



A B O U T F A C E<sup>®</sup>

# **FACIAL DIFFERENCE:** A LEARNING RESOURCE FOR HEALTHCARE PROVIDERS



## OBJECTIVE

The purpose of this resource is to educate healthcare providers about the facial difference community to ensure proper terminology use, cultivate respectful patient interactions, and promote facial difference resources.

## INTRODUCTION

A facial difference refers to a congenital, acquired, or episodic change in an individual's appearance involving their face. Many individuals in Canada are living with a facial difference. The facial difference community encounters historical and ongoing marginalization, stigma, and discrimination as a result of ignorance and negative stereotypes.<sup>1</sup>

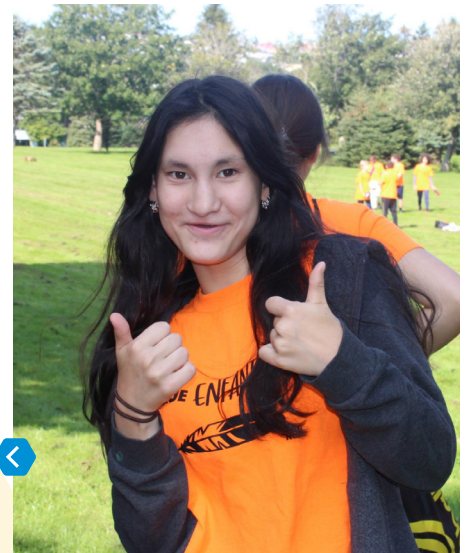
To provide safe, inclusive, and patient-centred care to the facial difference community it is essential for healthcare providers to use appropriate language and terminology, and appreciate the unique needs of individuals with a facial difference.

This module harnesses case-based learning to educate healthcare professionals about the facial difference community and relevant patient resources, so that professionals may provide optimal inclusive and informed care for this population.

Please note permission has been appropriately obtained to share all the included patient photos and stories.



Alec was born with Goldenhar Syndrome, which is a congenital condition resulting in incomplete development of the eye, ear, and spine. Alec participated in an AboutFace "Beyond my Face" video and campaign in 2020, sharing his passion to one day become a film director.



Alexis is from St. John's, NL, and loves to spend time doing aerobics, gymnastics, horseback riding and track. Alexis has cleft lip and palate, a congenital facial difference, and has had many reconstructive surgeries. Alexis says, "The main thing I want people to know about how to treat someone with a facial difference is that it's important to be kind. I know that if they were the ones with a difference they wouldn't want people to be mean to them."



AboutFace Canada forum group, from left to right: Kelsey, Kariym, Namrit, Colleen, Elisabeth, Diana and Alim



# ADDRESSING PATIENTS WITH FACIAL DIFFERENCES

Individuals with a facial difference may refer to themselves in a number of ways:

- A person with a facial difference
- A person living with a facial difference
- Facially different
- A person with a specific condition or syndrome (e.g., an individual with vitiligo)

## TYPES OF FACIAL DIFFERENCES

The different types of facial difference are classified as congenital, acquired, and episodic.

### Congenital

Congenital facial differences are present at birth. Examples include fetal alcohol syndrome, birthmarks, nevi (moles), and trisomy 21 syndrome.

### Acquired

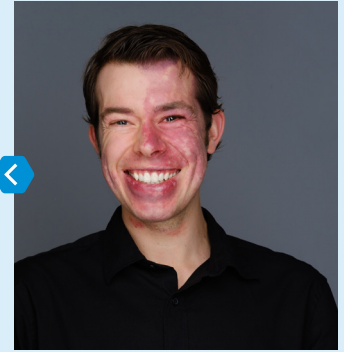
Acquired facial differences are absent at birth, and instead develop later in life; examples include burn scars, vitiligo, and facial paralysis.

### Episodic

Episodic facial differences may come and go; examples include acne, and alopecia areata.

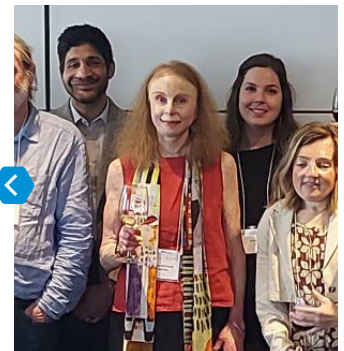
Among these differences, some are isolated facial differences (such as acne or vitiligo), and others are part of a larger constellation of symptoms, also known as syndromes (such as trisomy 21 syndrome).

*Liam has a port wine stain birthmark, which is a type of congenital facial difference. He participated in the Headshot Project, an initiative to provide professional headshots to the facial difference community and spread awareness.*



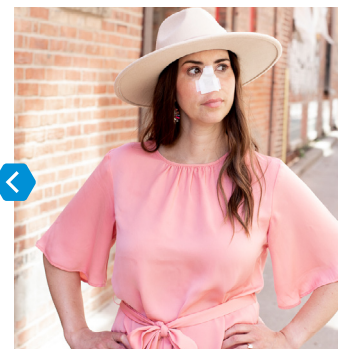
*Elizabeth has a hemangioma, which is a type of congenital facial difference. She launched AboutFace in 1985, as the only charity in Canada that supports individuals of every age with any type of facial difference, and their families.*

*Charlene is pictured here in an orange shirt with other members of AboutFace. Charlene sustained burns to her face, an acquired facial difference, secondary to a plane accident.*



*Jillian has a congenital facial difference, Sturge Weber Syndrome. She is passionate about her job as a nurse and also her fitness hobbies.*

*Trish has an acquired facial difference due to nasal cancer resection. Surgical resection of her nasal structures saved her life after the rare cancer resisted aggressive radiation, and as a result, she keenly advocates for the facial difference community.*



# LANGUAGE



**Parker has a facial difference, Goldenhar Syndrome. He says when someone is staring at him, he'll sometimes say, "You look curious. Do you have any questions?"**

## PATIENT'S PREFERRED TERMINOLOGY

- The most important terminology to use is the one the patient prefers. Healthcare professionals must respect the patient by tailoring their communication to the patient's preference.

## PHRASING

- Do not use terms like facial disfigurement, defect, or anomaly. Instead use facial difference.
- Do not minimize, such as using "just" to describe a condition: for example, "just a birthmark."
- Do not refer to your patient firstly by their facial difference, for example, a "cleft palate patient." Instead use person-first language, for example, "the patient with a cleft palate."

## WHAT TO AVOID

- Do not stare excessively at the person's facial difference.
- Do not speak exclusively to a caregiver and/or assume who will make the patient's medical decisions.

## PROFESSION-SPECIFIC CONSIDERATIONS

- Patients with a facial difference can have a wide range of medical needs: for example, zero intervention to multidisciplinary needs.
- Provide patient centered care.
  - Do not assume a patient's goals of care.
  - Do not assume a patient's facial difference always requires cosmetic correction or that a specific "beauty standard" is their goal.
  - Centre the patient in the discussion of treatment, and objectively lay out care options.

## CONSENT TO TREATMENT

- When a caregiver requests a non-urgent treatment for a facial difference in a pediatric patient, discuss the option of deferring until the child is capable of providing consent or assent.

**CITATION:** Parker – AboutFace. Parker [Internet]. Toronto (ON): AboutFace; [cited 2024 Nov 20]. Available from: [https://aboutface.ca/our\\_community/community-stories/parker/](https://aboutface.ca/our_community/community-stories/parker/)



# UNDERSTANDING THE STIGMA

## MEDIA AND CULTURE

### FILM INDUSTRY

#### The “Villain”

- There is a history of painting facial differences as the mark of a “villain”.
- This is a form of othering that promotes fear of people with a facial difference.
- Examples include Scar from Lion King, Two-Face in Batman, Dr. Isabel Maru (Doctor Poison) in Wonder Woman, and The Elephant Man.



*The Lion King*



*Two Face from Batman The Dark Knight*

#### The “outcast” or “fool”

- There is a convention that a facial difference may be something to taunt, or that it’s associated with a lower level of intelligence or psychosocial status.
- Examples include Austin Powers taunting a man with a large facial mole; Hunchback of Notre Dame; the Anomalous Man Sketch by Saturday Night Live portraying a “hideous” and unlovable person with a facial difference; The Elephant Man, who had a skin and bone disease and was made the star of a travelling circus.



*Austin Powers “Mole” Scene*



*The Anomalous Man Sketch from Saturday Night Live*



*The Elephant Man*

### MEDIA

#### Filters and Photo Editing

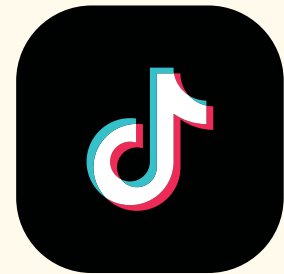
- Conventional beauty filters or photo editing can further ostracize those with a facial difference by promoting harmful, unrealistic beauty standards.
- Distorting filters modify faces from conventional configurations, thereby ridiculing these simulated appearances without recognizing the harmful message this demonstrates to people in the facial difference community.



*Snapchat "Distort 4 Lens" enlarges one eye and widens the nose and palpebral fissures.*

### MODEL INDUSTRY AND CELEBRITIES

- Messages of facial symmetry and perfection are heavily pushed as celebrities are scrutinized for their appearance across multiple media platforms.
- Some celebrities with a facial difference (e.g., Winnie Harlow, a model with vitiligo), serve as positive role models for the facial difference community.
- It is important to appreciate, however, that only certain facial differences seem to be deemed beautiful or acceptable by society.



*Winnie Harlow, Breakfast Television Interview*





### COSMETICS AND COSMETIC SURGERY

- Makeup can be a form of self-care and/or art; however, the industry frequently pushes a message of facial perfection and how to cover imperfections.
  - People with a facial difference may feel pressured to use these tools, instead of embracing their natural appearance.
- Commodification of facial difference happens when a facial difference is intentionally created to sell a product.
  - For example, drawn-on freckles have become a popular makeup trend.
  - Such standards are problematic because they send the message that only specific or mild forms of facial difference are acceptable.

- A person with a facial difference can feel pressured to seek cosmetic surgery to “correct” their facial difference according to conventional beauty standards that may not align with their personal perception of their beauty.

*Drawn-on freckles* <



*Person Seeking Cosmetic Surgery* <



### DISABILITY AND INTERSECTIONALITY

#### Disability

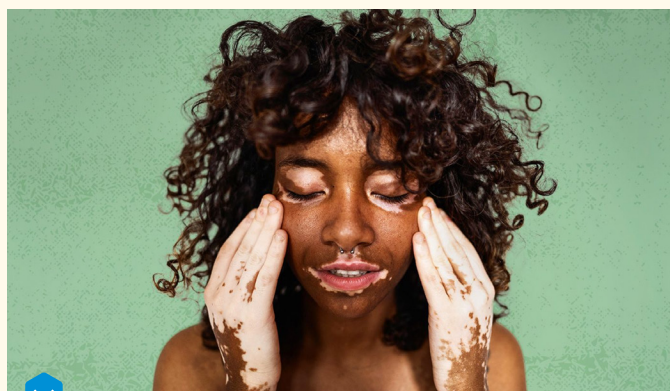
- Facial difference may be associated with a disability directly or indirectly; however, this varies with each patient.
- Many facial differences are not associated with any disability.
- Do not assume cognitive or physical ability based solely on facial difference.

#### Intersectionality

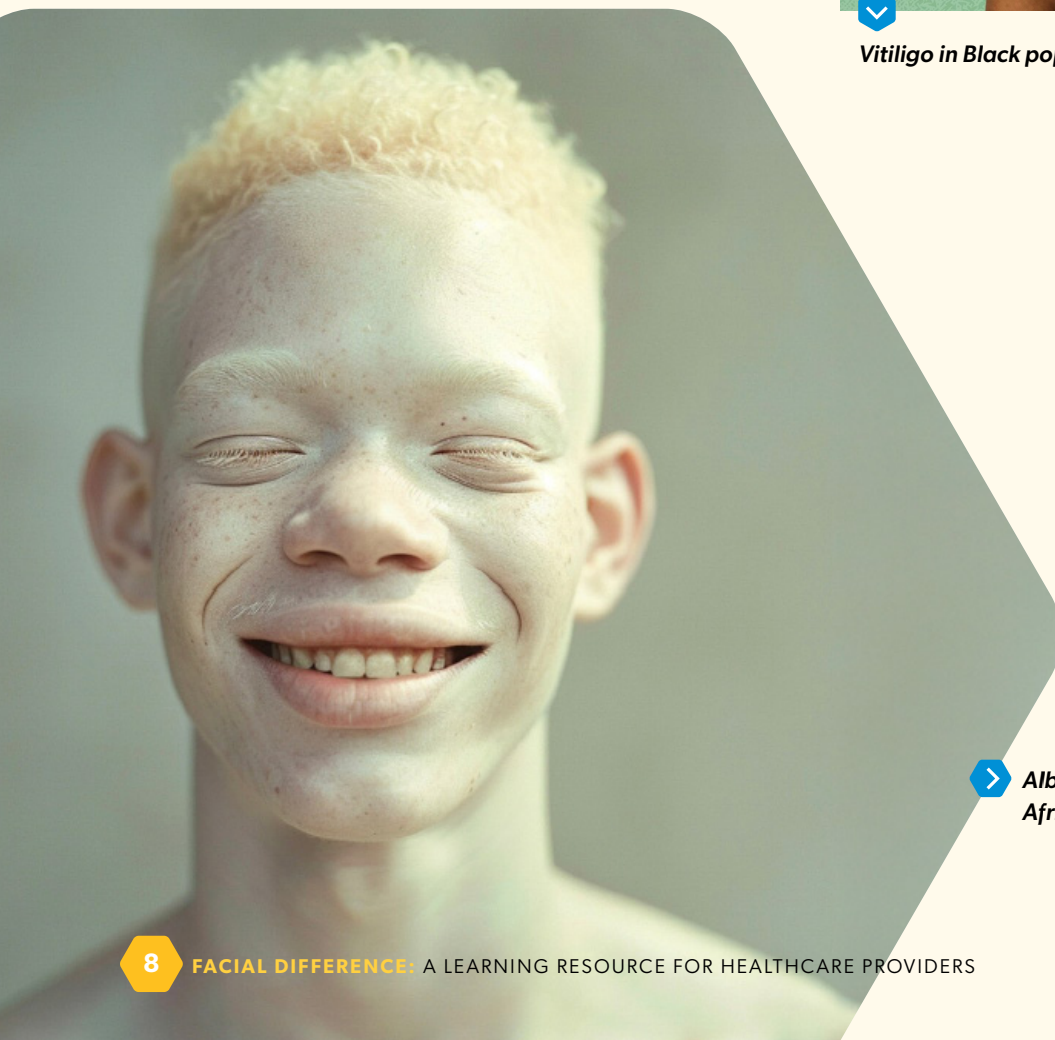
- Patients with a facial difference may have overlapping identities, including but not limited to Indigenous, racialized status, 2SLGBTQIA+, and refugee status.
- The perception of facial difference may vary across communities and therefore influence the patient's goals of care and values.
- The patient's intersectionality within these groups and their unique needs should be discussed to optimize care.



**Intersectionality Flag**



**Vitaligo in Black populations**



**> Albinism is stigmatized in African populations.**



### EXPERIENCES OF PATIENTS WITH A FACIAL DIFFERENCE

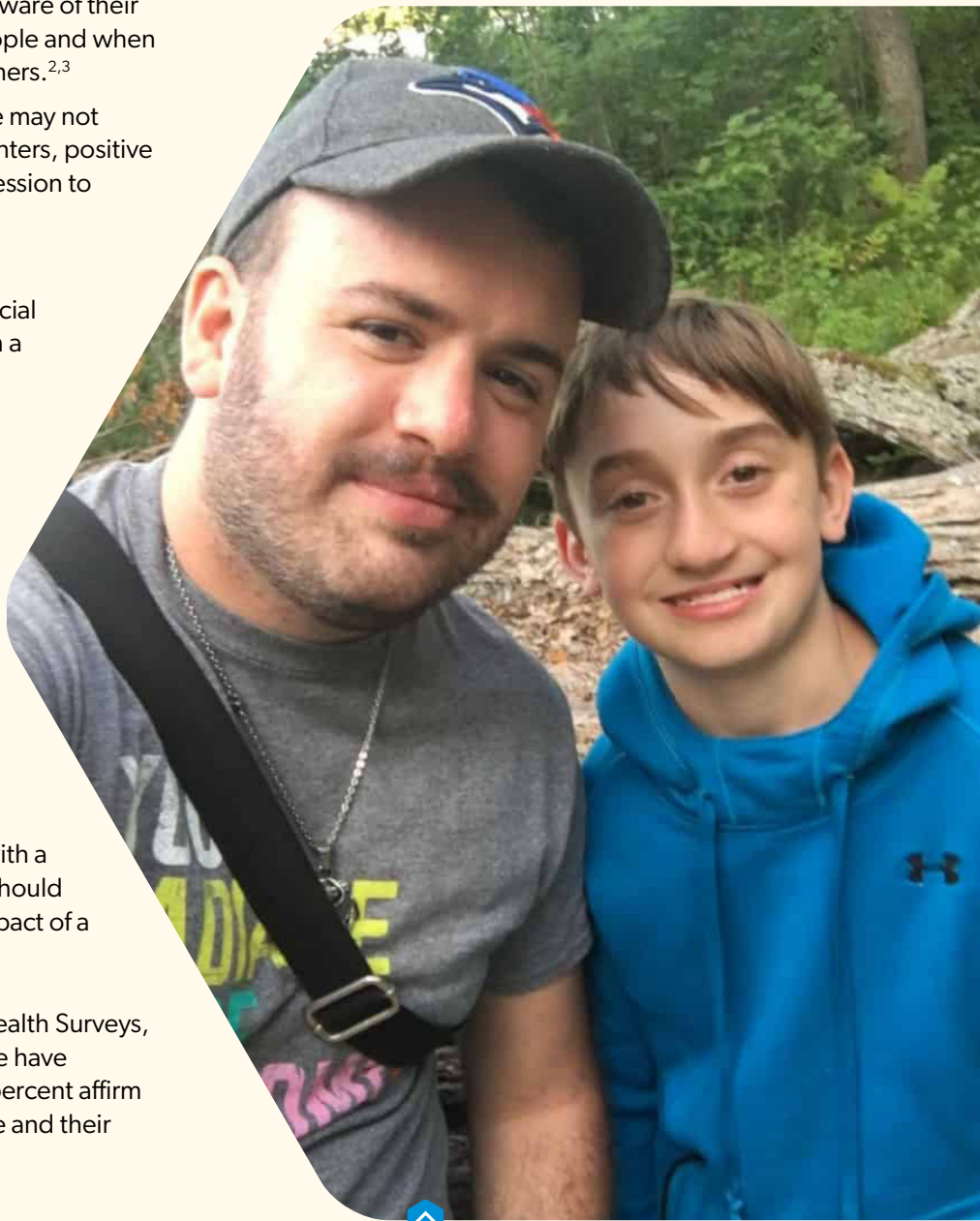
#### Social interactions

- Bullying and teasing are unfortunately common experiences among those with a facial difference.
- People with a facial difference are more aware of their facial condition when they meet new people and when they have to explain their condition to others.<sup>2,3</sup>
- Although a person with a facial difference may not always have control over negative encounters, positive social skills could improve their first impression to strangers and minimize stigma.<sup>4</sup>

#### Psychological impact

- The psychological impact of an altered facial appearance is significant for patients with a craniofacial condition.<sup>5</sup>
- Family and supportive figures play an important role for most patients.
- Studies show that particularly women with a facial difference can experience a below-average quality of life compared with the general population.<sup>6</sup>
  - Those patients who deviate from this statistic tend to have actively participated in the choice to undergo surgical treatment, demonstrating the importance of patient-centred care.
  - When facilitating the care of a patient with a facial difference, healthcare providers should carefully consider the psychological impact of a patient's condition.

According to AboutFace Canada Mental Health Surveys, 93 percent of people with a facial difference have experienced mental health issues, and 70 percent affirm a connection between their facial difference and their mental health.



*AboutFace Canada Camp Trailblazers, counsellor Tyler and camper Brayden; both were born with cleft palate. Camps like this facilitate connections within the facial difference community, providing opportunity for people to build confidence in themselves and validate their experience of facial difference.*

**CITATION:** Tyler and Brayden - AboutFace. Tyler [Internet]. Toronto (ON): AboutFace; [date unknown] [cited 2024 Nov 20]. Available from: [https://aboutface.ca/our\\_community/community-stories/tyler/](https://aboutface.ca/our_community/community-stories/tyler/)

### Trauma-informed care

- Definition: Care offered to patients that begins with the belief that trauma can impact any individual and can affect the illness experience.
- Patients with a facial difference may have had stigma in their personal life and also in the healthcare system. Their healthcare provider should therefore aim to recognize this harm and seek to minimize and not further perpetuate it.

*AboutFace Canada committee members who also represent the facial difference community.*



*Zoe and her mother. Her mother says that when Zoe was diagnosed with Treacher-Collins syndrome, their number one priority, along with accessing the best medical treatment, was to give her the tools she needs to feel strong, beautiful, and confident.*



# CASE EXAMPLE #1

## BACKGROUND

Fazayl is a 17-year-old recent high school graduate, with plans to pursue studies in neuroscience. She is passionate about advocacy for individuals with a facial difference and has completed phenomenal advocacy work with AboutFace.

Fazayl was born with a port wine stain birthmark. This birthmark is a type of hemangioma, visualized as a deeply pigmented, red-violaceous mark on the skin, and typically caused by an aggregation of capillaries. A port wine stain can be present in isolation or associated with syndromes such as Sturge-Weber syndrome. For Fazayl, the birthmark is located on the right side of her face, across her cheek, extending up to her brow and down to her lip.

We spoke with Fazayl about navigating her life growing up with a facial difference, especially as it relates to the healthcare system. By reflecting on her experience, Fazayl provides excellent insight into the role healthcare professionals can play in supporting patients with a facial difference.



*Photos of Fazayl (from left to right) prior to her laser treatment, during laser treatment, and after laser treatment.*

## Q&A WITH FAZAYL

**How did your condition affect your interactions with peers and educators during your school years, and what support did you find most helpful?**

Fazayl first experienced insensitive comments about her birthmark in grade 2, when classmates questioned and taunted her about this facial difference. At the time, Fazayl had no access resources for individuals with a facial difference, so this was a difficult time in her life.

In middle school, she became more self-conscious about her birthmark and began using makeup to cover it up. At the same time, Fazayl started intensive laser therapy. From 12 to 18 years old, at regular intervals, she had laser treatments involving pulsed dye laser. The laser therapy ultimately showed success, but she experienced bruising and swelling for several weeks following the procedure. This was more difficult to conceal with makeup, and peers would often comment or ask questions about her appearance. At the time, Fazayl did not feel equipped or prepared to answer questions about her facial difference and how it would evolve during her laser therapy journey.

Fazayl recalled that by speaking with her teachers in advance of her treatment, especially about the nature of her laser therapy, they were able to anticipate challenges associated with her treatment schedule and provide support. Fazayl credits the AboutFace community for its pivotal role in her personal acceptance of her facial difference and for enhancing her confidence in interactions centred on her birthmark.

### DIAGNOSIS, TREATMENT, AND INTERACTION WITH HEALTHCARE PROVIDERS

**How was your condition diagnosed, and what were your initial interactions with healthcare providers like? Who are some of the key members of your healthcare team, and how have they supported you in managing your facial difference?**

Fazayl explained that her family physician was the first healthcare practitioner she encountered about her birthmark. She was young when her family visited their family physician, who was blunt and direct in communicating the nature of her birthmark and facilitated her referrals to specialists.

Appointments with her dermatologist were the most positive; this physician was attentive to her anxieties regarding laser therapy. Despite Fazayl's young age and the involvement of her parents in treatment decisions, the dermatologist frequently involved her in decision making and carefully explained the procedure to her.

Overall, Fazayl wished the healthcare professionals involved in her care were more attentive to the social aspect of her facial difference. Although she did not feel uncomfortable speaking about this, she does wish that healthcare professionals would take more initiative in facilitating these conversations.

**TIP:** For children with a facial difference, it may be helpful to have a conversation that explores the social aspect of their experience, starting with more general questions about how they feel at school and what supports they have in place.

**How do healthcare providers generally address your facial difference in both related and unrelated medical settings? What terminology do you prefer they use?**

Fazayl said healthcare professionals typically used the term "birthmark" when referring to her port wine stain. She uses both birthmark and facial difference. The proper terminology for each patient may differ, and in most patient-provider settings, it is appropriate to allow patients to choose their preferred way to be addressed and then consistently use this terminology.

For Fazayl, terminology and assumptions can be challenging to navigate. In both medical and non-medical settings, Fazayl had negative encounters in which individuals made assumptions, such as "who burned you?" or "who punched you?" when first addressing her facial difference.

### REFLECTION

**Reflecting on your overall journey, what do you wish healthcare providers knew about caring for people with a facial difference?**

Fazayl wishes that healthcare providers were more aware of the unique nature of facial differences, especially how this relates to a person's psychosocial well-being, because the face is a part of the body that's visible at all times. Practitioners need to consider this aspect of a patient's experience as part of their medical assessment. They can facilitate a discussion about the patient's psychosocial experience when assessing a patient for a clinical situation related to their facial difference.

Although a facial difference may make up some part of an individual's identity, Fazayl understands she is a unique person beyond her birthmark. She encourages practitioners to take the time to understand their patients as individuals, outside of their facial difference, and avoid making assumptions.

She also encourages all practitioners working with individuals with a facial difference who may be seeking treatment to be transparent about the treatment process. For example, she appreciated the honest and clear discussion about expectations for her laser therapy when she was in middle school, including the potential for some swelling after the procedure that would make her birthmark more noticeable.

Finally, regardless of the patient's age, Fazayl encourages practitioners to centre the patient as much as possible, by including them in discussions about their facial difference and any treatment that may be planned. This advice rings true for all patients, whether they have a facial difference or not.



# CASE EXAMPLE #2

## BACKGROUND

Kyle Hynes survived burns in 1998, following a severe house fire caused by an electrical malfunction. At age 5, Kyle sustained burns over 89 percent of his body. His journey has involved numerous visits to the Shriners Hospital in Boston for skin grafts and reconstructive surgeries, and extensive support from his community in Eastern Canada. Since the early days of his recovery, Kyle has been dedicated to supporting other burn survivors, initially by setting up a welcoming office in the hospital playroom and later through his involvement with various support organizations.

## Q&A WITH KYLE

**Could you introduce yourself and share a bit about your journey with a facial difference? How did you acquire your burns, and what was your experience growing up with them?**

Kyle Hynes introduced himself as a burn survivor since 1998. He explained he was five years old when an electrical fire in his home resulted in burns covering his body. He said that growing up with these burns was challenging, but he focused on maintaining a positive outlook. He has since pursued a career in IT, attended flight school, and currently serves as a general manager for a helicopter company.

Attending “burn camps” during his childhood was incredibly beneficial. As an adult, however, he found fewer support systems were available. When he advocated for more support for adults, he was introduced to the Canadian Burn Survivors Community (CBSC), where he is now co-chair of the Burn Survivor program and helps organize peer-to-peer events.

**How did your condition affect your interactions with peers and educators during your school years, and what support did you find most helpful?**

Kyle’s community was very supportive, and he did not experience bullying. During his transition back to school, his teachers and medical team helped by educating his classmates and the school community before he returned, which made him feel accepted. His small hometown of 15,000 people was very welcoming. However, when he moved to a larger city, he noticed that people would sometimes stare, which was a new challenge. His family and medical team helped him develop a mindset of positivity, and he learned to handle these situations with confidence. Peer-to-peer support was also highly important in this process.



*This Is My Story: Kyle Hynes*

**CITATION:** Kyle [Internet]. Canadian Burn Survivors; [date unknown] [cited 2024 Nov 20]. Available from: <https://www.canadianburnsurvivors.ca/committee>

## CASE EXAMPLE #2 continued

### DIAGNOSIS, TREATMENT, AND INTERACTION WITH HEALTHCARE PROVIDERS

**How was the severity of your burns diagnosed? Can you describe the treatments and surgeries you've undergone since the incident and how your treatment plans have evolved over time?**

The severity of his burns was assessed through various medical evaluations. Since age 5, he has undergone over 70 surgeries, including skin grafts, reconstructions, and prosthetics. Treatments included nose and ear reconstructions, neck skin releases, and foot prosthetics. Most of his surgeries were performed at Shriners Hospital in Boston, where he travelled approximately twice a year while living in Newfoundland. His treatment plan has evolved to address both functional and cosmetic needs.

**What were your initial interactions with healthcare providers like? Who are some of the key members of your healthcare team, and how have they supported you in managing your facial difference?**

His healthcare team included therapists, nurses, and doctors who became like family. The nurses and therapists were incredibly supportive, not just physically but emotionally. They always asked about his feelings, set achievable goals, and involved him in decisions about his care. They always balanced positive activities with the more challenging aspects of treatment, such as bandage changes. Their approach was always positive, which made a significant difference in his recovery.

**How do healthcare providers generally address your facial difference in both related and unrelated medical settings? What terminology do you prefer they use?**

He is comfortable with how they address his condition as long as they speak respectfully. He appreciates that they would gauge how he was feeling on any given day and adjust their approach accordingly. Some people prefer jokes or a lighthearted approach, while others may prefer to be serious. Regardless, it's always important to acknowledge the patient's feelings and be respectful.

### REFLECTION

**How have your experiences with a facial difference influenced your goals in life and your work with the Children's Burn Survivors Canada (CBSC)? How did your journey of helping other burn survivors begin and evolve?**

His experiences motivated him to support other burn survivors. After attending burn survivor camp, he realized the importance of peer support. As an adult, he found that there were few support systems available, so he became involved with CBSC to advocate for increased support for burn survivors. Hosting peer-to-peer events and participating in conferences have allowed him to give back and help others succeed.

**Reflecting on your overall journey, what do you wish healthcare providers knew about caring for people with a facial difference?**

He wishes healthcare providers would engage more personally with their patients. Being involved in both the good and challenging moments of a patient's life shows genuine care. Passionate, empathetic care goes beyond medical treatment and helps build a stronger connection with patients. Creating opportunities for patient conferences and community involvement can significantly impact their well-being.



## SUMMARY FOR HEALTHCARE PROVIDERS

- Use the facial difference terminology your patient prefers.
- Inquire about psychosocial health, seeking specifically to understand how their facial difference may affect their daily life.
- Consider intersectionality and trauma-informed care in your interactions with patients.
- Do not assume their goals of care; your treatment discussion should be patient-centred, and tailored to their specific needs.
- Communicate expectations and outline the management process, explaining clearly how the treatment may alter their appearance both during and after treatment.
- Be an advocate for your patient and encourage connections within the facial difference community.

# DISCUSSION SCENARIOS

The following scenarios are designed to promote peer discussions that may be either self-guided or facilitated by an instructor.

## SCENARIO #1

**You are a third-year medical student in a plastic surgery clinic. A 5-year-old girl with prominent ears comes into the office accompanied by her mother. Her mother states that her daughter is being bullied in school because of her ears, and expresses interest in surgery to help her daughter feel more welcome in school.**

**How would you counsel this patient? When a caregiver wants to change the facial appearance of a child for social or personal reasons, what responsibility do healthcare providers have in guiding them? What factors should be considered in the decision to proceed with surgery?**

**Answer:** To counsel this family, you could begin by acknowledging the emotional toll of bullying and explore how it affects the child's self-esteem. Provide information on the surgery (e.g., otoplasty), discussing the risks, benefits, and limitations. Also emphasize that while surgery might change her daughter's appearance, it may not fully address bullying, as this often stems from broader social issues. Although the child is not capable of consent, her feelings about her appearance and her ability to understand a procedure should be explored. The option to delay surgery to a later time when she is able to provide assent or consent should be discussed. This allows the child greater bodily autonomy over their facial difference. It may also avoid unnecessary traumatization from invasive medical procedures. The option to delay should, however, be balanced against whatever further difficulties may be associated with the surgery if done at a later time (e.g., due to decreased elasticity of ear cartilage) and variable financial coverage of the surgery in Canada for older age groups. The decision of whether or not to proceed with surgery ultimately rests on a risk-benefit discussion, including a conversation about the social stigma associated with facial differences.

## SCENARIO #2

**You are a second-year medical student shadowing in a dermatology clinic. A 55-year-old trans male patient comes in for consultation on a lesion to the lip. On examination, you notice a large, hyperpigmented scar on his forehead. Your supervisor asks, "How did you get that scar?" The patient replies that he doesn't remember. The supervisor then responds, "Really? That's it? I thought you'd have a good story — a close call or something." The patient appears embarrassed but gives a small smile.**

**What would you do in this situation?"**

**Answer:** In this situation, you should prioritize empathy and respect for the patient's autonomy and privacy. Since the supervisor's comment may have made the patient uncomfortable, it is important to reflect on the importance of approaching physical differences with sensitivity and an open mind. Not all scars or facial differences have a dramatic backstory, and assuming they do—or pressuring someone to share—can be invasive and dismissive of the patient's experience. As a second-year medical student, it may be difficult to speak up in the presence of a more senior or staff physician. If you have an opportunity to debrief with your supervisor afterwards, you could discuss mindful ways to ask patients about their visible difference. This could lead to a conversation about how curiosity, though often well-meaning, can sometimes make patients feel objectified or pressured to share personal information.



### SCENARIO #3

You are a first-year resident in family medicine. You are working in the after-hours clinic with one of your more senior co-residents, a Black woman who has active segmental vitiligo. A 25-year-old woman who works in the beauty industry comes into the clinic as a patient. At the end of the encounter, the patient says to your co-resident, "You're so beautiful! I sometimes wish I had vitiligo so I could stand out like that model, Winnie Harlow." Your co-resident looks uncomfortable but offers a polite smile.

**What would you do in this situation? Why might the patient have responded this way, and what effects might it have on those with a facial difference that's less-openly accepted by society?**

**Answer:** If you sense your co-resident's discomfort, you could begin by gently redirecting the conversation to acknowledge the patient's intent, while moving away from the comment. For example, you might say, "It's wonderful to appreciate unique features, but each person's experience with a facial difference, like vitiligo, is very personal." This response would validate the patient's appreciation, while subtly highlighting that admiration doesn't always recognize the complexities of living with a visible difference. Afterward, it would be important to check in with your co-resident to make sure she felt supported, as handling these interactions respectfully is key to a positive workplace culture. The patient's comment likely came from a place of support, though it may reflect how society tends to selectively celebrate certain facial differences while overlooking the challenges they can bring. Admiring a visible difference because it is currently "in style" doesn't fully appreciate the stigma that often accompanies such differences. Being a true ally involves offering support regardless of trends or popular perceptions of beauty.

## REFERENCES

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- 5) Singh VP, Moss TP. Psychological impact of visible differences in patients with congenital craniofacial anomalies. *Prog Orthod.* 2015;16:5.
- 6) Okine E, Helms JA, Luhrmann T. A critical analysis on quality-of-life in women with visible facial disfigurements. *Spec Care Dentist.* 2024 May 7.

# RESOURCE GUIDE FOR YOU AND YOUR PATIENTS

## Webinars

AboutFace Webinars

## Podcasts

myFace, myStory

## Publications

### Teachers' Guides:

A Teacher's Guide to Supporting a Student with a Facial Difference (English & French)

### Children & Youth Guides:

Building Self-Esteem for Children and Youth with Facial Differences (English & French)

### Parent & Guardian Guides:

A Parent's Guide to Building Self-Esteem

### Practitioner-Tailored Resources:

The Importance of Language and Communication for Practitioners

## Organizations

AboutFace (Canada)

Face Equality International

MyFace (U.S.)

## Programs

AboutFace Programming for Patients

Face It Online (U.K.)

## Connecting Communities

Changing Faces Online Community (U.K.)

myFace Online Groups (U.S.)

## Additional Resources

### Media Representation

myFace YouTube Channel

*The Human Face* (BBC Documentary, 2001)

### Children's Fiction with Characters with Facial Differences

*Wonder*, by R.J. Palacio

*Smile with Simon*, by Patricia Ann Simon

### Young Adult Fiction

*A Face for Picasso: Coming of Age with Crouzon Syndrome*, by Ariel Henley

### Adult Fiction

*Eleanor Oliphant is Completely Fine*, by Gail Honeyman

### Memoirs

*Ugly*, by Robert Hoge

*Normal: One Kid's Extraordinary Journey*, by Magdalena and Nathaniel Newman

### Nonfiction

*Changing Faces: The Challenge of Facial Disfigurement*, by James Partridge

*The Facemaker: A Visionary Surgeon's Battle to Mend Disfigured Soldiers of WWI*, by Lindsey Fitzharris





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