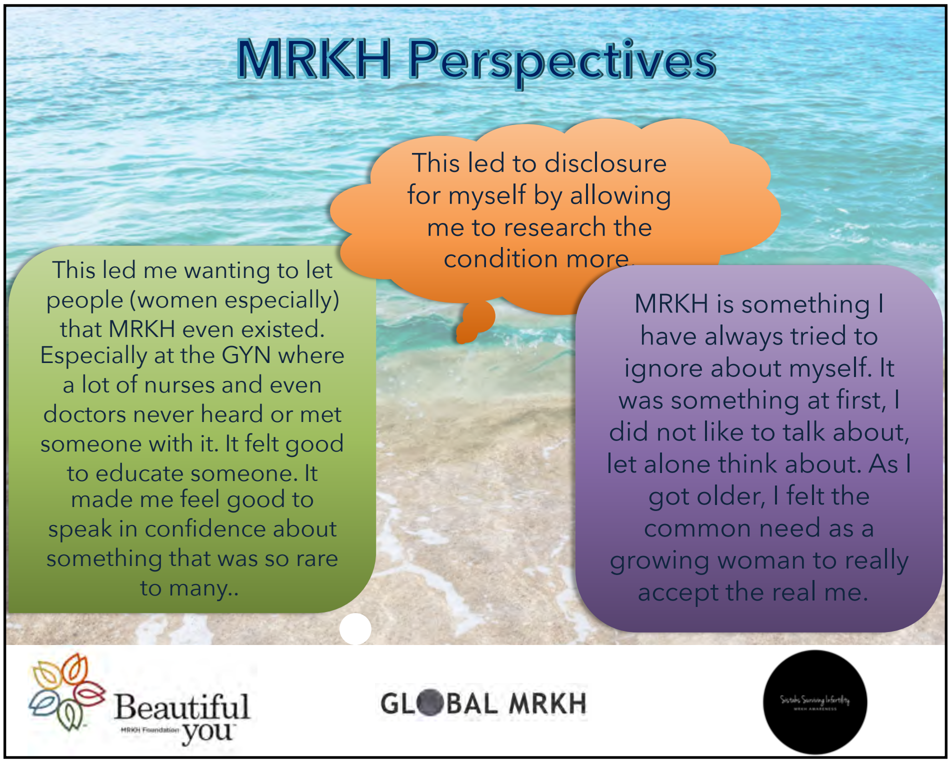

MRKH Perspectives

This led to disclosure for myself by allowing me to research the condition more

This led me wanting to let people (women especially) that MRKH even existed. Especially at the GYN where a lot of nurses and even doctors never heard or met someone with it. It felt good to educate someone. It made me feel good to speak in confidence about something that was so rare to many..

MRKH is something I have always tried to ignore about myself. It was something at first, I did not like to talk about, let alone think about. As I got older, I felt the common need as a growing woman to really accept the real me.

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MRKH Perspectives

CANADIAN

Hi Jaclyn! I was diagnosed at 14 years old. As a white, straight Canadian woman I think I have a LOT of privilege in disclosing my diagnosis. I am SO happy that this question is being asked. Personally, when connecting with other people with MRKH I have tried to be aware of how the cultures and subcultures they are apart of may make disclosing the diagnosis more difficult and do my best to empathize. When I was diagnosed I remember my parents being so concerned about keeping it a secret because they were afraid people would take advantage of me sexually in high school or would shame me by questioning my own gender or sexuality. Thankfully the experiences I have had disclosing my diagnosis have been overwhelming positive. I know that is not the case for everyone and my heart goes out to every person who feels like they will be less accepted as a human being if they share this part of themselves.

SWEDISH

I'm from sweden, was diagnosed 2008, there was no information to be found so I made a wikipedia-page about us. I think the hardest part for others to understand is that it's a lifelong struggle. I love playing with my niece and nephew but afterwards I'm emotionally drained and need time for myself. And it's super hard to not get mad at bad parents 😂

BRITISH–PAKISTANI, MUSLIM

I think people often overlook the cultural and religious barriers one can face with MRKH. I come from a culture where speaking about sex, vaginas, infertility etc openly is not common. For the most part I was never able to speak about my vaginal issue with my family, wasn't so bad with the missing womb part. To this date I've never spoken to my mum or anyone in my family about what dilation would actually entail...dreading it! It's almost like there's an embarrassment to it, it not being 'normal'. Sex is something that should happen after marriage, in some cultures using a tampon is frowned upon let alone using a dilator!

Similarly when it comes to meeting a future spouse, different cultures and religions allow for different things. If 'dating' isn't encouraged the idea of disclosing MRKH to a man is quite daunting because you aren't able to build that comfort first, it's more an arranged family affair. You fear that's what you'll be judged on because the person hasn't had enough...

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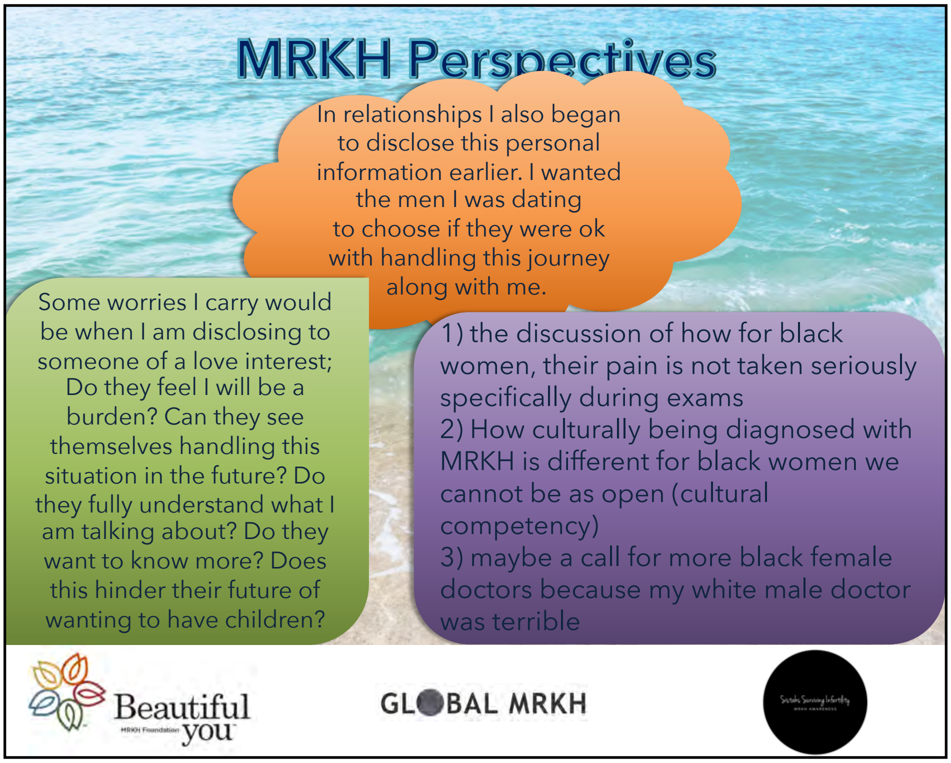


MRKH Perspectives

In relationships I also began to disclose this personal information earlier. I wanted the men I was dating to choose if they were ok with handling this journey along with me.

Some worries I carry would be when I am disclosing to someone of a love interest; Do they feel I will be a burden? Can they see themselves handling this situation in the future? Do they fully understand what I am talking about? Do they want to know more? Does this hinder their future of wanting to have children?

1) the discussion of how for black women, their pain is not taken seriously specifically during exams
2) How culturally being diagnosed with MRKH is different for black women we cannot be as open (cultural competency)
3) maybe a call for more black female doctors because my white male doctor was terrible

MRKH Perspectives

PARTNER PERSPECTIVE

So....as you were saying with MRKH, my girlfriend (now fiance) was diagnosed with MRKH at 16 years old and always thought it would ruin her chances at having her happily ever after. Therefore she was extremely scared to tell me to the point she would start having panic attacks whenever we would talk about our future (family, jobs, careers, new homes, new chapters, ect.) And I don't think she realized that I don't love her because she can bare my children. I love her because of who she is and MRKH only shows me how much stronger of a woman she is! She not only carried that burden for years. But she thought she had to protect me from it. Which is far from the case, even though I know it is one of the hardest things to fathem for a woman I only thinks it makes them stronger in every aspect. So all in all I think you should talk about

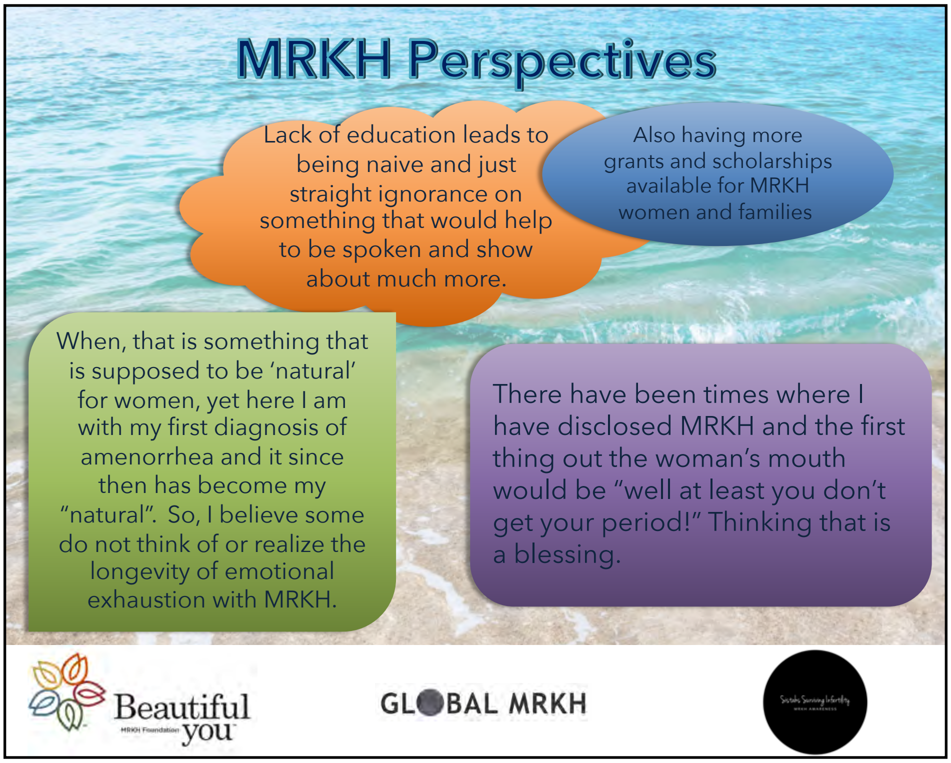
ALIENATED

Hey Jaclyn - firstly just wanna say I'm so excited to follow your surrogacy journey, and super happy for you & your husband!
I'm Sophie from the UK, and I feel like people don't understand how alienated it can make you feel. I often feel disconnected from other girls, especially when they're talking about fertility and babies, which is a subject they're more than welcome to talk about, I think sometimes it's just not taken into account how I may feel about it, or anyone else with fertility issues x

DIAGNOSIS & PARENTS

Hi! Responding to your question about MRKH and what people are NOT thinking about....

I don't think people realize how impactful this information (especially when you find out) is to you, your personal relationship with yourself, or the challenges you'll face. Within the MRKH community (which has been SO powerful recently), I don't think we address how to have these conversations at 16,17 years old with daughters. As a 17 year old patient, you may not get the details or ask the right questions which can cause confusion for years. Parents may not handle the information well and when that's the case, how is the 17 year old programmed to then think about MRKH? Generally pretty negatively. And this is not even considering religious or cultural factors.



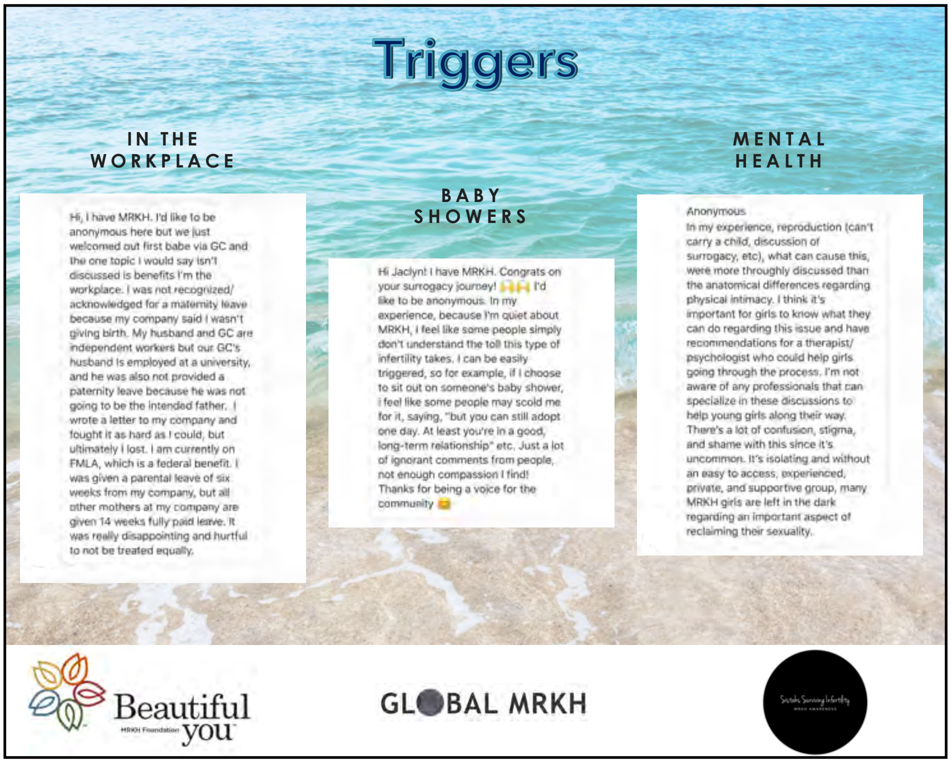
MRKH Perspectives

Lack of education leads to being naive and just straight ignorance on something that would help to be spoken and show about much more.

Also having more grants and scholarships available for MRKH women and families

When, that is something that is supposed to be 'natural' for women, yet here I am with my first diagnosis of amenorrhea and it since then has become my "natural". So, I believe some do not think of or realize the longevity of emotional exhaustion with MRKH.

There have been times where I have disclosed MRKH and the first thing out the woman's mouth would be "well at least you don't get your period!" Thinking that is a blessing.



Triggers

IN THE WORKPLACE

Hi, I have MRKH. I'd like to be anonymous here but we just welcomed out first babe via GC and the one topic I would say isn't discussed is benefits I'm the workplace. I was not recognized/ acknowledged for a maternity leave because my company said I wasn't giving birth. My husband and GC are independent workers but our GC's husband is employed at a university, and he was also not provided a paternity leave because he was not going to be the intended father. I wrote a letter to my company and fought it as hard as I could, but ultimately I lost. I am currently on FMLA, which is a federal benefit. I was given a parental leave of six weeks from my company, but all other mothers at my company are given 14 weeks fully paid leave. It was really disappointing and hurtful to not be treated equally.

BABY SHOWERS

Hi Jaclyn! I have MRKH. Congrats on your surrogacy journey! 🙌🙌 I'd like to be anonymous. In my experience, because I'm quiet about MRKH, I feel like some people simply don't understand the toll this type of infertility takes. I can be easily triggered, so for example, if I choose to sit out on someone's baby shower, i feel like some people may scold me for it, saying, "but you can still adopt one day. At least you're in a good, long-term relationship" etc. Just a lot of ignorant comments from people, not enough compassion I find! Thanks for being a voice for the community 😊

MENTAL HEALTH

Anonymous

In my experience, reproduction (can't carry a child, discussion of surrogacy, etc), what can cause this, were more throughly discussed than the anatomical differences regarding physical intimacy. I think it's important for girls to know what they can do regarding this issue and have recommendations for a therapist/ psychologist who could help girls going through the process. I'm not aware of any professionals that can specialize in these discussions to help young girls along their way. There's a lot of confusion, stigma, and shame with this since it's uncommon. It's isolating and without an easy to access, experienced, private, and supportive group, many MRKH girls are left in the dark regarding an important aspect of reclaiming their sexuality.

MRKH Perspectives

My experience with MRKH has been me spending time wondering if other women born with this condition feel like me? I have come to understand that most of us share the same thoughts and feelings. I understand that no matter the culture, we all have a journey, and, in that journey, we experience shame, issues with acceptance, fear, and pain, to name a few. I am growing in understanding that there are no cultural differences in MRKH. MRKH is a condition that we all journey through.

Beautiful you MRKH Foundation

GLOBAL MRKH

Sistahs Surviving Infertility
MRKH AWARENESS

tips from Christina and Amy

DISCLOSURE TIP BY AMY

YOU WILL MAKE MISTAKES.

THE FIRST THING I TOLD MY NEW COLLEGE ROOMMATES WAS, "HI, I'M AMY AND I WAS BORN WITHOUT A UTERUS." 😂

SOMETIMES I CLEAR ROOMS AND OTHER TIMES I FIND A CAPTIVATING AUDIENCE. THEIR REACTIONS ARE ABOUT THEM, NOT ME.

DISCLOSURE TIP BY CHRISTINA

Have an honest conversation with your family as to who you want this vulnerable information shared with (if anyone at all). This is YOUR diagnosis and no one should disclose this highly personal information, but you.

Dr. Susan Carroll

DISCLOSURE TIP BY SUSAN

'I often wonder if there's a lot of pressure to disclose because of social media.. It's a very personal decision and a process not an event. I'm glad I gave myself the time I needed to do it my way.'

Rima Zigaitis

DISCLOSURE TIP BY RIMA

DISCLOSURE IS MY CHOICE.

I SAY WHO, I SAY WHEN, I SAY HOW MUCH.

Tips from the team

Tips from the team

Badia Atcherson


DISCLOSURE TIP BY SUNNI

Gradual


DISCLOSURE TIP BY BADIA

I WILL BE A VOICE FOR BARREN WOMEN," WERE THE WORDS I SURPRISINGLY SAID DURING THE PASSING OF THE TORCH AT MY GRADUATION FROM SEMINARY COLLEGE. I MADE THAT PROMISE BEFORE LEARNING ABOUT MY CONDITION. I DIDN'T KNOW IT HAD A NAME, AND IT IS MRKH.

THERE'S PURPOSE IN GODS CREATIONS. HE MADE NO MISTAKES WHEN HE CREATED YOU AND ME.

Sunni Anne Ball

Tips from the team


DISCLOSURE TIP BY BRITTANY

"YOU DON'T HAVE TO DISCLOSE ANYTHING. YOU DON'T OWE ANYONE AN EXPLANATION.

ONLY DISCUSS THINGS YOU'RE COMFORTABLE WITH AND WITH PEOPLE YOU'RE COMFORTABLE WITH."


DISCLOSURE TIP BY ERINN

QUESTION I ASK MYSELF BEFORE DISCLOSING:

"WHAT AM I TRYING TO GET OUT OF THIS? WHAT DO I WANT OR NEED?"

Brittany Boone, MA

Erinn Webb, MA, RDT

Tips from the team

DISCLOSURE TIP BY JACLYN

IF YOU DECIDE TO TELL SOMEONE IN YOUR LIFE ABOUT MRKH, YOU ARE INCREDIBLY BRAVE. IF YOU CAN'T DISCLOSE BECAUSE OF YOU CULTURE OR RELIGION, YOU ARE STILL INCREDIBLY BRAVE. IF YOU REACH OUT TO ANOTHER MRKHER, YOU ARE BRAVE. IT TAKES A LOT OF COURAGE AND RESILIENCE TO LIVE WITH MRKH. GIVE YOURSELF GRACE, TRY NOT TO COMPARE YOUR BEAUTIFUL JOURNEY WITH ANYONE ELSE'S. NO ONE IS YOU, AND THAT IS YOUR POWER!

Jaclyn Misch

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SUMAAVI