Guiding C3G patients through the transition of care between pediatric and adult providers

C3G can be diagnosed between the ages of 5 and 15. A subtype of C3G, dense deposit disease (DDD), is most often diagnosed in children. C3G is a chronic, progressive disease which means children diagnosed will have this disease for the rest of their lives. As they approach their late teens and early 20s, children will transition from pediatric to adult providers. This means a new care team and a shift away from family-oriented care to patient-centered care.

The key to a successful transition is preparation. See the table below to help you and your family with the transition process.

This period of transition between care providers can cause missed appointments, lapses in medicine, and a general lack of care. Because C3G is a progressive disease, it is important to take charge of your health to reduce the risk of your disease getting worse. Being proactive and prepared is the best way to take charge of your health.

Ages 11-17 — **18** — **Ages 19-25** — **26** — **Age 27+** →

Transition Phase 1:
PEDIATRIC CARE (FOR PARENTS)

START CONVERSATIONS EARLY ON

- Talk about C3G and explain what it is
- Talk openly about how they feel about having C3G
- Brainstorm questions for appointments with your child

INVOLVE YOUR CHILD

- Show them how to make appointments and refill medicines
- Keep track of appointments on a calendar that you can access together
- Give your child their own insurance card to carry

WORK TOGETHER

- Create a medical summary document, including medicines, and update it frequently
- Talk with the pediatric doctor about what the transition to adult care will look like

COMMUNICATE

- Ask for recommendations for adult providers
- Make a plan for how your doctor will communicate with your new provider

Transition Phase 2:
JOINT PEDIATRIC AND ADULT CARE

RESEARCH AND COMMUNICATE

- If you plan to move, research potential providers in the area
- Visit potential adult providers
- Talk with your parents/guardian about taking charge of your own health and the responsibilities you will have
- Write down any questions or concerns you have

TAKE RESPONSIBILITY

- Update your medical summary and provide this to any new doctors
- Provide contact information of your pediatric provider to your adult provider and vice versa so they can easily communicate
- Call your new adult provider and ask if they need any information before your first appointment and any documents you need to bring to your first appointment

PLAN

- Have a plan for when your insurance may change whether this is through a new job or when you are no longer receiving insurance through your parent/guardian.

Transition Phase 3:
REGULAR ADULT CARE

BE EMPOWERED

- C3G is a chronic and progressive disease. Be proactive and take charge of your health to support your overall well-being and quality of life.
- It's important to feel comfortable with your providers. If something doesn't feel right, you always have the option to find a new provider.

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Transition for the patient

Transitioning away from providers that you have seen for a long time can bring up a lot of emotions, like fear and anxiety, which are completely normal. Making a good transition plan and being involved can help ease these feelings and set you up for success.

WHAT YOU CAN DO:

1. **Ask questions.** Talk to your parents and providers about the transitions and ask any questions that come up.
2. **Take charge**. When you turn 18 you will be legally in charge of your healthcare. Before then, talk to your parents about keeping a copy of your medical records, making your own appointments, and other ways you can collaborate to be more involved in managing your care.
3. **Think ahead!** Your teens and 20s are transitional in all areas of life. Think about where you want to be in the future and how you can set yourself up for success to get there.

Teens Take Action! Have you:

- Received your own health insurance card?
- Made a copy of your medical records OR set up access to electronic health records?
- Written down the contact information for your providers?
- Scheduled an appointment by yourself?
- Refilled medicines by yourself?

This transition might be happening when other things are changing, like school or work. Attending many appointments and taking medicines daily might make you feel different from other people your age. It's natural to want to be like everyone else and you might feel like skipping appointments or not taking your medicines. ***This is dangerous when you have C3G because skipping appointments or medicine can make the damage to your kidneys worse, even if you can't feel it.*** Over time, this damage can lead to kidney failure which means you will need dialysis or a transplant.

WHAT YOU CAN DO:

1. **Talk to your friends about C3G.** Let them know what it is and how it affects you.
2. **Use your phone.** You can set an alarm or download an app to remind you when to take your medicines.
3. **Tell your care team how you are feeling**. They can help you navigate some of these complexities and refer you to mental health professionals for additional support.

Living with a chronic disease is not easy, something you probably know well from growing up with one. You may feel sad, anxious, or depressed at different times. Talk to the people in your life about what you are going through and consider seeking professional mental health care. This can be from a social worker, counselor, or therapist. Having a support system can help you take care of your mental health and take care of your kidneys.

Transition as a parent/guardian

You have probably grown used to being the "driver" of your child's care. It can be difficult to process this transition and hand over control of their care. Involving your child early on in their care can make this transition easier for all members of your family.

WHAT YOU CAN DO:

1. **Involve them early**! Talk openly about C3G and use full names of medicines, procedures, and doctors.
2. **Find support.** There are many support groups for parents of children with chronic diseases that can provide support from people who understand your experience.
3. **Take care of yourself.** Your health is just as important as your child's. Eating healthy, being active and keeping healthy habits can make sure you continue to show up for them. Taking care of your mental health is just as important. Talking to a professional such as a therapist or counselor can provide additional support.

To learn more about C3G visit:
KidneyFund.org/C3G

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