



myFace

Transforming Lives: Navigating Adolescence with a Craniofacial Condition: Strategies for Empowerment and Success

myFace is pleased to collaborate with the American Cleft Palate Craniofacial Association (ACPA) to present this educational program



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Welcome and Introductions



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Presentation



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Disclosures

- **Meredith Albert, PhD**, has no disclosures
- **Canice E. Crerand, PhD**, has no disclosures



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Objectives

- To identify stressors and to describe strategies for effective stress management
- To provide strategies to help navigate the social world of adolescence
- To empower adolescents to set goals, plan for their future, and increase their independence and self-efficacy both in and out of school



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Adolescence Defined.....

- A time of independence and identity seeking
- A time of “storm and stress” that occurs between the ages of 14–24 years (G. Stanley Hall, 1904)
- A period of “moratorium” when a person is free from responsibility and seeks to develop identity between the ages of 12–18 years (Erik Erikson, 1958)
- Any person between the ages of 10–19 years (World Health Organization, 2023)



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Transitions and Stressors

Milestone/Transition

- **Physical** development
(height, weight, puberty)
- **Cognitive** development
(abstract thinking; form own ideas)
- **Social** development
(peers > family; romantic interests)



Stressor/Challenges

- Preoccupation with appearance
- Self-consciousness
- May have different views from parents (politics, religion, rules, etc.)
- Exposures to risky behaviors (alcohol, vaping)
- Social media use/bullying



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Identity Development

- Who Am I?
- How am I similar or different from peers?
- What do I want to do with my life? Career? Family?
- Imaginary Audience
- Identity development as a source of stress



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Identity Development

- Children and teens with craniofacial differences may feel different from peers
- Normalize and validate
 - Talk about similarities to peers and common struggles associated with adolescence
 - AND validate feelings of being different related to having a craniofacial condition



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Identity Development

- How to support your teen during this time:
 - Reflect on '**hidden benefits**' or positives that may have come out of their experiences (e.g., empathy, inner strength, resiliency, belief in one's ability to handle stress and hard times)
 - Recognize that there may be times when they may want to avoid talking about differences—and at other times, they may want to discuss them directly—and this may shift over time
 - Keep lines of communication open
 - Educate and involve them in their medical and/or surgical care



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Parent-Child Conflict

- Why won't my teenager talk to me?
- What do we argue about?
- Car/transportation, phone, social media, school, sports/outside activities, friends, clothing, medical/surgical decisions, nutrition, bedtime
- Nurturing
- Independence
- Responsibility



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Strategies to Improve Parent-Child Communication

- Space and Respect
- Listening vs. Hearing
- Scheduled Talk Time
- Back and Forth Notebooks
- Texting
- Clearly outlined rules & consequences



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Example: Rules List

Topic	Rule	Consequence
Phone Usage	2 hours per day	Loss of phone privileges for a day
Putting Gas in the Car	Gas tank should have ½ tank at all times	Loss of car for a day
Chores	Laundry, Dishes, Mowing Lawn	Separate consequence for each expected behavior
Grades	Family to discuss expected grades	Family to discuss consequences for missed assignments, poor grades etc.

Rules should be: **CLEAR and ACHIEVABLE, with APPROPRIATE CONSEQUENCES**



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Social World of Adolescents

- Peers play a central role in the lives of adolescents
- Friendships are important to development
 - Source of validation and support
 - Model for healthy relationships in adulthood
- Social circle expands outside of the family to include friends, dates/romantic interests/relationships, teammates, club members, adult mentors/coaches, work colleagues/bosses



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Social World of Adolescence

- Quality or quantity of friends?
 - Quality—having a best friend/one good friend who is supportive and trustworthy can protect teens from mental health risks (depression)

- Social media is increasingly a part of socialization and social development for teens
 - Group chats/texts
 - Whatsapp, Snapchat, Instagram, TikTok, YouTube
 - Gaming



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Social Media



- Talk about pros/cons of social media
- Importance of 'IRL' and online friends
- Consequences of posts
 - Adolescents may not be able to accurately think through long-term consequences
- Monitor your child's social media activities and accounts



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Strategies to Support Social Development

- Types of Support
 - Youth with craniofacial conditions may benefit from having support from other peers with craniofacial conditions AND peers in their daily lives
 - Online or hospital-based groups, national support organizations like myFace
- What to do when your teen does not seem to be socializing enough?
 - Volunteer work
 - Extra-curricular activities
 - Church/faith-based groups
 - Mentor younger children (camps, sports teams, etc.)



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Cyberbullying

- Bullying that occurs over digital devices (phones, tablets, computers)
 - Social media, email, text messages, chat rooms, gaming communities, IM/DM
- Sending, posting, or sharing negative or mean content about other people or trying to embarrass or humiliate others



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Cyberbullying

Where it is occurring can help determine how to report it:

- School-based platform or activities: contact school administration.
- Friends/peers: Reach out to parents of bully.
- Contact the platform administration to remove content, block users, delete accounts, etc.:

<http://www.cyberbullying.us/report>

- Contact the police or local law enforcement for threats of violence/aggression, blackmail, stalking



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Teasing & Bullying

- Risks are higher in youth with craniofacial conditions due to appearance, speech, and/or learning differences
- Middle school is often time of greatest risk
- Rates of bullying often decline by high school
- Teens may struggle with social exclusion even if overt bullying declines
- Bullying and social exclusion can have negative impacts on adult adjustment (e.g., anxiety, depression, body image dissatisfaction, low self-esteem)



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Strategies to Handle Teasing and Bullying

- Validate feelings and offer support
- Tell your child that the bullying is not his/her fault
- Address concerns with adults in environment where bullying occurs (bus, school)
- IEPs and bullying—can include protections, social skills support
- Problem solve together: explore options about how to handle it, consider teen's perspectives and choices about strategies with contingencies (e.g., if their strategy doesn't work, what is next step)



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Strategies to Handle Teasing/Bullying

- Ask open-ended questions (“Tell me about your day—what was a high point or a low point?” vs. “Did you have a good day?”)
- Look for signs such as damaged or missing property, clothes; avoidance of going to school or riding bus; story that doesn't match up with your observations
- If you notice changes in your child's mood, behavior, or have concerns that they may be thinking about suicide or harming another child, consultation with a mental health professional is recommended



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Social Transitions and Facial Differences

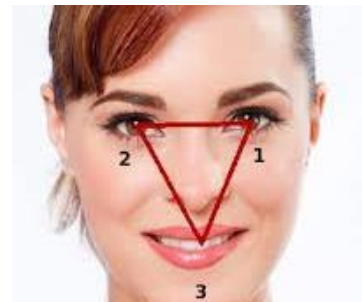
- New schools, activities, jobs, etc. involve meeting new people who may be unfamiliar with your child and their craniofacial differences
- Having a facial difference can create social challenges
 - Staring
 - Questions
 - Lack of eye contact
 - Loss of anonymity—not being able to ‘blend in’ with the crowd



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Social Transitions

- Humans are hard-wired on a brain level to notice differences
- We are also naturally drawn to faces – particularly the eyes and mouth since these play a role in communication
- Can be helpful to think about noticing or staring as ‘neutral brain response’ rather than an indication of cruelty



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Social Transitions

- Adolescents may benefit from their improved abilities to engage in perspective taking
- Why might other people stare or look away when they notice a person with any type of difference (e.g., wheelchair, amputation, hearing aid, scar?)
- Have they ever noticed a person with a difference and wondered about what caused it or how it affects them? How did they react in that situation? How would they change their response/reaction?



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Making the First Move

- Confident body language (standing up straight, making eye contact, smiling)
- Introducing yourself (“Hey, I’m Canice, what’s your name? Great to meet you.”)
- “Small talk” conversation starters (e.g., weather, traffic, school assignments, current events)
- Open-ended questions (“What do you think about...”)



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Making the First Move

- Look for commonalities (“I love Taylor Swift, too! What’s your favorite album?”)
- Bringing up difference in a casual way (rather than waiting for a question).
 - “Yeah, my day was OK. I just got back from a doctor’s appointment. I have to go every year for a check-up related to my cleft lip and palate. No more surgery for me right now which is awesome. Let’s figure out some fun things to do this summer!”



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Questions about Appearance/Speech Differences

Explain---Reassure---Distract/Deflect

- 1) Prepare a **brief explanation** about your craniofacial condition (“I was born with a cleft lip and palate—I had a split in my lip and roof of my mouth.”)
- 2) Offer some **reassurance** (“It’s Ok, it’s not a big deal, I had some surgeries when I was a baby. Sometimes it affects how I talk and how well others can understand me. Let me know if you need me to repeat something.”)
- 3) **Steer the conversation in another direction**, preferably onto something that you may have in common (“Hey, what was our science homework assignment for tonight? Do you want to study together for the exam?”)



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Mental Health

- Common mental health concerns among adolescents:
- Depression
- Anxiety
- ADHD
- Adjustment
- 1 in 6 U.S. youth aged 6–17 experience a mental health disorder each year (NAMI)



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What is *normal teenage stuff* versus *psychopathology*?

- Behaviors & Symptoms to Monitor
- Examine day to day functioning
- What has changed?
- How successful is adolescent in school?
- What do peer relationships look like?
- What kinds of activities does the teen participate in both in and out of school?



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Common Signs & Symptoms to Monitor

- Excessive worrying or fear
- Feeling excessively sad or low
- Confused thinking or problems concentrating and learning
- Extreme mood changes, including uncontrollable “highs” or feelings of euphoria
- Prolonged or strong feelings of irritability or anger
- Avoiding friends and social activities
- Difficulties understanding or relating to other people
- Changes in sleeping habits or feeling tired and low energy
- Changes in eating habits such as increased hunger or lack of appetite
- Multiple physical ailments without obvious causes (such as headaches, stomach aches, vague and ongoing “aches and pains”)
- Inability to carry out daily activities or handle daily problems and stress

(NAMI: National Alliance on Mental Illness – www.nami.org)



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Strategies to Support Positive Mood and Reduce Anxiety

- Professional help: When & Why?
- Be the Parent, Not the Professional
- Pediatrician, School-based Counselor, Therapist, Psychologist, Psychiatrist
- Psychologytoday.com
- Apps on the Phone
- Relaxation Strategies and Ground Exercises
- Craniofacial Differences and Deep Breathing
- 988 Suicide & Crisis Lifeline



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Apps

- Headspace – www.headspace.com
- Calm – www.calm.com
- Three Good Things – apple store, android, google
- Happy Not Perfect – happynotperfect.com



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5, 4, 3, 2, 1 Strategy

- **FIVE** things you see around you. Furniture, Pencil, Smudge of dirt on the window, anything in your surroundings.
- **FOUR** things you can touch around you. Hair, the ground, a pillow, a watch, clothing items.
- **THREE** things you hear. Any external sound. Wind, ticking of a clock, passing car, furnace.
- **TWO** things you can smell. Soap, hand sanitizer, candle, garbage can.
- **ONE** thing you can taste. Taste in your mouth, gum, mint.



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Categories Exercise

- Choose at least three of the categories below and spend a few minutes naming as many items as you can in each one:
- Movies
- Countries
- Books
- Cereals
- Sports Teams
- Colors
- Cars
- Fruits & Vegetables
- Musicians
- Animals
- Cities
- Famous People



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Transitions

- School: High school, college, vocational school, workforce
- Promote independence and self-esteem (choices and control)
- Responsibility in decision making
- Goal-setting (SMART Goals)
- Executive functioning



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SMART Goals



Specific (*I want to earn money this summer by getting a job*)



Measurable (*I will spend thirty minutes/day reviewing job ads, drafting my resume; I will apply for # of jobs each week*)



Achievable (*I will apply for summer/entry-level positions/look for employers that hire for the summer vs. applying for full-time, permanent jobs*)



Relevant/realistic (*I want to build my resume, meet new people, earn spending money*)



Time-bound: (*I will start my job search in April with the goal of starting a job in June after school ends*)



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Resources

- School-based/classroom interventions
- Social skills training programs
- Peer groups for adolescents with craniofacial conditions and families
- Camp programs
- Individual/Family Therapy (e.g., cognitive-behavioral):
 - Cognitive restructuring/reframing
 - Coping strategies
 - Problem solving skills
 - Managing anxiety and relaxation skills
 - Building positive self-esteem and self-efficacy



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Resources

Books for Parents and/or Teens

- *Queen Bees & Wannabes: Helping Your Daughter Survive Cliques, Gossip, Boys, and the New Realities of Girl World* (Rosalind Wiseman)
- *How to Talk So Teens Will Listen and Listen So Teens Will Talk* (Adele Faber)
- *Smart but Scattered Teens: The "Executive Skills" Program for Helping Teens Reach Their Potential* (Richard Guare, Peg Dawson, Colin Guare)
- *The Body Image Workbook for Teens: Activities to Help Girls Develop a Healthy Body Image in an Image-Obsessed World* (Julia V. Taylor)
- *The Emotional Lives of Teenagers: Raising Connected, Capable, and Compassionate Adolescents* (Lisa Damour)



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Resources

Mental Health Websites

- Association for Behavior and Cognitive Therapies: <http://www.abct.org>
- American Psychological Association <http://www.apa.org>
<http://effectivechildtherapy.com>
- Anxiety and Depression Association of America
<http://www.adaa.org>
- American Academy of Child and Adolescent Psychiatry
<http://www.aacap.org>
- WorryWiseKids.org <http://worrywisekids.org/>



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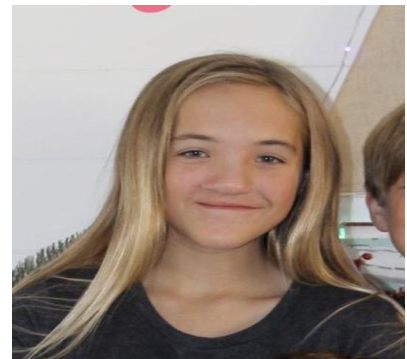
Resources

- Changing Faces
<http://www.changingfaces.org.uk/>
 - Information for patients, families, professionals, teachers about coping with appearance differences due to any cause
- Stop Bullying
<http://www.stopbullying.gov/index.html>
 - Information for patients, families, professionals, and teachers about preventing and addressing bullying
- <http://www.cyberbullying.us/report>



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Hailey's Cleft Story



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Highs and Lows



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Advice



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Contact Information

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Jackson's Cleft Story



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Highs and Lows



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Reflections and Advice



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<https://www.linkedin.com/in/jackson-doane-ab1582242/>



Questions & Answers





Closing Remarks

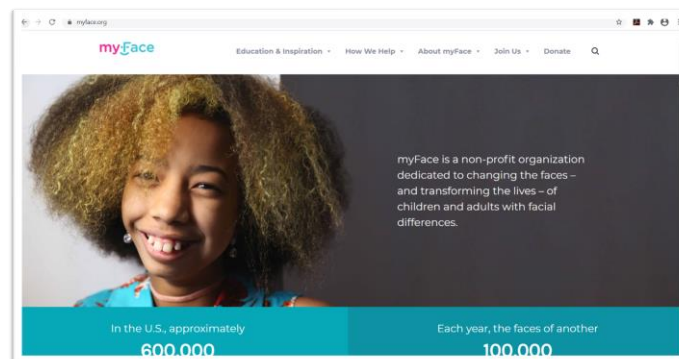


Stephanie Paul
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For additional information and resources
visit [myFace.org](https://myface.org)



Or email us at
info@myface.org



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myFace Adolescent Support Group

myFace offers a FREE Adolescent Support Group for teenagers (ages 14 – 18) with a facial difference of any kind

Sessions are 1 hour in length, and take place on zoom one Sunday per month

Dr. Eric Riklin, a clinical psychologist who has Crouzon Syndrome, is the Group Facilitator

For more information, or to join the group, please visit our website at: www.myface.org/online-groups, or contact Dina Zuckerberg at dina@myface.org



Dr. Eric Riklin



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Upcoming Events at myFace: Podcast

A new episode of our *myFace, myStory* podcast debuted today

Wednesday, June 15th

on all podcast platforms + YouTube

This month's episode will be a conversation With Morgan McGahan, Sara Pollak, and Emily Krebs - three best friends born with **Apert Syndrome**. Register at:

www.myface.org/mystory/



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Upcoming Events at myFace: Races for Faces



Join us on **Saturday, September 23rd**
for a 5K walk, musical performances, carnival games, a raffle, and prizes
Pier 62 at Hudson River Park in NYC
www.racesforfaces.org



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Upcoming Events at myFace: Webinar

Join us for the next webinar in our **Transforming Lives Webinar Series:**
Orthodontic Management of Cleft Lip/Palate – October 2023



Pradip R. Shetye, DDS, BDS, MDS
*Associate Professor of Plastic Surgery
(Orthodontics)
NYU Langone Health
Associate Professor of Orthodontics
NYU College of Dentistry*

**Further information about this webinar will be
available soon on the myFace website**



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Thank You

Please complete the evaluation at myface.org/adolescentsurvey