

Every smile  
tells a story



# 2019 Adults Cleft Conference

**The Studio, Glasgow, Scotland**

Saturday 14 September 2019





The **Cleft Lip and Palate Association (CLAPA)** is the only national charity supporting people and families affected by cleft lip and/or palate in the UK from diagnosis through to adulthood.

# What's today all about?

- The highlight of the year for CLAPA's Adults Project, the CLAPA Adults Conference is an opportunity for people affected by cleft from across the UK to come together, share their stories, ideas, highlights and frustrations with likeminded people.
- A unique opportunity for health professionals and individuals with cleft to come together in a more casual environment.
- The content in today's conference has been hand-picked based on what you told us in the 2018 roadshow and survey as being important to you.
- During the breaks and during the workshops, having a chance to talk with others affected by cleft, health professionals and the friendly CLAPA team.

# An introduction to Scotland Services

**Gillian McCarthy**  
**Scotland and Northern Ireland Manager**

**Gillian.McCarthy@clapa.com**

**07586 045402**

# History/Funding

- October 2014 - 1 Part time member of staff
- September 2015 - 1 Full time & 1 Part time member of staff
- September 2017 – 1 Full time & 2 Part time member of staff
- September 2018 - 1 Part time member of staff

# Services

- Parent Support
  - Feeding Service
  - Bumps & Babes (NHS)
  - Local activities/events/meet up groups/Christmas parties
  - Adventure days (8+yrs)
  - Adventure weekends (8+yrs)
  - Peer Support
  - Adult Services
- 
- Patient Voice
  - Awareness raising
  - Clinic Volunteers
  - Fundraising

# Imposter Syndrome: Living with 'just' a cleft palate

CLAPA Adult Conference 2019 – Iona Wallace



# IMPOSTER-SYNDROME

It's not unusual to feel like you're about to be exposed as a fraud,  
they've been gathering evidence on you for a while



# THE COMMON CONCERNS OF AN ADULT WITH A CLEFT PALATE

3 main complaints are:

- Speech
- Eating and drinking
- Hearing

These can impact on:

- Relationships
- Employment
- Psychosocial well-being

# MY BATTLE WITH IMPOSTER SYNDROME



# ‘DISFIGUREMENT DOESN’T EQUAL DISTRESS’

***“A significant proportion of participants experienced psychosocial distress in relation to their visible difference”***

Clarke *et al.* (2004): P777 - 782

***“Results demonstrate a dissociation between objective and subjective measures with only subjective assessment predicting psychological outcomes.”***

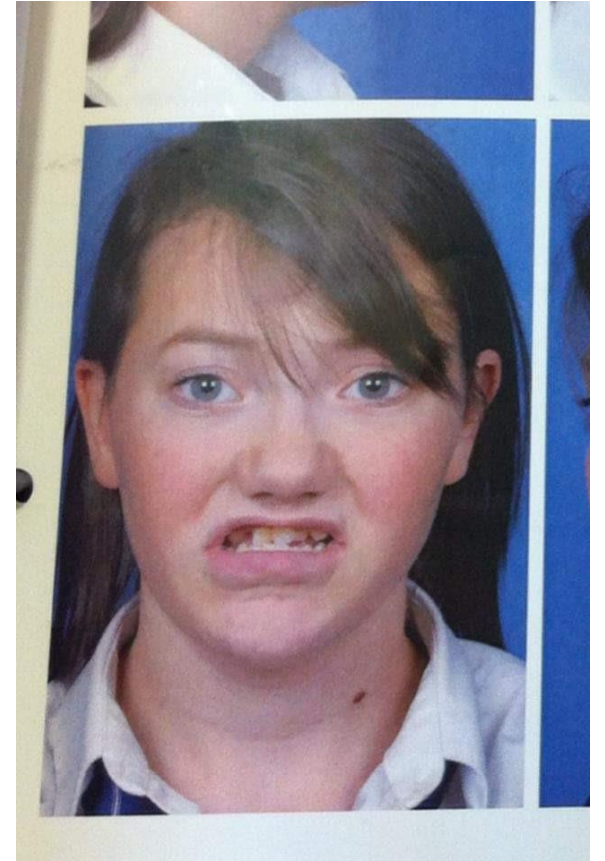
Butler *et al.* (2007) P239 - 248

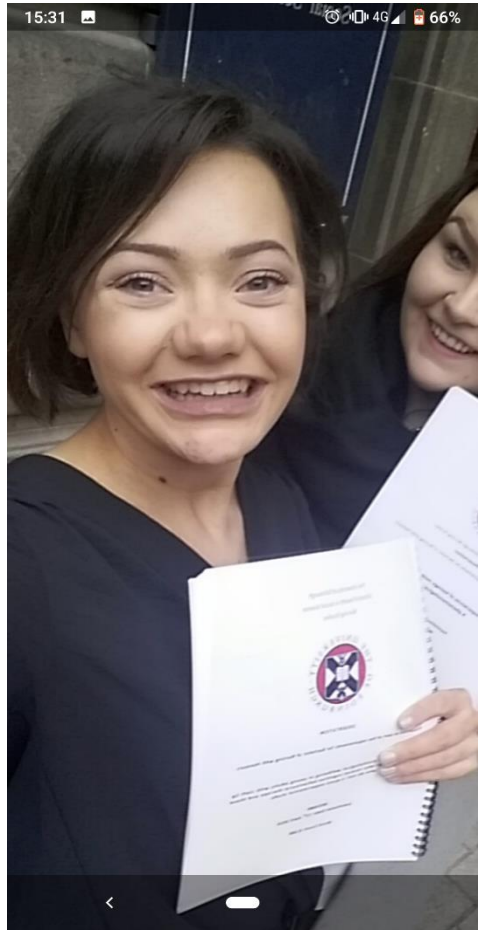
***“Patient's satisfaction with facial appearance is more important than the objective severity of the deformity”***

Duivenvoorden *Et al.* (2012): P777-282



# Photo Timeline







**SOMETIMES**

**WE COULD ALL USE A  
LITTLE HELP**

memegenerator.net







WHAT NEXT?



Thanks for listening!

# Speech and Language Therapy

Adult CLAPA conference

14<sup>th</sup> September 2019

Lisa Crampin

Cleft Specialist SLT

# Quick speech lesson!

- Resonance
- Airflow
- Articulation
  
- Velopharyngeal function
- Fistula
- Occlusion



# Communication

# Referrals

- Orthognathic surgery / ENT / Audit clinics
- Opting in
- New service / New technologies available
- Change of career / Family
- Social Media / CLAPA / Word of mouth

# Assessment

- Clinical speech assessment
- Multidisciplinary team discussion
- Palatal investigation clinic

# Intervention

- Articulation therapy
- Communication therapy
- Surgery
- EPG
- Ultrasound
- Obturator
- Nasometer
- Speech bulb
- Nasal valves

# Factors to consider

- Job
- Family
- Travel
- Readiness for change
- Expectations



# Children's Services vs Adult Services

- Children's service more standard
- Adult services vary across UK
- Government priorities
- Audit ages
- Resources

# *Why are you not good enough?*

*Exploring Self Esteem*

Dr Jess Hare

Principal Clinical Psychologist

National Cleft Surgical Service for Scotland

# *What is self esteem?*

Esteem:

from Old French *estime* (noun), *estimer* (verb),  
from Latin *aestimare* 'to estimate'; used  
figuratively to mean 'assess the merit of'



# *What is self esteem?*

(E)valuation: What something's *value/worth* is;  
how far it meets expected criteria

# What is self esteem?

(E)valuation: What something's *value/worth* is;  
how far it meets expected criteria

## The Necropolis Is this your business?

★★★★★ 3,331 Reviews

#20 of 309 things to do in Glasgow

Sights & Landmarks, Cemeteries

📍 50 Cathedral Square, Glasgow G4 0UZ, Scotland

🕒 Open today: 07:00 - 19:00



# What is self esteem?

(E)valuation: What something's *value/worth* is;  
how far it meets expected criteria



Reviewed 2 weeks ago

## Beautiful with Great City Views

We walked up to the Necropolis and was very glad we did. Beautiful and eerie spot with great city views. The Cathedral is also right there and a nice historic corner of Glasgow. Its free as well.



Reviewed 14 July 2019  via mobile

## Gorgeos cemetery overlooking Glasgow

If you're looking to get a great view of the city at no cost then definitely head over to the Necropolis. Not only does it have a badass name, but you can see the entire city up to the river and get an aerial view... [More](#)

# *What is self esteem?*

(E)valuation: What something's *value/worth* is;  
how far it meets expected criteria

●○○○○○ Reviewed 12 June 2018  via mobile

## Nothing like the one in Paris

I have no idea why this place is always on a top ten list for Glasgow; I wouldn't exactly call it a destination. I know it has a history but it's too clean and not overgrown or creepy or anything like where I'd want to hold a seance. All that travel for nothing! We had to take the candles back to Manchester and start all over for something a bit more atmospheric...

[Show less](#)

# *What is self esteem?*

Esteem (valuation) varies based on...

- Characteristics of the thing
- Criteria of 'worthiness'
- Estimation of the evaluator

...all of which can be subjective



# *What is self esteem?*

Self Esteem:

How worthy / valuable we consider  
ourselves to be

# *What should people be?*

What criteria exist for *people*?

i.e. what makes people *worthy/valuable*?



# *What do you value in people?*

- What do you value most in people?
  - People you know
  - Other role models

YOU

# *What do you value yourself on?*

- Your values?
- Others' values?



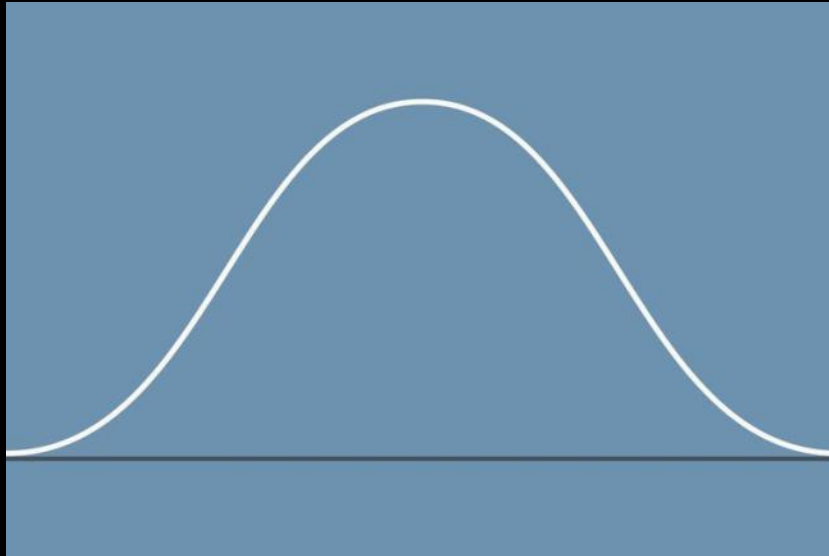
# *Why don't we think we are good enough?*

- Rejection hurts- recall 'shortcomings' others told us (based on their standards)
- Self fulfilling prophecy...
- Is it acceptable to like yourself?



# *Rethinking 'good enough'*

- We ARE NOT all good at everything
- We WILL NOT meet everyone's standards



# *Rethinking 'good enough'*

1) Decide what you value about people



# *Rethinking 'good enough'*

2) Decide what you think isn't important





# *Rethinking 'good enough'*

- 3) Give yourself **permission** to like yourself
- It does not make you 'arrogant'
  - It is vital for wellbeing



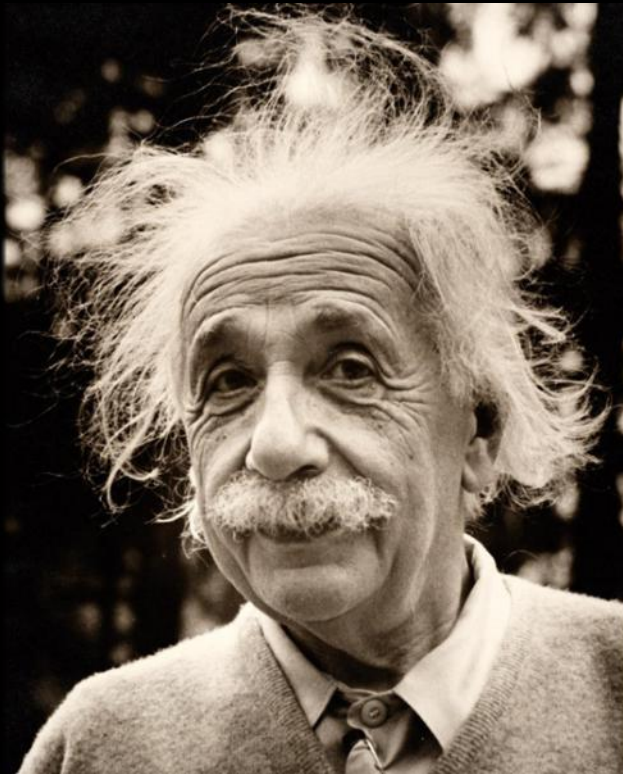
# *Rethinking 'good enough'*

4) Notice your 'inner critic'- is it harsher to you than it is to others?



# *Rethinking 'good enough'*

5) Notice when others' standards differ from your own



Everybody is a genius.  
But if you judge a fish by its  
ability to climb a tree, it will  
live its whole life believing  
that it is stupid.

*~Albert Einstein*

# *Self Esteem and Cleft*

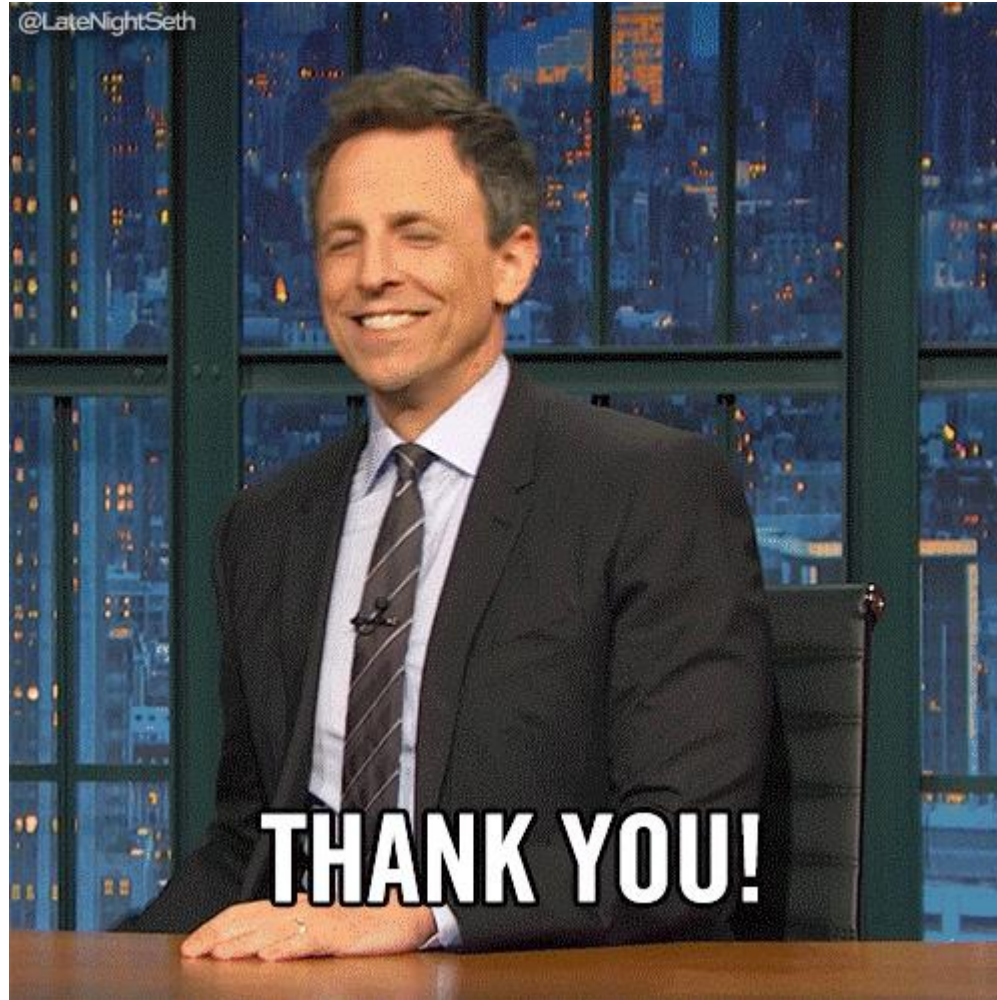
Low self esteem a frequent issue brought to Cleft Psychology services:

- Need to prove 'normal' to others
- Try extra hard to please others- conditional acceptance
- Some have experience of teasing/bullying
- Messages from treatment- need 'fixing', therefore broken, inadequate

*Any questions / comments?*

gg-uhb.CleftPsychologyScotland@nhs.net

# Thank you





# Thanks for coming

- Keep sharing your moments from the day on Twitter & Instagram using #CLAPAcnf2019
- We like you, do you like us?  
[www.facebook.com/groups/CLAPAdults/](https://www.facebook.com/groups/CLAPAdults/)
- Keep up to date with the Adult Services Project at  
[www.clapa.com/adultservicesproject](http://www.clapa.com/adultservicesproject)

