PELVIC HEALTH MATTERS: A WEBINAR SERIES FOR WOMEN WITH MOBILITY IMPAIRMENTS

SESSION 2 OF 4: PELVIC HEALTH FOR GIRLS WITH MOBILITY IMPAIRMENTS

APRIL 20, 2016

1:00 P.M.

Captioning Provided by:
Closed Caption Productions, LLC
P.O. Box 278
Lombard, IL 60148
www.ccproductions.com
Phone: (844) 335-0911

***

REALTIME CAPTIONING AND/OR CART (COMMUNICATIONS ACCESS REALTIME TRANSLATION) ARE PROVIDED IN ORDER TO FACILITATE COMMUNICATION ACCESSIBILITY AND MAY NOT BE A TOTALLY VERBATIM RECORD OF THE PROCEEDINGS.

***
Good morning and afternoon to everyone. And welcome to the Pelvic Health Matters Webinar Series. It is exactly 1:00 p.m. here in Houston. We are going to record this webinar.

Before we begin this session today we would like to review some of the features of the remember nature platform. My name is Rachel Markley and I will be serving as the moderator for this session. This program is brought to you as a collaborative effort by TIRR Memorial Hermann, Baylor College of Medicine, the American Congress of Rehabilitation Medicine's Spinal Cord Injury Interdisciplinary Special Interest Group, and the Christopher and Dana Reeve Foundation.

Individuals are joining us today using a variety of media including the webinar platform, listening via the telephone and using real-time captioning. A copy of today's PowerPoint presentations are available on our website at www.bcm.edu/crowd. This session is being recorded and will be archived on our website soon. Our presenters will provide us with valuable information today and at the conclusion of the presentation there will be an opportunity for everyone to ask questions. You may submit your questions using the chat area within the webinar platform. We will address these questions at the end of the session so feel free to submit them throughout the presentation. Now I would like to introduce the director of center for research on women with disabilities. Dr. Nosek?

Thank you. Are you able to hear me now?

Yes, we can hear you now.

Good. Thank you. I would like to welcome everyone and thank you for your enthusiastic response to our webinar series so far. We've had some very interesting questions and comments in response to our first session on our introduction to Pelvic Health Matters Webinar Series and I would like to encourage everyone to continue sending us your comments. If I can get my screen to advance, bear with me please.

This is the second in our series of four webinars. This session will focus on pelvic health transitions for girls with mobility impairments and our guest speaker will be Dr. Ellen Fremion. Our Pelvic Health Initiative, which is the overarching program, was explained during our last seminar but I wanted to repeat a few of the items that we went over at the beginning of the last session. First of all, our funding sources, as Rachel mention, the first is TIRR Memorial Hermann. The second is Christopher Reeve Foundation. And third is the Women's Health Task Force of the American Congress of Rehabilitation Medicine Interdisciplinary Spinal Cord Injury Special Interest Group. And we have also received support from all presenters in the series, including Dr. Fremion.

No one has any financial conflict of interest to expose. And briefly I would like to give another word of thanks to our medical advisors and our community advisors. Dr. Fremion has been a founding member of our advisory committee. She is a pediatrician and an internal medicine physician and she is currently director of the Transition Clinic at Texas...
Children's Hospital and Assistant Professor in the Department of Internal Medicine and Pediatric Medicine at Baylor College of Medicine. Dr. Fremion has been a valuable member of our team in the Pelvic Health Initiative for Women with Mobility Impairments and has given us some very valuable insight on issues related to transitions for girls with mobility impairments. We're very excited today to bring to you Dr. Ellen Fremion. Dr. Fremion?

>> ELLEN FREMION: Hi, everyone. I'm very excited to be with you today. One second as I switch over our screen here. Can everybody see my presentation now?

>> RACHEL MARKLEY: Yes, we can see everything. Thank you.

>> ELLEN FREMION: All right. Perfect.

As Peg said, my name is Ellen Fremion. I'm an Internal Medicine and Pediatrics Physician. I work at two locations; one is at Texas Children’s Hospital with the Spina Bifida clinic. I'm doing a program to help adolescents with Spina Bifida as they prepare to transition to adult care but they are still engaged with the pediatric hospital, and I also work in the Baylor Transition Clinic, which is a clinic for adults that have transitioned from pediatric care. So I do primary care for those adults with physical and intellectual disabilities due to childhood onset conditions. And we also do comprehensive care in a medical home style. So we have social workers, nurses, and physicians that support the health care and well-being of those adolescents and young adults.

So I'm excited to share with you my experiences and information on helping young women transition from pediatric to adult care who have physical disabilities.

So our discussion points today are as follows. So first of all, we need to talk about how the individual and family roles change during transition. I think this is really important to begin in thinking about patient-centered care. Then, we're going to talk about the things that you have to navigate. There's funding, things that you have to navigate for transition, the change in providers from pediatric to adult providers, and preparing for adaptive adult life. We're going to address some of the health concerns today, including changes in body function, bowel, bladder and sexual health, focusing on pelvic floor health, adult health care issues for women that have physical disabilities, and mental health. Finally, after going over these things that are oftentimes challenging and stress provoking to both patients, families, and providers, we want to capitalize how we can keep a positive perspective during transition.

So I wanted to use a case example that will help us navigate through our discussion topics today. This case is just an example, it's not a real patient but highlights some of the commonalities that many young adults share that have physical disabilities.

So Maria is a 17-year-old. She is a junior in high school. She has mid-lumbar Spina Bifida, neurogenic bowel and neurogenic bladder as well. She primarily would use a wheelchair to get around her community. She lives with her mom and younger sister. She enjoys helping her family and hanging out with her boyfriend on the weekend. She
would eventually like to go to college and be a social worker. She is here for her annual Spina Bifida clinic visit with her mom.

As many pediatric conditions go, there's usually a multidisciplinary team that's assigned to a specific condition. In the case of Spina Bifida it's common for them to see multiples of specialists as well as therapists on one-day clinic and this is oftentimes how they engage in my transition program that I have at Texas Children's as well.

So let's talk about some of the issues to help Maria transition well. So first of all, role changes during transition. Care management changes. Teens become more independent in their management and they progress in these skills in a usual, typical way. They start out with just obtaining skills. This might be understanding what their medications are or how to cath by themselves or how to do their own self-care. Then, they learn how to do those routines on a daily basis while they're at school or a part-time job. Then, they learn how to monitor for problems, when things don't go as expected how they can detect those problems and who should they call, and finally they learn how to navigate care. Figure out how to get supplies, medication refills, call the doctor to make an appointment, and that sort of thing.

So parents change as their teenagers change. They change from a manager who does everything from medical care to navigating the health care system, to becoming more of a monitor or coach as their teen begins to manage their routines and starts going to visits by themselves. And then finally they change to an adviser, which many adults with and without disabilities need to call up their parents and say hey, how do you do this. I haven't ever encountered this one before.

Medical decisions change. Teens change from giving their assent or being a part of the medical decision where the parent still makes that final say in whether or not they can receive the medical care, to consenting at age 18 if they don't have an intellectual disability that impairs them from giving consent. Then parents change too to mirror this. They change from being the primary decision maker to the decision supporter, to help their teen make good, informed decisions.

So how can we support this change? The first thing is to set expectations and maintain confidentiality. I find with the teenagers that start in my transition program, that that first visit is still very much like a similar pediatric visit where the parent expects they're going to be the one that gives the history and is the primary person that converses with the doctor, but we have to change those roles. So I usually say I want your parents to be supportive of you, but I want to hear from you first. Because you as a teenager are starting to practice going to the doctor by yourself. I also set the expectation that I will meet with the teenager independently. And then finally they change to an adviser, which many adults with and without disabilities need to call up their parents and say hey, how do you do this. I haven't ever encountered this one before.

We want to talk about confidentiality. What are those things that we need to share if a
teenager has a problem? And what are the things that can remain confidential or just between the patient and the doctor? So, for example, things that would put the patient at risk, if they're having an acute medical problem, if they're having an acute emotional problem that needs to be addressed, because there's likely harm that's going to happen to the patient. Those are things that we have to breach confidentiality for. But if they're struggling with self-identity, if they're having questions about their sexual health, those things can remain confidential until there's a concern for harm. Of course, if the young adult is 18 years old and they're able to give their own consent, then it's by law something that we have to maintain confidentiality for everything, unless the patient gives permission or wants to talk about that with their family members.

So the next thing I talk about is practice. Everybody needs a little practice, and parents need practice too on how to be a coach. So I always explain to both the patient and the parent that everybody is going to make mistakes as they practice. So it's important to forgive one another and to set out expectations and just be a good communicator to make sure that we all mature and grow as we need to.

It's also important to evaluate the level of independence. Because everybody is a little bit different. I have some patients that can't do their daily management, such as cathing or giving themselves medications, and I have some that are ready to navigate their own health care for themselves. It's important to understand both for the patient and the provider where are we starting. Then we can create action plans to improve towards goals in small steps.

So let's go back and look at Maria. Maria is changing. Currently Maria is able to cath her bladder independently, but sometimes she needs help doing these regiments on time. So what goals and action plans can we help Maria to grow in independence?

In this case what I would do, I would help her to make a daily routine chart. From the time she gets up to the time she goes to bed, what are those usual daily things she has to do, showering, bathing, skin checks, medication, going to school or doing homework are all important things. She may set alarms to help her remember to cath or take medications on time. And I always have them make a checklist chart. That way they can check off when they did the action correctly. This also allows them to review this with their parent who's their coach. Instead of the parent reminding them to do the action when it needs to take place, now the parent is more like the quality manager, where they just assure that the individual is doing their own daily care. And then they can also have a team meeting. So either start off daily meeting with the teen and their parents to make sure that their daily routine is working out well for them, and then they can eventually wean off to weekly and hopefully the teen will be able to progress and manage by themselves.

Also Maria's doctor explains that it's important for Maria to practice meeting with the doctor by herself as part of the exam and gives her the option that day to have that individual meeting or have it scheduled for next time.

Next we need to navigate funding. This is oftentimes surprising to families, because they find their pediatric providers sometimes don't mention it, but it's essential to access to
care and their future. What happens when somebody with a disability turns 18? When they're able to give consent for their medical treatment, if they're able and don't have an intellectual disability, and two, they have to apply for adult disability determination and supplemental social income. Without that somebody cannot have Medicaid to support their health care needs, so this is essential and important. One thing to know about Medicaid is that below the age of 18, the financial considerations are based upon the family's income. But above 18, it is just based upon the individual's earnings. Now, it's important also to protect the individual's assets. For example, if somebody gets some graduation money from high school and that exceeds the limitation for SSI, then they will not be able to have Medicaid. So there's other things such as a special needs trust or other things that we can protect the assets for the individual, but also allow them to have insurance and support for their medical care and daily living. The arc is a great resource to look into a special needs trusts.

Private insurance. Adults who are dependent on their parents, can remain on their parents' insurance past the age of 26, but parents have to go to their employers' HR department and ask for a form. That form has to be signed by a medical doctor stating that the individual that's dependent on their parents had that disability start before the age of 26 or in childhood. And that will allow them to remain on their parents' private insurance.

Medicare. So similarly to private insurance, adults who are dependent on their parents are eligible to receive Medicare benefits from their parents. But because they get an SSDI check, that sometimes is over the amount that they're allowed to have for Medicaid, and they can lose their Medicaid. Often times families don't know this happens, only that their services stops and they don't understand why so it's important to understand this information. If the young adult with the disability or dependent with a disability receives Medicare, they need to look into Medicaid to make sure that it's still standing. Adults with disabilities can reenroll in Medicaid under the Pickle Amendment. You can Google that to understand that more. The next thing is if an adult has a disability and has paid into Medicare, they can be eligible for themselves and more information on that is available on medicare.gov.

Navigating also has to do with finding appropriate adult providers once you transition. So transition to adult care often occurs between ages 18 and 21. But there’s some flexibility around that, depending upon the patient and their provider. Oftentimes insurance, facility access, the specialization of the adult provider are the factors that determine who the patient is going to see. I would say insurance is probably number one. The other consideration is if you’re a young adult that is planning to go to college, you want to make sure that you have a medical professional close to you that if you have any kind of cold, cough, as well as exacerbation of your chronic condition, that you have somebody there that's familiar with you. You may also go to a big medical center if there's a special center that takes care of your particular condition. And it's important to have that local person be in contact with your larger center that takes care of your needs.

So how can we prepare for this transition? First, talk about transition with your pediatric doctors early. I recommend starting around age 14 if not even earlier. Since transitions
change, any preparation and expectation can help this transition to go more smoothly. Next you need to get organized. So that means having all of your care team written down and who is managing what condition for you. You need to write down your needed items, including medication, supplies, and adaptive equipment and you need to have an up-to-date care plan. This would include a surgical history and a medical history as well as what are your chronic conditions that you’re managing right now and what’s the plan for each. This helps to have a smooth hand-off with your next team as well as help the individual and their parent understand the care better. We need to prepare for meeting a new adult doctor. Adult doctor, the perspective is really different than pediatric doctors. Again, the pediatrician often talks with the parents to see what's going on and does a well check and that sort of thing and really knows you. But the adult doctor may be less familiar with your condition and really wants to hear from you. So it's important to bring your question list to your physician so that you can make sure that your care is adequately taken care of. And then also you may have to teach them about your particular condition and your needs for an exam. So don't be afraid to do that. That's okay. And bring your care plan with you so that we can make sure that the hand-off goes smoothly.

Transition.org is a great website with many handouts for providers and patients as well as families.

Next we have to talk about adaptive adult life or preparing to live independently. This can look different for different people. If you’re preparing to go to college and are going to stay in a dorm, you need to think about what supports you need to support your college life. Or if you're planning to go to work or live in an apartment, it's important to consider all of these factors. So look around at your home. What particular adaptations do you need? Changes in your bathroom, in your bed, and your transfers, write those down. What provider or nursing services are needed? And I usually think about this in if you had to stay a whole weekend by yourself, what could you do for yourself and what do you need help with? This will give us a good idea of what supportive services are needed. What about transportation? Do you need car modifications or adaptive driving? What is the public transportation around your home or community? Next is how independent is the individual in their self-management and care navigation? This goes back to those role changes that we’ve talked about previously. Next we have to practice self-advocacy discussions. I find for many people, this is really awkward. And sometimes something that we really dread. I have to tell about my disability again, people say? Or I don't want to draw attention to myself. Sometimes it's really important for you in a compassionate, nice, professional way, to state what your needs are so that you can have the adaptive supportive living that allows you to participate in your medical care and community.

Next, these are a lot of items to deal with, so it's important to make small goals and action steps to improve independence and to feel successful.

To support working and higher education there are vocational rehabilitation service, in Texas we have something called DARS, our Department of Rehabilitative Services. There are programs that work with high schools as well as adults including vocational testing, job integration and supportive services for transportation, including wheelchairs,
orthotics, car adaptations, and the like. It's also important for somebody that has mobility impairment to understand their rights. So the ADA.gov has all the listed rights that talk about how an employer cannot discriminate against somebody with a disability and has to provide the modifications needed for that person to be employed in their facility. So it's really helpful in supporting self-advocacy to understand those things.

It's also important to note that if you have SSI and Medicaid, the amount you work may change your insurance if it exceeds that amount. But there's other services that can help you with insurance. So speaking with a DARS advocate or a social worker can help make sure that you have continuous coverage.

So transition planning for Maria. So first of all, let's talk about funding. So Maria has Medicaid, pediatric Medicaid and pediatric disability determination due to her mobility impairment. So what does Maria need to do at age 18? She needs to go to the Social Security office and file for adult disability determination and that consideration is based on Maria's income only, not her parent's.

Next we need to talk about providers. Maria works with her doctor team to make a medical summary. And what should be included? Diagnosis, surgeries, medications, supplies, care teams and numbers, and a current care plan. And then Maria and her pediatric doctors make a transition plan for the long-term. They decide that Maria will continue to see her pediatric doctors through the age of 18 but already she's given a list of recommended adult providers to review and get familiar with. Call the office for a tour or something like that to make sure they can meet her needs. Adaptive adult life. She can be referred for vocational training and adaptive driving. Maria and her mom are asked to make a list of things she needs to help her become more independent or identify the support she needs.

Let's switch over and talk about some of the health concerns for teenagers and young adults that have mobility impairment. First of all, mobility. Functional decline is very common during the teenage and young adult years. This is due to growth, sometimes obesity, worsening contractures, skeletal deformities, and sometimes the prognosis of the condition itself. Adaptive aids may need to change. Somebody may go from using a walker or orthotics to primarily use a wheelchair to access their communities. Exercises and therapies can help maintain function and these need to be done on a daily basis to ensure that contractures are minimized as well as the mobility a person does have is maintained as long as possible.

Pain is a huge issue and it really affects quality of life for people with disabilities. Pain may be due to muscle strain such as using your wheelchair or neuropathic pain if there is a contracture pushing on nerves and causing entrapment. Physical therapy, repositioning, both in their wheelchair or in their bed can help with these things. Pain regimens are also important, and this may include not only medication, but mental health techniques or stretches that can help improve pain and quality of life. I find oftentimes if somebody has a new wheelchair and the wheels are not positioned correctly, a lot of times they'll get shoulder strain. They can go back to the company and ask them to review the wheelchair and positioning for the patient.
Bone health. There's lots of controversy over how to detect and how to treat disuse osteoporosis for people that have mobility impairment. There's a lot of research, some of it coming from NASA on how best to follow this condition. People with physical impairment do have a higher risk of fractures of the long bones – the femur, the humerus or the upper arm, and then the tibia and fibula. These can be low trauma accidents, such as falling off a toilet seat or range of motion during physical therapy. These are different than the typical osteoporosis fractures that we think about in post-menopausal women which are wrist fractures or hip fractures or spine fractures. Sometimes the diagnosis using a DEXA scan that looks at that part of the body looking at the hip, back and wrist are sometimes not exactly what we use for the disuse osteoporosis detection. So we have to extrapolate from those tests. There also may be difficulty getting a DXA or bone density scan due to contractures or positioning. So again, we're extrapolating even from a diagnosis.

What can we do? Calcium and vitamin D are helpful and wait-bearing exercises and maintaining mobility can also support bone wellness. I think there's more to come from literature regarding other therapies like bisphosphonate or other medications that can be used to treat osteoporosis for this population.

So bowel conditions. Transition concerns particularly for people with neurogenic bowels or other bowel impairments include incontinence. It's a huge quality of life concern. I've had patients that have had incontinence during exams on dates or when they start work which is an awful place to have an accident where they need assistance in cleaning up. Constipation is also not ideal, as it can cause pain and further complications such as dilated bowel, diverticula or bowel obstruction. Bowel regimes are definitely needed and are needed on a regular, daily basis. Bowel regimes may have to change. There may have been a bowel regimen such as an enema regimen that a patient needs assistance with. There might be other options that support them better to maintain their bowel regimen independently.

What are the treatment options? I always start off with oral medications making sure that the bowel, the stool is soft and formed. Then rectal stimulants such as enemas, typically people can do it by themselves, can help stimulate the bowels and control timing of bowel movements. There's also transanal irrigation systems you wash water into the sigmoid colon and relieve bowels that way. Or antegrade enemas, otherwise known as MACE. There's a small stoma on the right side of the abdomen and the patient is able to insert a catheter and flush their entire bowels usually once every day or every other day to ensure they have their entire bowel cleaned out - that's a great regimen. Usually that surgery has to be done in pediatrics. There are a few adult surgeons that do them. It's typically urology doctors that put in the stoma in order to do the antegrade enemas but it allows for a lot of independence. It's a good option if people do need surgery.

It's also important to know how various foods and the menstrual cycle affect bowel regulation. Spicy foods and greasy foods can cause increased accidents. It's good to have a healthy amount of fiber but not too much so that there's not a gas problem. And then the menstrual cycle affects regulation. Oftentimes women find they're more
constipated and bloated the week before their menses and they have more frequent accidents or stool frequency on the week they have their menstruation. They may need to adjust their bowel programs at that time. It's important to have a daily routine spelled out and a management action plan, so that the patient as much as they're able to, can adjust their bowel regimen at home without having to come to the doctor every time.

Follow up and discussions for bowel management should be done on a routine basis with a primary care doctor. I ask my patients about how their bowel plans are going every time I see them to emphasize how important it is for their quality of life and well-being. A GI doctor sometimes can be helpful in figuring out plans and adjusting medication, and sometimes physical medicine doctors, especially those that are familiar with spinal cord injury are a great resource to manage bowel plans.

Bladder concerns. Dr. Fletcher spoke more in depth about bladder concerns for people with mobility impairments last week so I highly recommend looking at -- I'm sorry, two weeks ago. I highly recommend looking at her talk. But this is a brief summary of those things particular to the transition years. First, bladder dysfunction may progress or change with age. This sometimes can be due to puberty or long-standing high pressures in the bladder, so it's important to continually reassess bladder function on a routine basis.

Incontinence again is a huge quality of life concern. And we need to prevent complications such as kidney damage, increased stone burden, whether that be in the kidneys or the bladder, frequent infections that can cause worsening kidney damage or just make you feel bad and necessitate hospitalization. And then finally organ or pelvic prolapse.

Here are our bladder goals. So first we need to monitor for complications. So I ask my patients if they're having any difficulty inserting their catheter or they need a change in the size or type of catheter they're using to help them with their adaptation skills. I also monitor for increased UTIs as that might be a sign of another problem and changes in their continence. Again, this might necessitate a urological evaluation. My goals when I share with my patients and other staff are that we need to maximize regimen independence. Remembering the cath on time and doing all these steps as independently as possible. Even if somebody doesn't have the mobility and dexterity to do it on their own, how can we help them be more in charge of their regimen? Sometimes this looks like they're instructing their provider to help them or give me five minutes I'm going to finish this and then we can cath. These are ways that people can have increased autonomy and independence.

Continence is a huge factor for young adults as they're entering into the work force as well as into more intimate relationships. It's important for a young adult who is transitioning to adult care to establish with an adult urologist familiar with neurogenic bladder and sometimes you have to do a little searching to find out the type of urologist that can do that for you. So it's good to call ahead and make sure that they can provide services such as urodynamic testing and pelvic floor health.
Next is sexual health. Patients that have physical impairments need the same preventative care and education that any other woman would need. So they need the same health checks, that includes a Pap smear at age 21 if they are sexually active. That can be modified to the individual if they’re not sexually active, I may not do a Pap smear but talk about the importance of regular monitoring. We need to monitor for organ prolapse because it happens at a younger age, sometimes in their 20s or 30s, you'll see bladder prolapse, uterine prolapse, or all pelvic floor prolapse. So it's good to do an external exam to evaluate for that concern. It's important to talk to patients about the modifications that they need for well-woman exams. They may never have had one before so they may not know what those are. You need to point out we need to talk about any pain or feeling of embarrassment, discomfort as you move about the well woman examine and also explain everything as you’re doing it are tips I always remember. I also think about a table that can lower down to the floor to help with transfers and having extra pillows that might support patients, especially if they have scoliosis.

It's important to talk about menses, sexual health and function, relationship safety as women with disabilities are at higher risk for abuse, and child bearing and the risk of having a child with their same condition and the risks to their own health if they are to carry a child. Again, it's important for them to begin with OBGYN care as a young adult and we want to make sure they check in that the OBGYN facility can facilitate their concerns. There are some educational resources I found helpful to help parents talk about sexual health with their children with disabilities as well as a paper I think is appropriate for providers and families.

Menses and contraception. So menstrual problems can include pain, hygiene, and heavy flow. How do I change and do hygiene with a physical disability. And contraception options as well as discussion with families are important considerations.

So again, it's important to set expectations with teens and families regarding confidentiality. So it's important for teenagers to understand that they can ask about their sexual health, any questions with their doctor, without their family knowing. Because they have to pick up a prescription with their family if they’re younger than 18, it's likely that their family member is going to find out that they are prescribed birth control pills but they can buy anything over the counter. Any barrier protection without parental consent, they can do that themselves. I oftentimes find that teenagers with physical disability have never spoken with their physician about any sexual health concerns by themselves. So it's just really nice, and they really welcome talking about this topic.

So, first of all we all want to talk about pain management. Do you have heavy menses, cramping with your period? Non-steroidal anti-inflammatory really help, I usually recommend they take Motrin or ibuprofen every six to eight hours the first couple of days with their cycles that helps with the cramping and contraceptive therapies that lighten the flow can also help with pain management. Flow management is important just for hygiene and care. Long-acting oral contraceptives, such as pills that are for every three months can be helpful. An IUD placement can be helpful for menses flow. It can almost eliminate menses and has to be replaced every ten years, but this needs to be individualized as some women may not be able to have an IUD secondary to organ
prolapse. And Implanon, a progesterone therapy that is inserted into the upper arm, can be nice for flow management. I tend not to recommend that patients with disabilities at increased risk for disuse osteoporosis receive Depo-Provera injections for menses. Patients like it because they don’t have menses at all usually, but it creates an increased risk for osteoporosis.

Contraception is important to talk about in light in combination with other medications such as seizure medications and antibiotics. These sometimes increase the metabolism of oral contraception therapy making the oral contraceptive therapy less effective. So you can become pregnant or have breakthrough bleeding if you're on other medications that interact. Barrier methods are also important to talk about. And I always talk about the importance of having the define relationship discussion with your partner before you get in the mood. It's important to understand what they're thinking, what you're thinking about what are your goals and plans for the future.

Obesity is a huge concern, as it may cause problems with mobility and skin. Such as skin breakdown due to not being able to transfer as well. It's important to think about for lung function and pelvic floor function. It's important to address that. Sometimes the patients may need to meet with a nutritionist to ensure they have adequate nutrients as well as keep their calorie count correct for them. And it's important to address emerging adult health problems that you would see with any adult but may present early with people with disabilities. Such as high blood pressure, diabetes and sleep apnea.

Thinking about Maria’s health, we wanted to address her equipment, her range of motion, her skin, her bladder, if she's having frequent leaking she may need to have her cath regimen evaluated as well as follow-up with a urologist for bladder studies. For her bowel she uses a MACE which is that antegrade enema, but she can't set it up by herself. So with a MACE people hang up a bag of water on their shower and sometimes need a parent or caregiver to help with that. Sometimes I'll order an IV poll that helps them to raise their water for themselves. I also might consider an OT assessment at home just to help me have eyes and ears in the home to see what a patient may need to support their independence.

Sexual health. Maria shares that she is not sexually active, has heavy menses and wonders in the future about having children. Sometimes if you find that the patient doesn't want to start the conversation, I just ask them what they know. I might start talking about do they understand why they have a period? Has anybody ever spoken to them about their sexual health? Or I say many women with Spina Bifida, or whatever condition, they ask me if they are at higher risk for everything a child with Spina Bifida. Even teenagers at a very young age oftentimes have that question. So I talk about that. Particularly for women with Spina Bifida, they have about a 4% increased risk of having a child with Spina Bifida and it's recommend they take adequate folic acid supplementation.

We notice Maria has gained about 10 mounds in the last two years. We talk about diet. Having a body that is well-nourished and full of things that are good for your body. Think about food not being the enemy or comfort think about it as nourishing my healthy body.
so I am able to do all the things I need to do and feel good.

Mental health is a huge concern for young adults with disabilities as they struggle with anxiety, depression, self-acceptance, or even substance abuse. There are concerns with dealing with their health concerns within their community or school, adaptive living considerations that are unique to young adults and oftentimes challenging. And there are so many changes that are happening and change is stressful for everybody. So it's important to consider these issues. Talking about mental health, especially by a one-on-one with the provider and with the teen is so important. Peer groups can also help to help people feel like somebody understands where they're coming from and they can share empathy with one another. Counseling and adult mentors are so important to give them a hope and a healthy perspective. And I just encourage people to embrace adulthood. It's a new challenge and adventure.

Maria's mental health, she reports she was bullied in middle school about using a wheelchair and having incontinence. I find people have PTSD after middle school whether they have a disability or not. She does say that her family and boyfriend are supportive. We might want to encourage those relationships and talk about ways that Maria does feel supportive about those things which might help her in the future. She has a lot of anxiety about meeting new people and trying new things. So we can really help by supporting her in the clinic and practicing and seeing her often. She feels mostly happy but sometimes has bouts of depression especially when she's sick in the hospital for several months. I find these issues happen a lot of time with skin or wound infections that take several months to heal and really do make it not able for the patient to participate in their normal activities.

So here's a list, again, to help Maria. Peer group, counseling, regular follow-up. I see my transition patients every three months to help establish that relationship as well as make sure that their chronic condition has been checked. I focus on things that patients are good at and they've already achieved to give them that extra support. And then give them small goals that they can really be successful in that 3-month time period which helps them look forward to things they can do better.

Keeping positive perspective during transition. One, we have to have a plan. Get organized, we have to practice self-management skills as well as self-advocacy. And talk about the changes. Just because you don't want to talk about them doesn't mean they'll go away and oftentimes can lead to a crisis and we don't want that. I encourage patients if you don't know, then just ask me. It's not because you're stupid or trying to stick out or anything like that. It's just that I need to make sure that I'm explaining things in a way that you understand, because you have to do them at home to support the best you can be.

Make wellness a routine. So this includes self-management and good practices that we all need to do such as sleep, exercise, and healthy eating. And then embrace adulthood. It can be full of wonderful relationships with family and friends. We need to maximize independence, which includes freedoms, but also responsibilities and contribution to our family. And then we all need to contribute to the world in our own way. I always say there's unique gifts that one of my patients have. It's a matter of figuring out what those
are and how to best express them and keep their health and adaptive living in check so they can do all the wonderful things they're gifted at doing.

I loved this quote and it helps me to keep a positive perspective in helping patients through a very challenging but exciting time. And it says: If nothing ever changed, there would be no butterflies. And that's a good thing for us all to remember. Thanks so much to everybody who’s attended today.

>> RACHEL MARKLEY: Thanks, Dr. Fremion. I know I appreciated all that valuable information. I hope everybody else did. So as of right now, I don't see questions in the chat box. I'm going to just pause for a couple of seconds. If anyone wants to type those in the chat box it's the second button on the right under "leave" if you weren't sure where that was. Go ahead and type that in. And if you don't want to type them in right now, you can always send us an e-mail at crowd@bcm.edu and we will forward those on to Dr. Fremion or whoever can best answer those and try to get back to you fairly quickly.

I don't see any just yet. So I'm going to go ahead and wrap up. This concludes the formal webinar. If you still have questions about this or any of the other upcoming webinars in the series you can contact us at 832-819-0232. Or again at our e-mail.

Okay. And so we do have one question. Dr. Fremion, if you want to answer it. We have a question that says how do you address menses in people, girls with mobility impairments?

>> ELLEN FREMION: So, first of all, it has to be an individualized therapy. Nowadays in adolescent medicine, the menstrual cycle of a woman is considered the fifth vital sign with heart rate, blood pressure, and respiratory rate. So very important to understand the menstrual cycle. So I ask patients if they have regular menses, what age did they get them, all those general questions to get a good sense of what is menses like in their life. And then I ask them impact questions. So do you ever have to miss school because of your menses? Can you manage your menses by yourself? Because that gives you kind of an idea about how to target therapy. And then you want to ask about their sexual health and the impact as well.

So I might start out with talking about what patients feel comfortable with. Are they able to take oral contraceptives by themselves? That's always a good place to start because you can switch pills easily take them on or off but you want to consider other factors. Women with physical impairment chronically don't necessarily have an increased risk of DVTs as a change from baseline. But of course if they have increased infections or they have to be on other medications that may interact, oral contraception may not be the best option. The Ipmlanon which may make cycles lighter, again it is inserted in the upper arm, usually be an OBGYN. Again, it is a little more permanent but another option that's great and a Mirena is a great option that's placed by the OBGYN.

I see another question in regards to urology and gynecology who are sensitive to mobility impairment. So I am in Houston, so we use the Methodist transition urology clinic with Dr. Rose Khavari as well as Dr. Julie Stuart and Fletcher who is part of the health initiative
came from that clinic and we miss her very much but we love Dr. Khavari and Dr. Stewart. Recently we are starting to work with Dr. Tara Harris at the Texas Children’s Pavilion for Women. She is developing a clinic that is particular to young woman who have either physical or intellectual disabilities and need modifications for examination and therapy for disabilities. So those are the ways that I start. Hope that answers the question.

>> RACHEL MARKLEY: I can also answer a little bit to that. We discussed after the previous webinar possibly putting some of those resources up on the website as well. And we're still working to get those available. At least for the people in Houston.

So Dr. Fremion, if you could advance your slides please. Thank you. And so again, we would like to thank Dr. Fremion for sharing her time and knowledge with us. I would like to remind you again today’s session was recorded and it will be available very soon for viewing on our website. And slides are already up. I also would like to remind you of our two upcoming webinars on May 4th and May 18th. You can still register for those again at www.bcm.edu/crowd. And you should be receiving a link at any moment to an evaluation survey. It will come out right at 2:00 and we really appreciate it if you would help us participate in our efforts to improve our webinars as well as to help us identify future topics. And please take the survey even if you completed the one from the April 6th webinar. I don't see any other questions. So I would like to again thank everyone, and enjoy the rest of your afternoon.