

## Transition of care policy for youth & young adults

UCSF Pediatric Urology is committed to helping our patients make a smooth transition from pediatric to adult health care. This process involves working with youth, beginning at ages 12 to 14, and their families to prepare for the change from a pediatric model of care where parents make most of the decisions, to an adult model of care where youth take responsibility for decision-making. This means that we may spend time during the visit with the teen without the parent present to assist them in setting health priorities and supporting them in becoming more independent with their own health care.

At age 18, youth legally become adults. We respect that many of our young adult patients choose to continue to involve their families in health care decisions. Only with the young adults' consent will we be able to discuss any personal health information with family members. If the youth has a condition that prevents him/her from making health care decisions, we encourage parents/caregivers to consider options for supported decision-making.

We have a dedicated UCSF Lifetime Congenital Urology Program (L-CUP) that is designed to serve patients transitioning out of the Pediatric Urology clinic as they become adults. The goal of this clinic is to facilitate a smooth transition of care out of the Children's Hospital setting. The clinic is jointly run by pediatric and adult urology to provide uninterrupted, comprehensive urologic follow-up.

## What you need to know by the time of transition

- Your diagnosis
- Your medical history
- Your medications (why, when, how much?)
- Your medical team and pharmacy
- When you should call or be seen
- Emergency phone numbers
- Your medical insurance coverage
- Other community resources
- You should make sure that you establish a primary care physician that will serve as your point of contact to manage your overall healthcare once you become 18.

## Where can you get more information about transition?



Got Transition is an organization that helps to improve transition from pediatric to adult health care using new and innovative strategies for health professionals and youth and families. They have a lot of information for youth and families on their website:

[info@GotTransition.org](mailto:info@GotTransition.org)  
[www.GotTransition.org](http://www.GotTransition.org)

# Pediatric Urology Transition Of Care Policy & Information

## When does the transition happen?

We will collaborate with youth and families regarding the age for transferring to this transitional clinic, and recommend that this transfer occur before age 22.

## Transition is a process

Transition starts at age 12-14 and involves starting to build confidence in yourself to be your healthiest self. The process of transition should prepare you to listen, learn, and be responsible for your health.

## What should you do to prepare for the transition?

You should make sure that you establish a primary care physician that will serve as your point of contact to manage your overall healthcare once you become 18.

You can prepare by practicing scheduling appointments, calling in your medication refills, keeping a calendar of your appointments, sign up for MyChart, asking and answering questions at your doctors' appointments, and start thinking about what your goals of care are and what issues you want addressed.

## Where is the transitional clinic?

The transitional clinic is located at UCSF's Parnassus Heights location in the Urology Faculty Practice at 400 Parnassus Avenue, 6th floor. Parking is available in a parking structure or valet parking is available directly in front of the Faculty Practice building.

## What type of patients do we see?

We see patients with congenital urologic disease and those with urologic conditions diagnosed in childhood that will need long-term urologic care. These conditions include:

- Spina bifida
- Neurogenic bladder and bowel
- Bladder exstrophy and epispadias
- Intersex or difference in sexual development
- Cloacal anomalies
- Hypospadias
- Vesicoureteral reflux
- Prune belly syndrome
- Posterior urethral valves

## What happens at the first visit?

Before you arrive, you will be asked to fill out some paperwork about your current urologic care. When you arrive, you will fill out some questionnaires about what issues you would like addressed and what your current symptoms are.

You will be seen by a pediatric urologist (Dr. Hillary Copp) and an adult urologist (Dr. Lindsay Hampson). You can bring your family/friends into the room with you, although we will ask them to step out briefly so that we can perform a physical exam and make sure we address any concerns or questions you have that you might not want to talk about in front of them. The entire visit should last about an hour.

On your way out, we may ask you to stop by the lab or radiology department to get bloodwork or imaging studies done.

## What to bring to your first visit?

You should bring any supplies you regularly use (such as catheters) so that we can document what supplies you use and help to get supplies for you in the future.

You should also bring the names of any doctors you see regularly, such as your primary care physician, so we can send them a note about our visit.

## What happens after your first visit?

After your first visit, you will follow-up with Dr. Hampson for your regular follow-up visits. Dr. Copp will continue to be involved as a resource if questions arise or if you need surgery in the future.