

# Empowering Pediatric Patients With Chronic Medical Illness: Developing Youth Leaders for Improved Transitions to Adult Care



Celeste Lopez, M.D., Wendy Froehlich, M.D., Lauren Schneider, Psy.D, Claire Selinger, M.D.  
Stanford Hospital and Clinics, Lucile Packard Children's Hospital, Palo Alto, CA



## Summary

- Health care needs of adolescents with chronic conditions are often unmet as they transition into adulthood, which puts them at especially high risk for developing mental illness in addition to their medical illness.
- We have initiated the Pacific Adolescent Leadership Council (PALC), a mentorship group for pediatric patients with chronic illness and their college age counterparts as mentors.
- Focus is on developing strengths in youth that may contribute to improved disease management and the ability to advocate for oneself in the healthcare environment, as opposed to focusing on adolescent risk behavior.

## Methods

- Teenagers with a variety of chronic medical illness were recruited through health-care providers at the hospital and clinics, and college age mentors with chronic medical illness were recruited through the university and their health-care providers.
- The group meets monthly at the hospital and teenagers receive mentoring from the college student mentors and the college student mentors receive mentoring from each other and from professional staff, including psychiatrists and psychologists.
- Parents of teens and mentors meet at a separate Parent Council simultaneously to discuss topics pertinent to parenting a child with a chronic medical illness.
- All participants receive psychoeducation about common issues related to illness and treatment that patients face at these key developmental stages and discussion of ways to deal with issues such as stigma, adherence, and communication with the medical team.

## Purposes

1. Provide social support for teens with chronic illnesses that will be reflected by decreased loneliness and increased locus of control, transition readiness and competence in self care.
2. Provide psycho-education to patients, families, health-care providers, and medical trainees with the goal of improving and/or maintaining adherence to medical treatments and generating more positive attitudes toward chronic illness.
3. Substantiating the effects of a replicable model of support for pediatric patients with chronic illness and treatment.

## Results

- The experience of sharing stories of both positive and negative experiences about doctors and illness was validating for the group and was the initial result of mentorship.
- Mentors and teens moved beyond a supportive stance with each other to become mentors to other patients, physicians and their community.
- Participants generated strategies (below) and teens have presented their insightful results and stories in multiple arenas such as a morning report for pediatric residents, a medical student class on working with children with chronic disabilities and nursing and social work forums.



## Top Ten Strategies for Doctors

1. **Remember that your patients are people, treat them as such**—it is easy to get wrapped up in curiosity or excitement, but we are *not* a case study or an object.
2. **Be humble**- be able to say "I don't know" and admit that you don't have the answer. *Admit* when you are wrong or have messed up in *any* way.
3. **Don't be deceptive**—Be *honest*. Do not withhold information or lie to us, it will only betray our trust and make us wary.
4. **Ask us!**—we are not children anymore; talk to the patient, not the parents. Talk to us about our condition(s), explain things to us (using diagrams if necessary), and ask *us* questions.
5. **Trust and Listen**— Listen to what your patients have to say and their concerns. Believe and trust in what we say.



6. **Be sensitive**-understand and be sensitive to the emotional impact of chronic health issues, remember when treating to keep the emotional and the physical *separate*—don't jump to conclusions.
7. **Be responsive**—answer emails and other correspondence and patient inquiries in a quick and timely manner.
8. **We are not our illness**—take interest in our lives outside of the medical, ask as about non-medical topics.
9. **Make us comfortable**—have a positive attitude, be empathetic, gentle, caring, and compassionate, joke when appropriate.
10. **Collaborate**- patients rely on you to provide care and recommendations based on information from a wide range of providers that they see.

## Advice to Psychiatrists from PALC teens

- "My psychiatrist treats me more like an adult even though I'm a teenager, which helps me think about how I'm going to balance all this out. I have become more honest with my mom because of this, because when I become an adult, I'm going to need her still because of my illness. The psychiatrist is helping me transition to being more responsible for my own care."
- "I felt babied by the child psychiatrist, the adult psychiatrist seems to make me want to figure out my own problems, and fix it myself. It is more cold, and not all of us are full grown adults. Starting when you're 15 or 16 the psychiatrist should start pointing out things, and showing me right from wrong, and not let me get away with stuff. They should start encouraging me to find a solution, instead of just giving me the answer."
- "Turning eighteen doesn't mean you're an adult, or ready to be independent, it's just a number. The psychiatrist should try to make me feel less dependent but still include my parents because I need them."
- "Be empathetic--please feel with us, not just for us. But don't feel compelled to say 'I know how it feels' when you don't know. In those cases, we would prefer to be told honestly that 'I do not know how it would feel but I am sorry that you are having a hard time.'
- "When you talk to a psychiatrist for the first time, you realize how much your mental health state and physical health are so together, they're not separate. Your attitude and everything that's happening to your health will have an effect on how you can handle your medical illness. Now I know that it's a balance, and I'm depressed because of my medical problem, and the psychiatrist can interact with me about the experience of being sick. When I found someone other than my parents to tell my feelings to, it helped a lot."