

MRKH and Mental Health

A diagnosis of MRKH can raise all sorts of challenges which make it hard to adjust. This page is informed by research into those with MRKH from different backgrounds, key challenges they have faced and how they have dealt with them. It also uses theories in Health Psychology which can help you adjust to MRKH.

Understanding your feelings towards your MRKH diagnosis

A diagnosis of MRKH can trigger different emotions; you may feel shocked, confused, isolated, lonely, anxious or feel low...These are all natural emotions to have and are very understandable because of the losses and challenges MRKH brings. It is common for those with MRKH to grieve after their diagnosis such as grieving their sense of self and their planned future. Allowing yourself time and space to grieve can be a useful process to cope with MRKH. You may want to go through this process alone or/and share it with people of trust. Your grieving period may not be limited to directly after your diagnosis and it is normal to take time to grieve at other life stages. For example, another time where some with MRKH grieve is when their close friends and family have children as this can act as a reminder of the losses MRKH brings. During grieving periods, your grief may fluctuate and disrupt your daily life, some days more than others which is a natural response to this kind of situation.

Figuring out your feelings towards MRKH can also impact your identity and feelings of self-worth. Some with MRKH find that it is hard to find their true self during and following their diagnosis especially where periods are often seen as a "path to womanhood".

You can give yourself permission to:

Take time to take care of your mental and physical health
Grieve
Choose what is right for you (treatment/ fertility/ disclosure....)
Seek support from others who have MRKH

Feel frustrated by others responses
Not know what to do
Communicate your needs to others
Have negative thoughts and emotions
Feel overwhelmed

Do not forget that MRKH is a syndrome not a defect.

Should I talk about my MRKH diagnosis?

Thinking about who to talk to and how to talk about MRKH may feel overwhelming. This is normal as it can bring up difficult feelings. Having MRKH may make you feel as though you are different compared to others without MRKH. Some with MRKH have described finding social situations uncomfortable and not knowing how to bring up the topic to their friends.

Others have explained not talking about MRKH as it was considered a taboo topic in their culture and/or religion. As MRKH is a very personal diagnosis, it may take time for you to come to a decision about whether to share your diagnosis. There is no right or wrong decision, and decisions will naturally differ between people. It is also important to remember that if you decide to do so you should think about who you are telling, are they trustworthy?

You might also want to think about what you want them to know and what you hope for as the outcome. Those with MRKH who shared their experiences of disclosure explained that it was beneficial for them to talk about their diagnosis to feel supported and accepted. Some people spoke about finding it helpful to start with talking to others with MRKH, and then deciding about telling others. You may find it helpful to do the same and, for example, connect with people on the MRKH Connect website and attend their events. This can help you form friendships with people who understand your struggles related to MRKH. It may be possible for MRKH Connect to put you in touch with people and groups from other countries than the UK. Women from different backgrounds can experience different challenges with MRKH so you may find it helpful to discuss them with someone who has had similar experiences to you.

“I was told from the age of 18, “oh you’re bringing shame to the family don’t talk about it”, I, I internalised that, so I thought it was some kind of dirty secret that I must keep uhm quiet, so hence I never spoke of it at all to... anyone”

“I think a lot of my, almost like formative years with defining how I feel about MRKH and my experience with MRKH was definitely impacted because of that support group [...] Having a safe space to vent, or even just be angry about things that were like MRKH-related. It was really nice to have a bond with people who connected over it.”

If you are currently in an MRKH support group, it is important to recognise how your experience might differ from people with other cultural background and religious beliefs and respect that other people’s experiences may differ to your own.

Coping with other people's responses

Those with MRKH have shared that after disclosing their diagnosis, some people had unhelpful responses like 'you are so lucky you don't have periods' or 'focus on the positives', which can understandably feel very hurtful. It is important to note that when others react in that way, it is probably because they are unsure about how to support you and aim to make you feel better. You may find it helpful to tell people what kind of support you need from them, for example you could say 'I just need someone to listen'. Potential negative reactions should not be considered as a reflection of who you are but an inadequate response from others towards your diagnosis.

Following disclosure, people close to you may struggle to adapt to your MRKH diagnosis or what to say or how to help you. It is important to keep, as a priority, supporting yourself first before helping others cope with it. This should not be viewed as your responsibility.

Preparing for medical appointments

Experiences of healthcare services, within the context of MRKH, differs between countries and for some, they do not feel like they received appropriate care and support to navigate their diagnosis.

"That's the most frustrating part, not having, or feeling like I don't have access to providers who actually know what they're talking about."

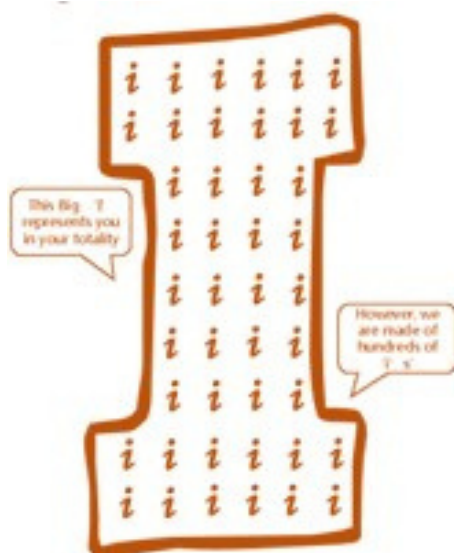
Seeing a new healthcare professional might feel daunting as they might not know about MRKH. You might find it helpful to send them before your appointment or bring to the appointment a resource explaining what MRKH is to not have to do it yourself. On the MRKH Connect website, the "What is MRKH" page provides a useful quick overview. Additionally, you can bring someone you trust with you to the appointment so that they can listen to the healthcare professionals with you, help you during the appointment or just be there for support.

In some cases, MRKH can be linked with secondary physical problems (MRKH type 2). The most common problems are renal, skeletal problems and hearing deficiencies. In rarer cases, there can be associated cardiac problems or a difference in the growth of hands or feet (this will be present at birth). MRKH is a syndrome which impacts many differently, a visit to a health professional is a good opportunity to check which type of MRKH you have.

Taking care of your mental health

Those with MRKH often report lower emotional wellbeing following diagnosis. It can be hard to cope with MRKH because of the concerns it can raise such as whether to go through vaginal lengthening, who to talk to about MRKH or what this diagnosis means for having children in the future if that's a path you decide to take. It is okay to give yourself time to answer these questions and to process your losses and grief before taking action.

An important factor that can help you cope with your diagnosis is to pay attention to how you integrated your diagnosis into your self-concept (how you think about yourself). If your diagnosis becomes the dominant part of your identity, it may be harder to cope with it. It is helpful to give space to the other part of your identity which matter to you. Here is an example below to help you think about this:



Above, the big letter “I” represents your overall identity and the small “i” the different parts of your identity. The small “i” can be a multitude of things such as your job/ studies, your hobbies, where you come from or your religion. For example: ‘I am a nurse’, ‘I like reading’, ‘I like pizza’, ‘I am a good friend’, ‘I am from the UK’... When first diagnosed, it may feel very overwhelming, and MRKH may take up a lot of space in your identity or it may make it harder to connect and enjoy other important parts of yourself.

As well, you may try to push MRKH out of your identity and not give it any space. Working towards having a balance can be helpful. Giving MRKH some space so that you can try to figure out how it fits within your life but making sure it does not take up all the space. You may find the following activities helpful to complete your ‘I’ and find your balance:

You may find the following activities helpful to complete your 'I' and find your balance:

- Write down all the different 'i's that are important to you and make you who you are.
- Make time to connect with the small 'i's that are important to you. Try to choose at least one thing each day to do that makes you feel connected to one of the 'i's that is not related to MRKH.
- Think about ways that you can make some space for MRKH such as writing how you feel, talking to someone you trust, asking for help when you need it or reading some of the resources on the MRKH Connect Website.

In summary, it is important to make space for your MRKH diagnosis while keeping and adding meaningful items to your big "I" and know that you don't have to do this alone. Whilst professional services are not available, or easily accessible everywhere there are peer to peer support and coaching services that can also be used. Check out some suggested resources here [Other sources of information](#).

You can find more information [About MRKH](#) as well as many testimonies and [blogs](#) of the challenges MRKHers, or those that [support them](#), have gone through and how they have coped. It also includes advice on [intimacy](#), [parenthood](#), and [life without children](#). There are also links to other [organisations](#) and resources from across the world.

Self-compassion activities

- [To understand your feelings towards MRKH you may find it helpful to write a Compassionate Letter to Self](#)

It can be really helpful to write a letter to yourself expressing compassion, acceptance and understanding. In the letter, be as kind, compassionate as you would be to a friend going through MRKH.

Write the letter as if it was from someone who knows you well. If you are finding it difficult to be compassionate to yourself, perhaps choose someone who cares for and accepts you totally for who you are- with all your past experiences and weaknesses, as well as your positives. This compassion person will be wise, kind, accepting and forgiving.

Remind yourself in the letter that we are all human, we all make mistakes, and we all go through difficult experiences and emotions. It's okay to allow ourselves to feel sad, angry, and upset...

Write what you imagine this friend might say to you now, as you think about yourself and your experiences. Write what your kind, wise, forgiving friend would advise you to do, what positive changes you might make. You can think about how, aside from your MRKH diagnosis, all the other things your friend sees in you.

How would this compassionate friend say these things in a kind, wise, forgiving and understanding way, wanting only the best for you. You can keep this letter in a 'compassion kit bag' or save it online to have an easier access to it when needed. You can find a link on how to create a compassion kit bag below. When you later come to read it, slow down and breathe before you start, and allow words to sink in, notice how you feel.

- Sometimes when we are going through a difficult time all our attention can be pulled into the past or worries about the future.

This simple exercise can help to just 'be' and bring you back to the present.

- 5 things I can see
- 4 things I can hear
- 3 things I can touch or feel
- 2 things I can smell or like the smell of
- 1 slow deep breath