2026 Conference and Family camp

# A conversation
# Epidermolysis Bullosa and oral health

## Information and questions answered

Hugh Trengrove

# Epidermolysis Bullosa – oral implications by type

**EB simplex**

Blisters and erosions

**Junctional EB**

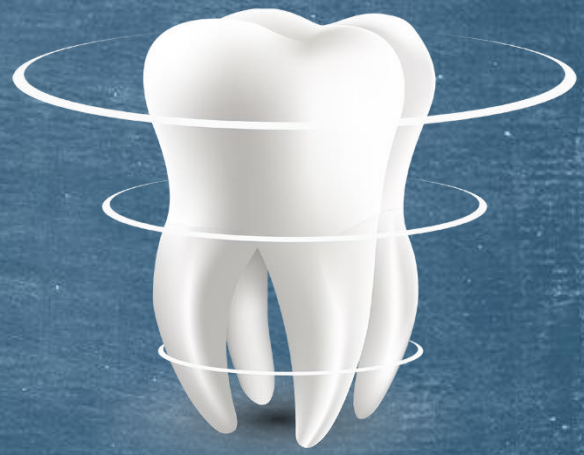
Blisters and erosions
Enamel defects (AI)
Failure of tooth eruption
(Perioral granulation tissue)
(Gum overgrowth)

**Kindler EB**

Blisters and erosions
Gum disease (rapidly progressive)
Enamel defects (AI and hypoplasia)
Microglossia
Tongue ankylosis
Vestibule obliteration
(Oral Squamous cell carcinoma - OSCC)

**Recessive dystrophic EB**

Blisters and erosions ++
Microstomia
Tongue ankylosis
Vestibule obliteration
(Tooth decay – OH)
(Tooth crowding)
(Oral Squamous cell carcinoma - OSCC)



**Dominant dystrophic EB**

Blisters and erosions
(Microstomia)
(Tongue ankylosis)
(Vestibule obliteration)

Krämer S, Hillebrecht AL, Bekes K, et al . Oral health care pathways for patients with epidermolysis bullosa: A position statement from the European reference network for rare skin diseases. J Eur Acad Dermatol Venereol. 2025 Jun;39(6):1080-1090.

# Epidermolysis Bullosa – oral implications

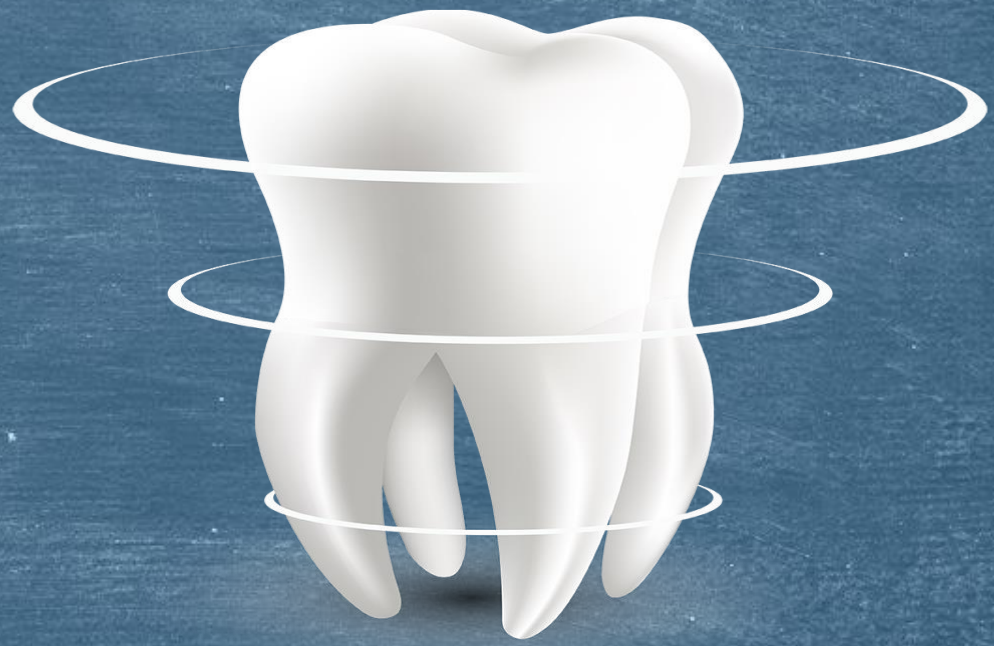
**Mucosal fragility**

**Reduced mouth opening**

**Dental enamel defects**

**Gum disease**

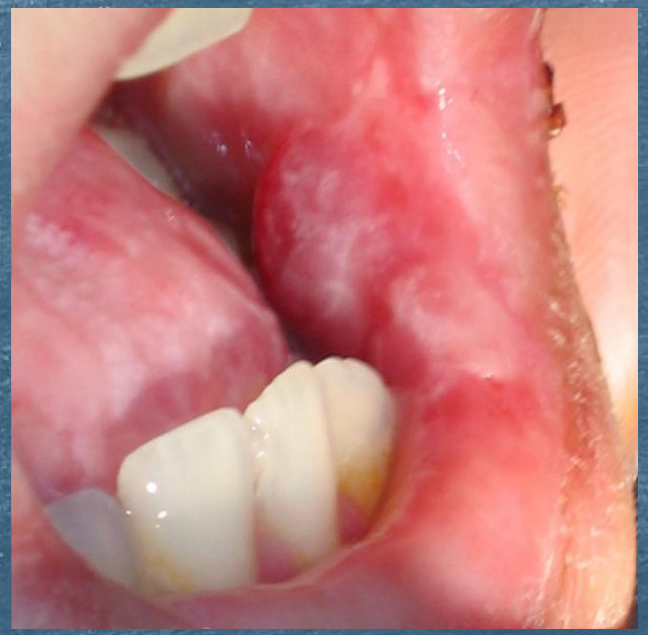
**Tooth decay**



# Epidermolysis Bullosa – Oral Implications

**Mucosal / skin fragility** Blisters/bullae, ulcers, lip crusting, scarring

Mouth 'activities' can be very painful with significant quality of life impacts



**Quality of life**

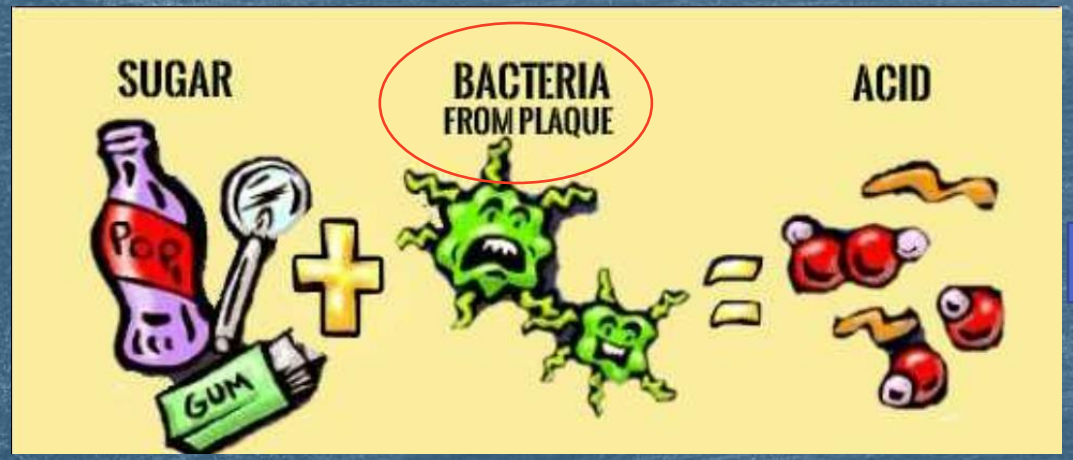
**Oral hygiene**

**Diet**

**Scarring**

} **PLAQUE**

# Epidermolysis Bullosa – Oral Implications

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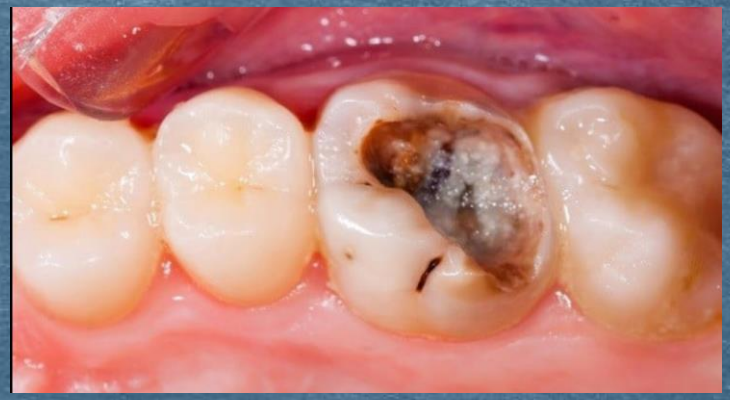
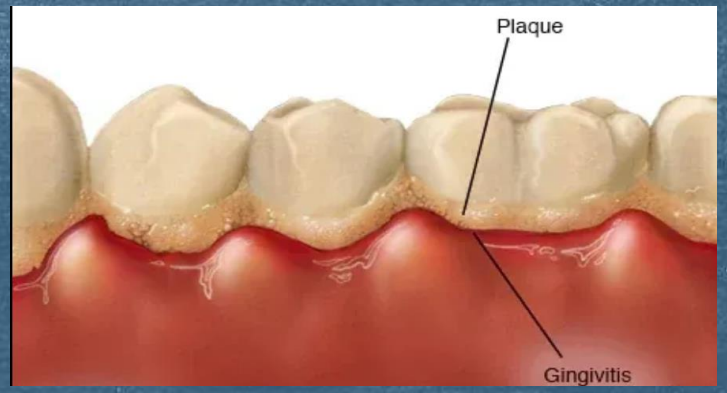


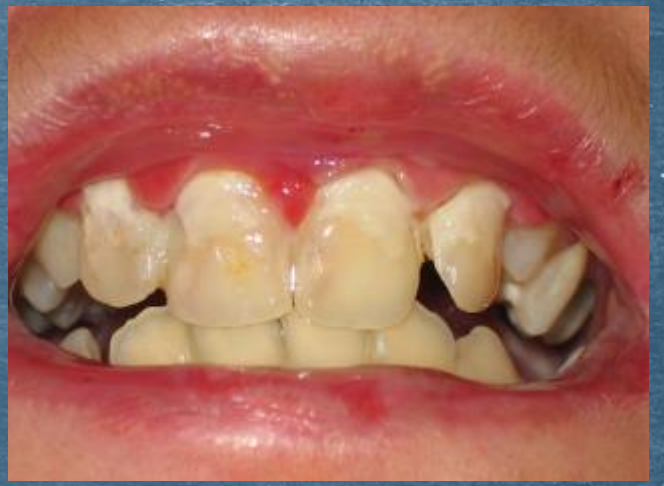


# Epidermolysis Bullosa – Oral hygiene

## Oral hygiene

The primary goal is to remove or disrupt plaque

**The key is to adapt and customise your approach**



## Cleaning aids

Manual toothbrush

Electric toothbrush

Oral irrigators

Moistened gauze

Cotton tipped swab

Interdental cleaners

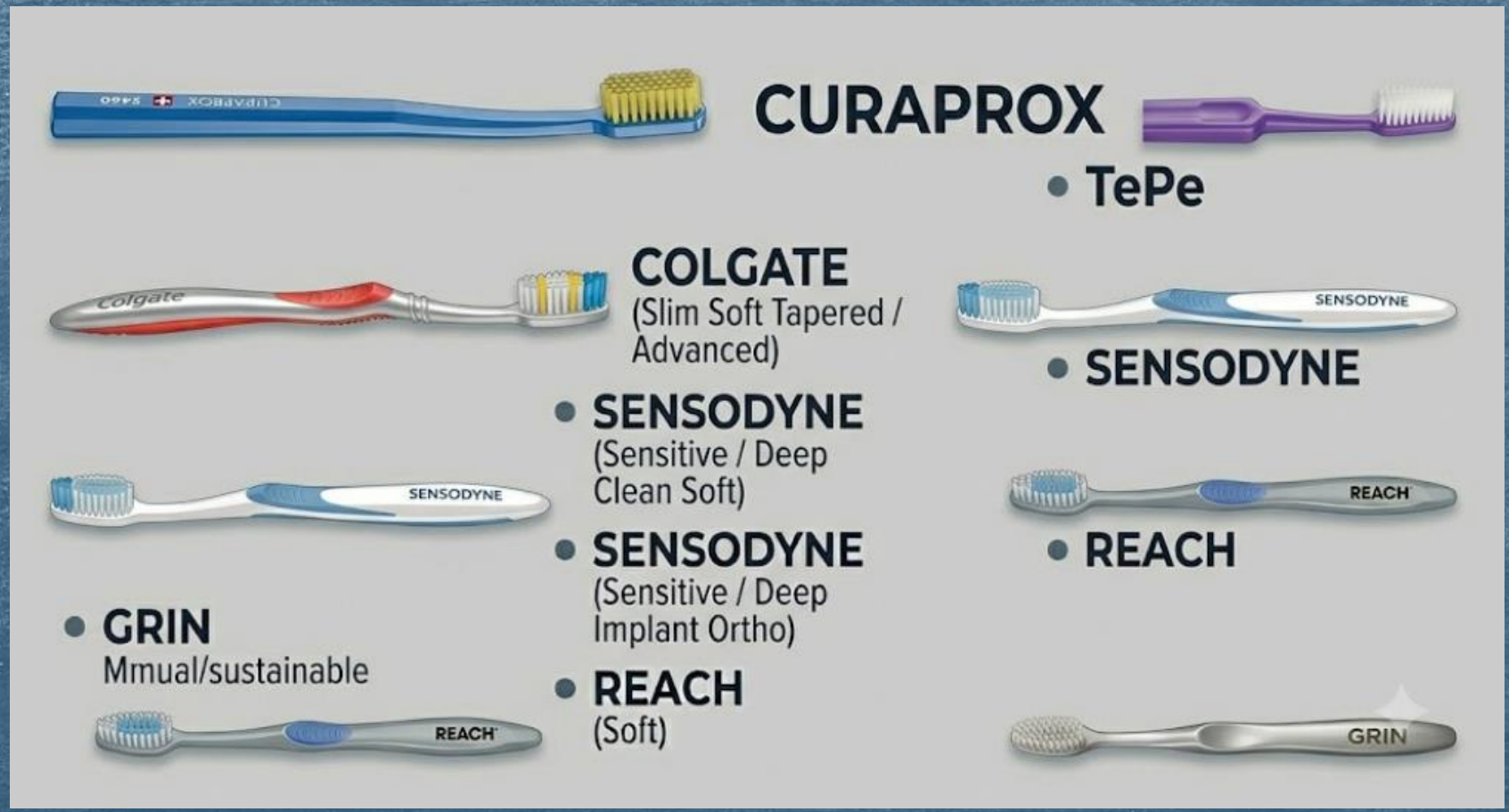
# Epidermolysis Bullosa – Oral hygiene aids

**Manual tooth brushing tips**

- Use a **small**-headed, **ultra-soft brush** (like a baby brush)
- Warm water
- Careful, short, gentle movements, avoid scrubbing
- If one area in the mouth is bad, leave but don't ignore other areas
- Customise brush handles (and bristles)

# Epidermolysis Bullosa – Oral hygiene aids

**Ultra soft toothbrushes**



# Epidermolysis Bullosa – Oral hygiene aids

## Selecting a toothbrush

Soft, extra soft, ultra soft bristles

Bristles with rounded ends / microfine tapered tips

Compact / small heads

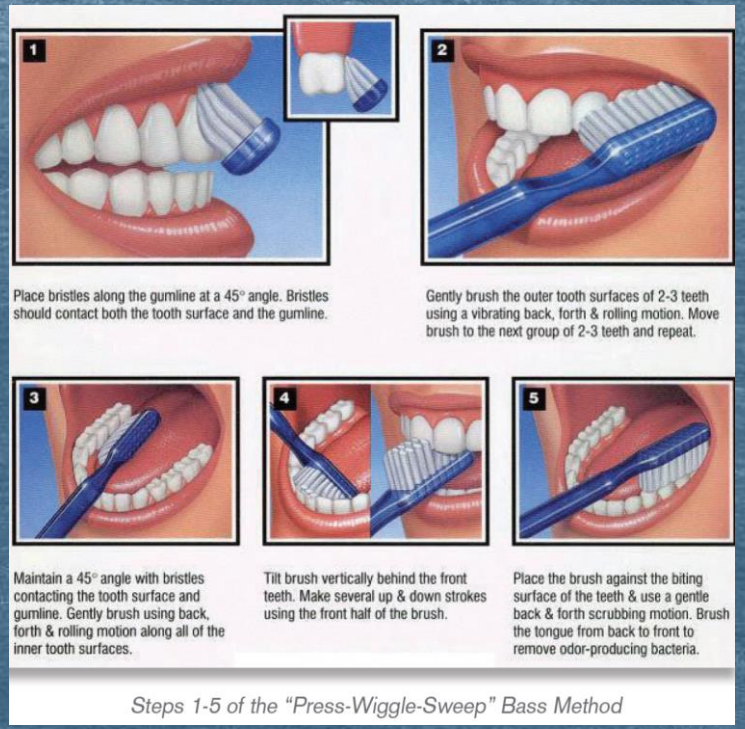
Consider the head shape – tapered or diamond shaped can be

Consider the angle of the head to the handle

Consider the grip

# Epidermolysis Bullosa – Oral hygiene aids

**Toothbrushing technique**



*Steps 1-5 of the "Press-Wiggle-Sweep" Bass Method*

**Electric toothbrush**

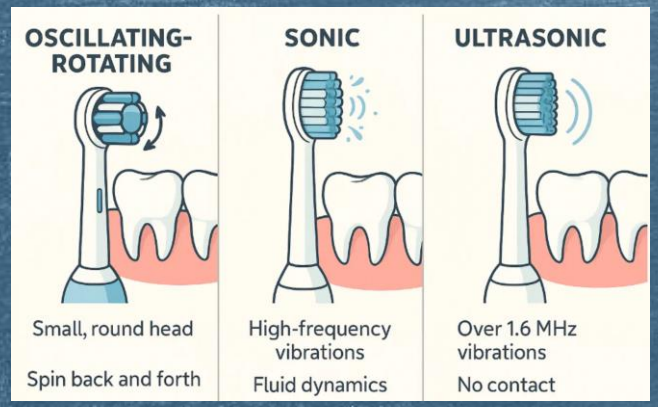
Read the manual

**Brush 2 minutes** **2x day** **Replace brush every 2-3 months**

**Children and motivation**

# Epidermolysis Bullosa – Oral hygiene aids

## Electric toothbrushes




Better plaque removal
- hard-to-reach areas
- micro-movements

Reduced manual dexterity, (motor does the work)

Built-in sensors (force & duration)

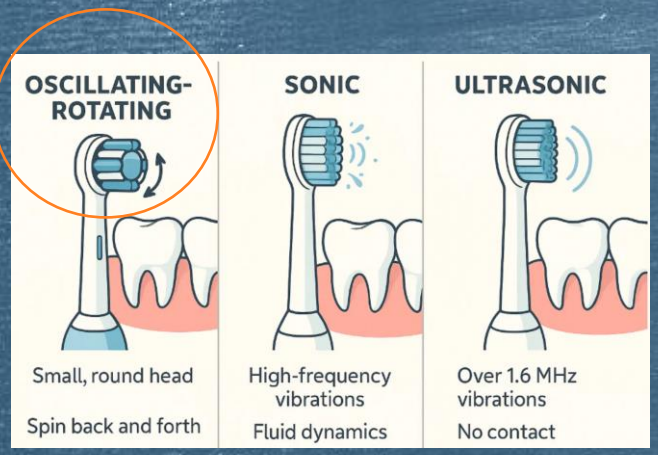
Technology

# Epidermolysis Bullosa – Oral hygiene aids

**Electric toothbrushes**

# Epidermolysis Bullosa – Oral hygiene aids

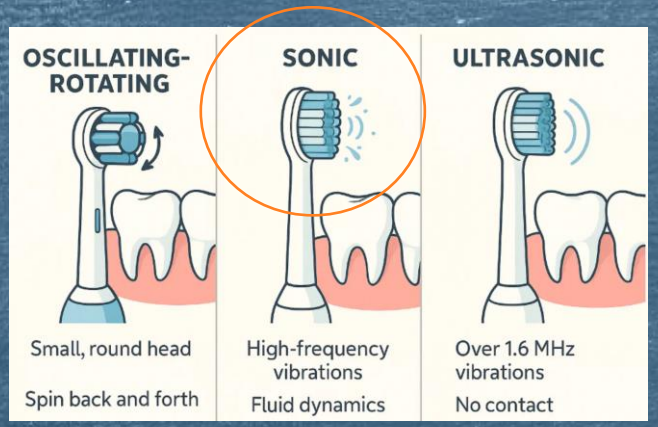
## Electric toothbrush – Oral B




**Oscillating-Rotating (and Pulsating) Action**
Oral-B models use physical, mechanical scrubbing.

# Epidermolysis Bullosa – Oral hygiene aids

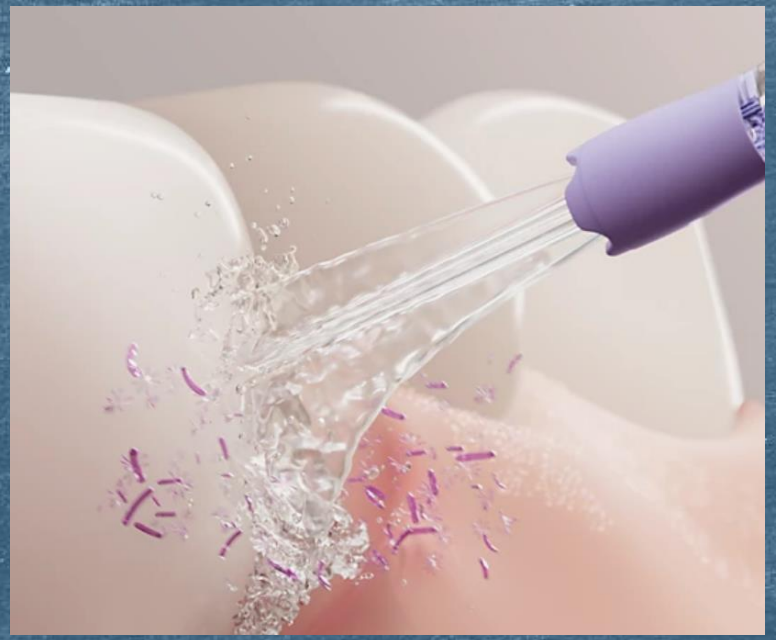
## Electric toothbrush – Philips Sonicare




Sonic technology pulses water between teeth, and its brush strokes break up plaque and sweep it away.

# Epidermolysis Bullosa – Oral hygiene aids

## Oral irrigators



Pulsating stream of pressurised water to clean food debris and plaque from between the teeth and beneath the gumline

- Orthodontics, implants and bridgework
- Limited dexterity
- Limited mouth opening
- ‘Disinterest’

Does not replace floss or interdental brushes

# Epidermolysis Bullosa – Oral hygiene aids

**Oral irrigators**

# Epidermolysis Bullosa – Oral hygiene aids

**Oral irrigators**

# Epidermolysis Bullosa – Oral hygiene aids

## Oral irrigators - Waterpik

**10 slide-pressure settings,** pulsed stream (~1,400 pulses per minute) that alternates tissue compression and decompression to flush the gingival sulcus

Cordless and plug in.

Interchangeable 360-degree rotating tips

# Epidermolysis Bullosa – Oral hygiene aids

## Oral irrigators – Philips Sonicare

Pulse Wave guided flossing for thorough 360° cleaning

Specialised **X-shaped nozzle (Quad Stream)**. This splits the water into four targeted streams to cover a wider surface area of the tooth and gumline at once

*Pulse Wave* technology, which creates distinct, rhythmic pauses in the water flow to cue you to glide the nozzle to the next interdental space.

Cordless and plug-in.

10 intensity settings

# Epidermolysis Bullosa – Oral hygiene aids

## Oral irrigators – Oral B Aquacare Series

**(Oxyjet / Micro-bubble)** The irrigator compresses air into the water to form millions of micro-bubbles to target anaerobic plaque bacteria under the gumline by introducing oxygen into the environment.

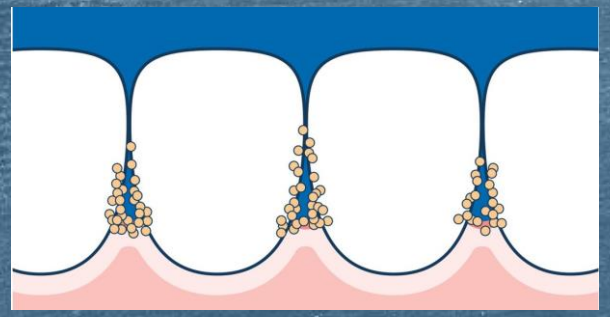
Engineered primarily around gentle, oxygenated gum care rather than high-velocity blasting

**3 distinct hydrostatic intensities including Sensitive:** A very low-velocity setting calibrated for inflamed gums, active ulcers, or sensitive teeth.

Cordless and plug-in. 10 intensity settings

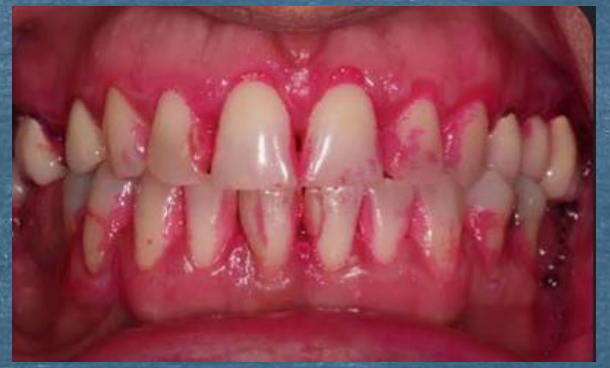
# Epidermolysis Bullosa – Oral hygiene aids

## Interdental care



Toothbrushes only reach the front, back, and biting surfaces—interdental aids clean the spaces where teeth touch.

Clear away trapped food debris and bacteria that cause interproximal decay (cavities that form between tight teeth).

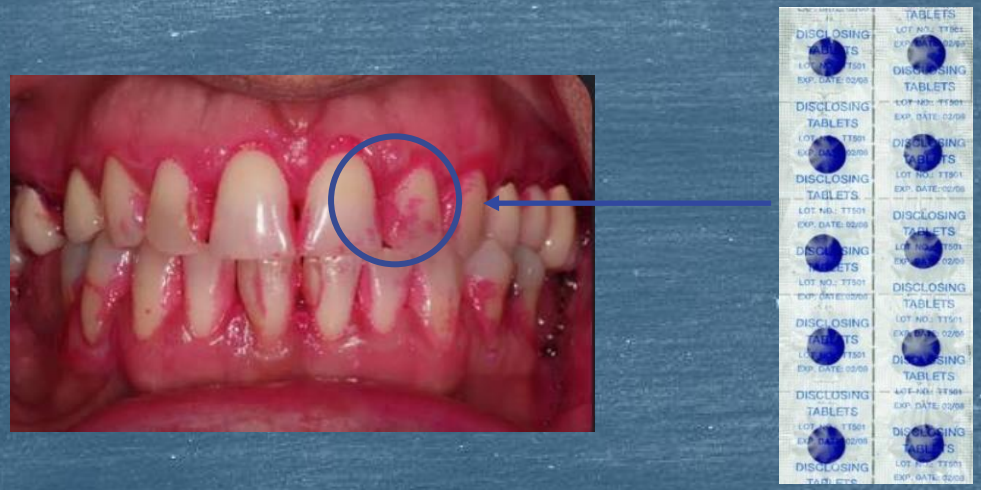


# Epidermolysis Bullosa – Oral hygiene aids

## Interdental care

# Epidermolysis Bullosa – Oral hygiene aids

**Interdental care – Plaque disclosure**



# Epidermolysis Bullosa – Oral hygiene aids

## Mouthwashes - antimicrobial


Colgate Savacol

Curasept

Curaprox Perio Plus

Chlorhexidine (0.2%) – alcohol free
Rinse 2 x day for 2 weeks every 3 months


Colgate Plax

Cetylpyridinium chloride (+ fluoride ☺ )
Suitable for daily use

Listerine – Essential oils

Colgate Peroxyl – hydrogen peroxide

Cepacaine – cetylpyridinium

# Epidermolysis Bullosa – Oral hygiene when it's BAD

**Ideas for when ulceration makes toothbrushing impossible**

Do not stop oral hygiene entirely

Pain relief !!!  EB team


Disrupt plaque

- Discontinue tooth brushing (or restrict)
- moistened gauze, cotton swabs,
- interdental brushes (Curasept Gingival Gel)

Rinse with water during the day, especially after meals

# Epidermolysis Bullosa – Oral hygiene when it's BAD

**Ideas for when ulceration makes toothbrushing impossible**

Do not stop oral hygiene entirely

Rinse with water during the day, especially after meals


**Chlorhexidine mouthwash** 5-10ml (2%) swish 30s spit, 1-2 day

**Sodium Bicarbonate / Saline Rinse** ½t of salt & ½t baking soda in a glass of warm water 4x day (?? sting).

**Saline Rinse** ½t of salt in a glass of warm water 4x day (?? sting)

# Epidermolysis Bullosa – Oral hygiene when it's BAD

**Ideas for when ulceration makes toothbrushing impossible**

Do not stop oral hygiene entirely


Careful diet – soft, puréed, or liquid high-energy, high-protein diet

Local pain control
- Numbing solution (lignocaine) before meals and bed
- ~~Difflam (Benzydamine) mouthwash or spray~~
- Aftamed (hyaluronic salt)
- *Oral7 DentaMed*


High fluoride toothpaste – finger to smear on teeth (gum line)

Curasept Gingival Gel - finger to smear on teeth (gum line)

Resume normal oral hygiene as soon as possible

# Epidermolysis Bullosa – Diet

**Diet**

Painful to eat - Tendency towards high-carbohydrate, soft or liquid diet

- Frequent sipping of sweet drinks or supplements

**High carbohydrate diet favors plaque formation - tooth decay / gum disease**

**Tips**

- Try to have sugary drinks or supplements with meals, not constantly during the day
- Rinse with water (or brush if possible) after eating
- Brush with fluoride containing toothpaste, spit but don't rinse after
- Work with dietitian / dentist

# Epidermolysis Bullosa – Microstomia

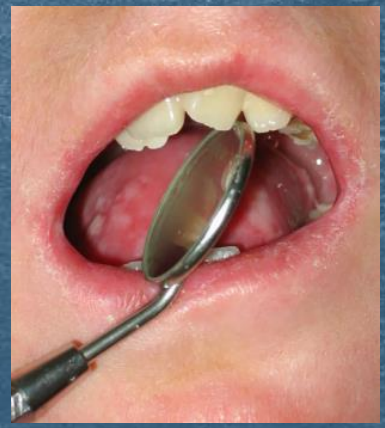
**Reduced mouth opening** Ulceration can lead to scarring

**Scarring**

Reduced oral opening (microstomia)
Reduced tongue mobility (ankyloglossia)
Space between lips/cheeks and teeth may disappear (vestibule obliteration)

Mouth scarring makes eating, speaking and dental treatment difficult

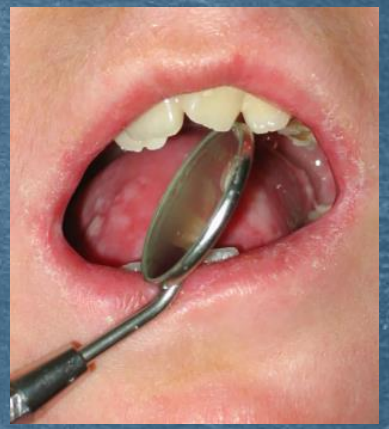
Microstomia tends to be progressive, worsening over time



# Epidermolysis Bullosa – Microstomia

**Reduced mouth opening**

**Daily "Gymnastics" for your Mouth**



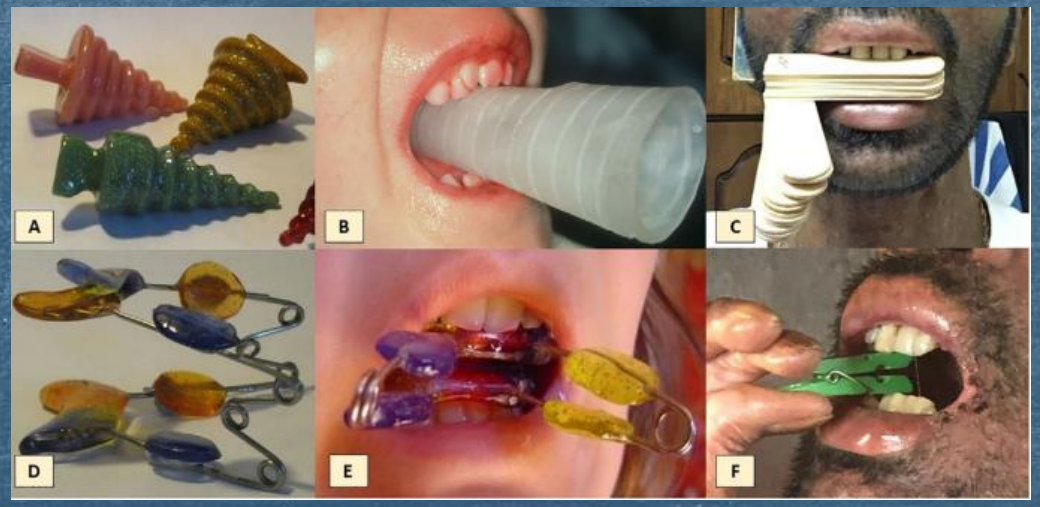
Prevention is absolutely critical

Must do everything possible to minimise scarring - 'friction'

Regular daily gentle jaw stretching exercises

Build into daily routine (meals, dressing changes, pre-dental work)

Devices available




# Epidermolysis Bullosa – Microstomia

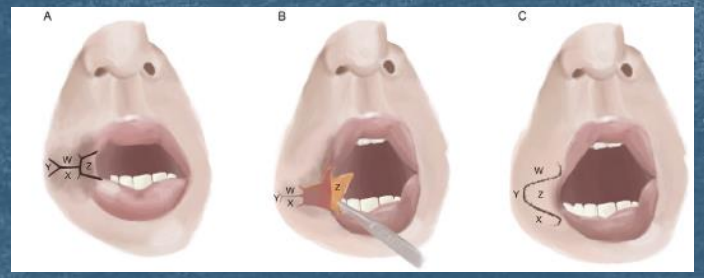
## Reduced mouth opening – Surgical options

**Mild, superficial scarring**
→ Skin grafts, small local cutaneous/mucosal flaps (Z-plasty, limited Y-V, rhomboid, trapeze)

**Moderate, localised commissural/mucosal scarring**
→ Y-V, rhomboid, or trapeze mucosal flaps; double Z-plasty; asterisk design if more widening needed

**Severe or diffuse perioral scarring, but local tissues viable**
→ More extensive local flaps (asterisk, nasolabial pedicle flap), possibly combined with grafts

**Very severe, deep, diffuse scarring with poor local tissue/vascularity**
→ Free flaps (RFFF for unilateral; windowed DIEP or similar for bilateral/extensive), often combined with local flaps for final commissure shaping




Jeong D, Saffari TS, Liao A, *et al.* Surgical Management of Microstomia: A Comprehensive Review of Treatment Options. JPRAS Open. 2025 Mar 7;44:178-193.

# Epidermolysis Bullosa – Microstomia

## Reduced mouth opening – Lasers

Fractional carbon dioxide ($CO_2$) laser resurfacing

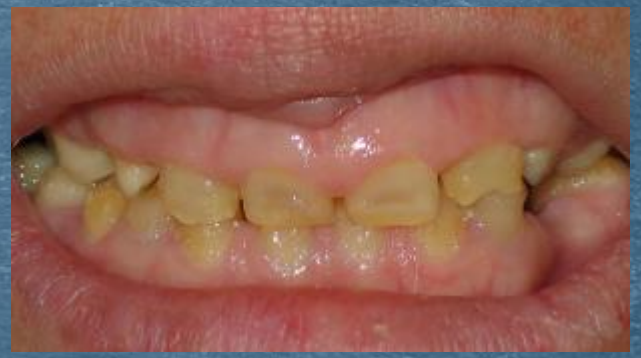

Ituarte BE, Rosa-Nieves PM, Schissel M, A pilot study of $CO_2$ laser-assisted drug delivery of hyaluronidase for the treatment of scleroderma-induced microstomia. J Am Acad Dermatol. 2026 Jan;94(1):363-365.

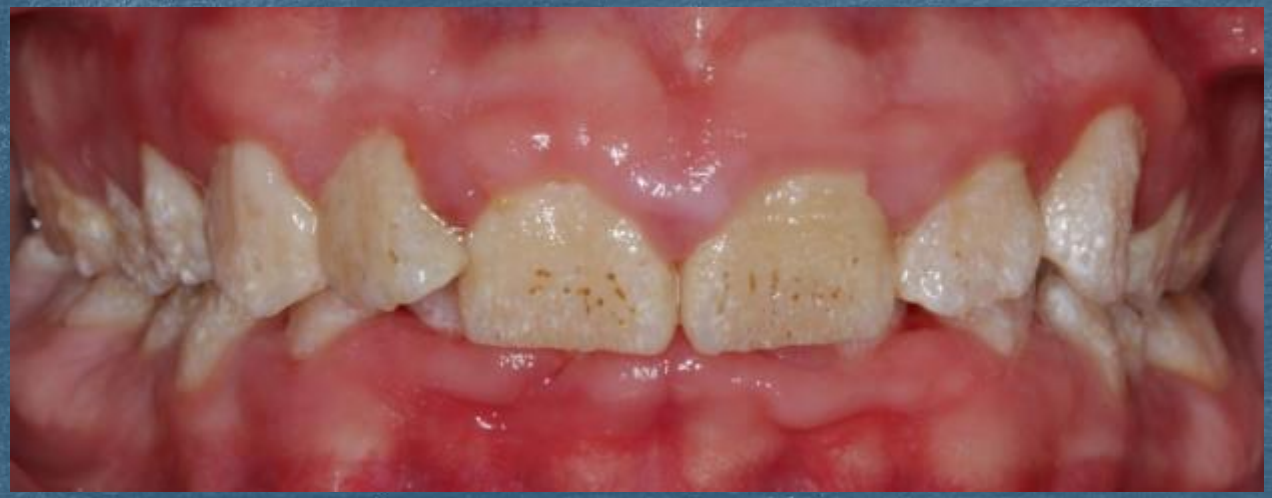
Salimi E, Assar S, Salimi A, Mohamadzadeh D. Fractional Carbon Dioxide Laser for Treatment of Microstomia and Rhytids in Systemic Sclerosis Patients. Mediterr J Rheumatol. 2024 May 21;35(3):459-463. doi: 10.31138/mjr.101223.fcd. PMID: 39463866; PMCID: PMC11500117.

# Epidermolysis Bullosa – Enamel defects

Enamel can be thin, pitted, discoloured, or missing

- Teeth may be sensitive
- Teeth decay more easily
- Teeth chip and wear down faster
- Teeth can look discoloured, unkept, 'ugly'

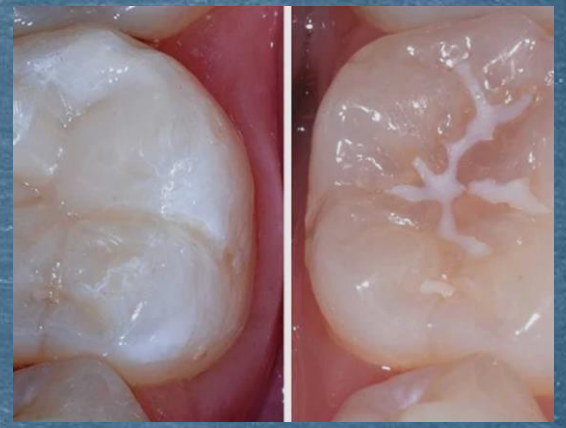


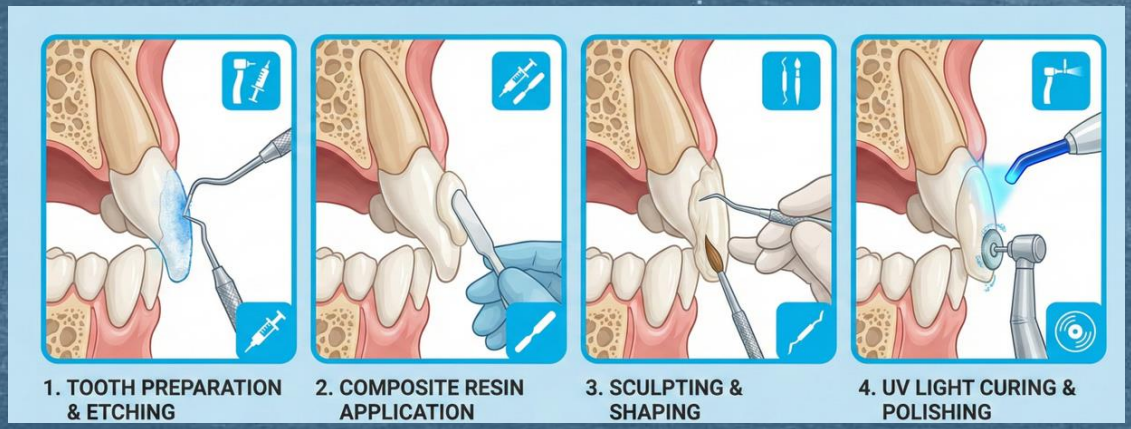


# Epidermolysis Bullosa – Enamel defects

Early protective coatings and coverings on teeth

Fissure sealants  Fluoride

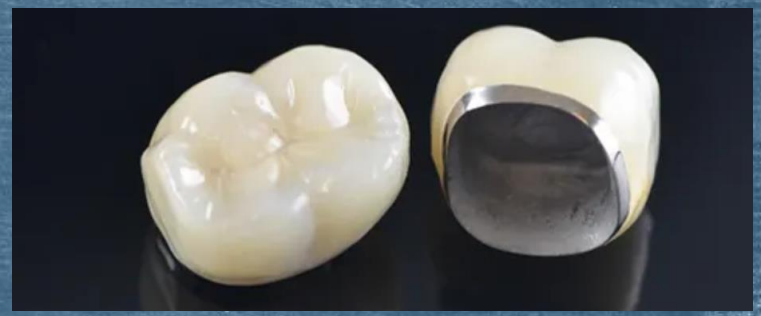





Bonded treatments

# Epidermolysis Bullosa – Enamel defects

## Crowns



**Prevention**
Fluoride treatments, diet, optimise home care – oral hygiene, sensitive toothpastes,

## Tooth decay

People with EB have more tooth decay

# Epidermolysis Bullosa – Enamel defects

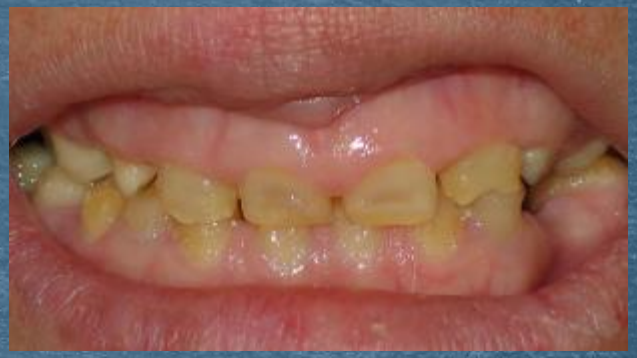
Regular dental examination

Early protective coatings and coverings on teeth

Fluoride treatments

Care with diet

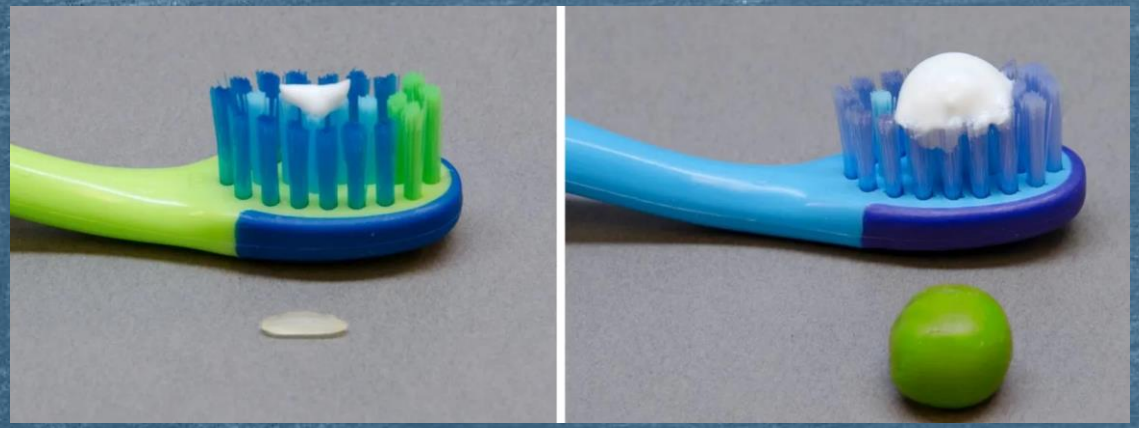
Optimise home care – oral hygiene, sensitive toothpastes



# Epidermolysis Bullosa – Oral hygiene aids

**Fluoride containing toothpaste**

At least 1000ppm fluoride – Adults and children



**Infants & Toddlers** *(First tooth up to 2 years)*
A bare smear - Rice grain size

**Children** *(Under 5 years)*
A small smear / half-pea size

**Children & Adults** *(6 years and over)*
A standard portion Pea-sized amount

High-concentration **5,000 ppm fluoride** (increased risk for decay)

# Epidermolysis Bullosa – Oral hygiene aids

**Fluoride containing toothpaste**

At least 1000ppm fluoride – Adults and children

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**Children & Adults** *(6 years and over)*
A standard portion Pea-sized amount

**May need to avoid**

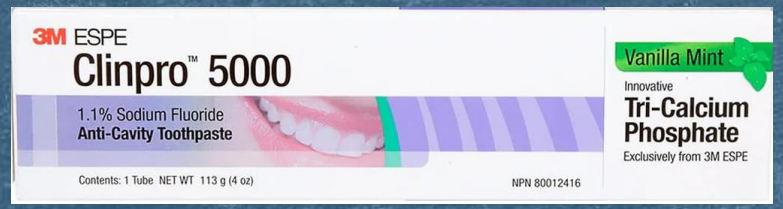
Sodium lauryl sulphate – foaming agent

Strong menthol / mint flavourings

# Epidermolysis Bullosa – Oral hygiene aids

**Fluoride containing toothpaste**

High-concentration **5,000 ppm fluoride** (increased risk for decay)



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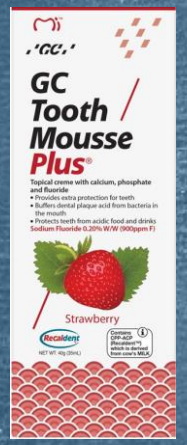
A standard portion Pea-sized amount

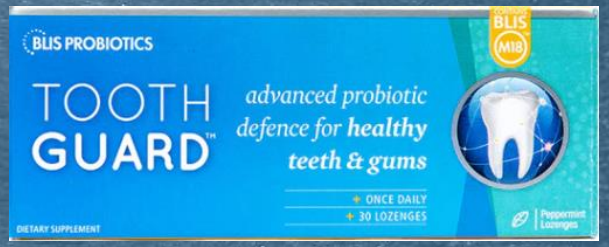
# Epidermolysis Bullosa – Oral hygiene aids




**RECALDENT**

Tooth Mousse - casein phosphopeptide-amorphous calcium phosphate CCP-ACP

**Probiotics**




?

**Nano-hydroxyapatite**


Grin Pro Enamel Care

No fluoride ☹


Red Seal Baking Soda
& Hydroxyapatite

No fluoride ☹

# Epidermolysis Bullosa – Gum disease

**Gum disease**

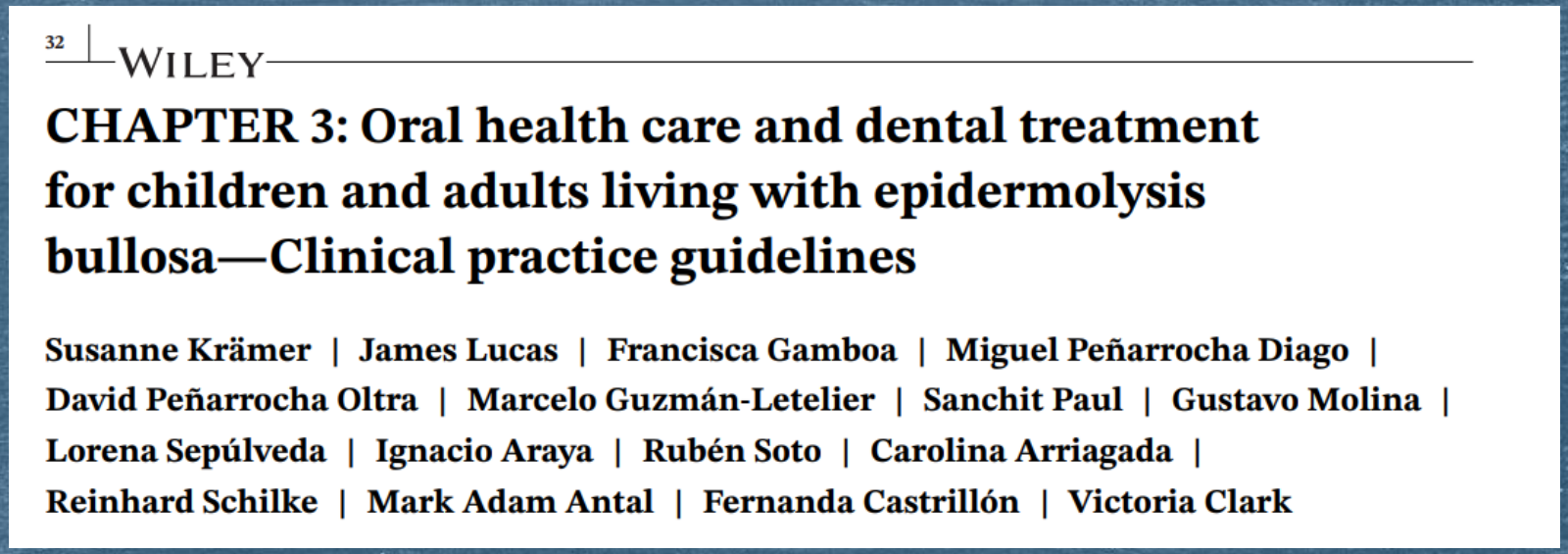
Fragile gums that get very inflamed and bleed easily.

Rapid gum and bone loss around teeth (early, aggressive periodontitis).

Very regular, gentle gum care and professional cleanings are essential.

Focus as much on the gums as on the teeth.

# What you should expect from your dentist

# What you should expect from your dentist

Have an understanding of EB (a whole person/life perspective)

Keep learning from you, and from EB guidelines and research

Understand the oral implications of EB

Have a strong focus on preventative care

Tailor your dental care to your EB type and your personal situation

Liaise and coordinate with your GP and EB specialist team

Partnership approach

# What you should expect from your dentist

Cool air-conditioned environment

Allocate sufficient time for the procedure

Allow you (patient) to position yourself (or parent caregiver position child)
Have regular breaks to rest and change position

Lubricate lips and areas that might rub with protective emollients (e.g., vaseline)
Repeat Repeat Repeat Repeat Repeat

Good analgesia

# What you should expect from your dentist

Your dentist needs to

**Be gentle, deliberate, focused and ensure the team is also.**

**Focus on prevention**

Lubricate and protect

Avoid pulling or sliding instruments along your mucosa

Avoid high volume suction – careful positioning

Care with air/water syringe

Moisten when possible (cotton rolls)

Check for blisters and drain with sterile needle retaining roof – enhance healing

No tape or adhesive dressings

Extra oral radiography

# **How to make your visit to the dentist the best** (it can be)

**You direct activity** – from positioning in the dental chair to leaving

Bring any pressure reduction items to the dental appointment

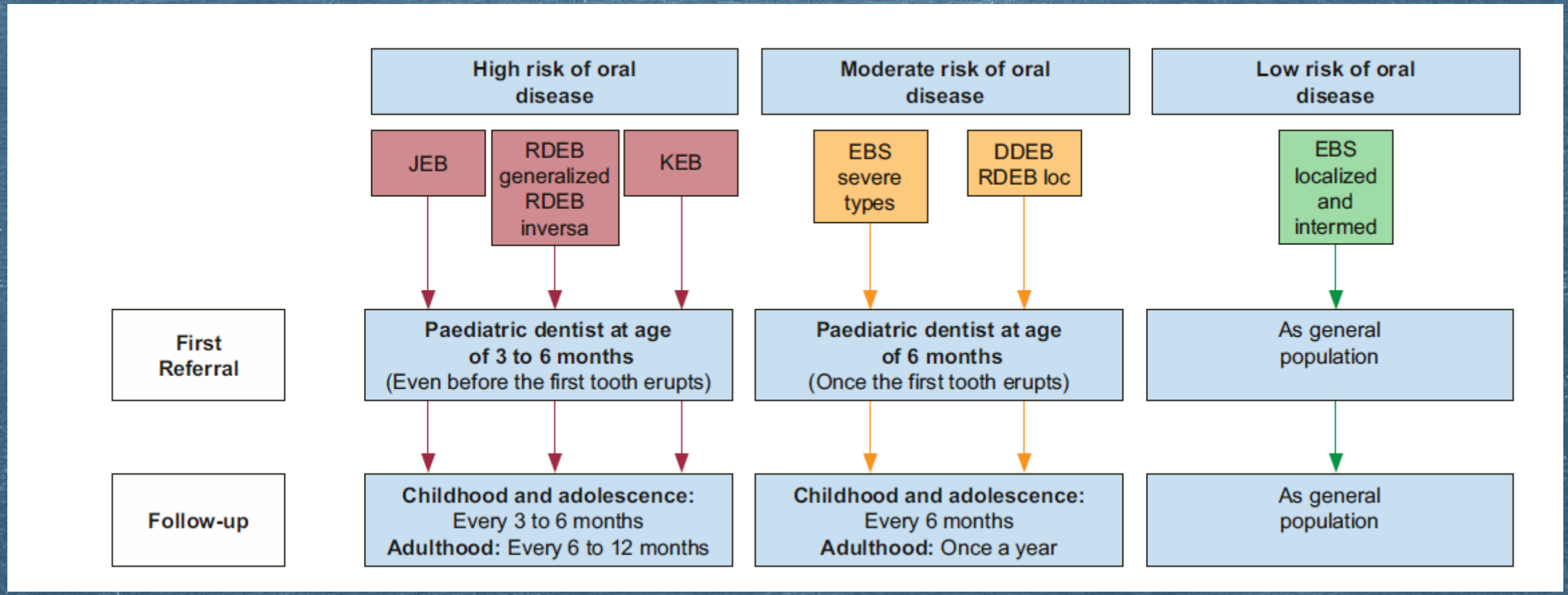
Lubricate lips and areas that might rub with protective emollients (e.g., vaseline)

Do gentle mouth-opening stretches before the appointment

Ask for breaks

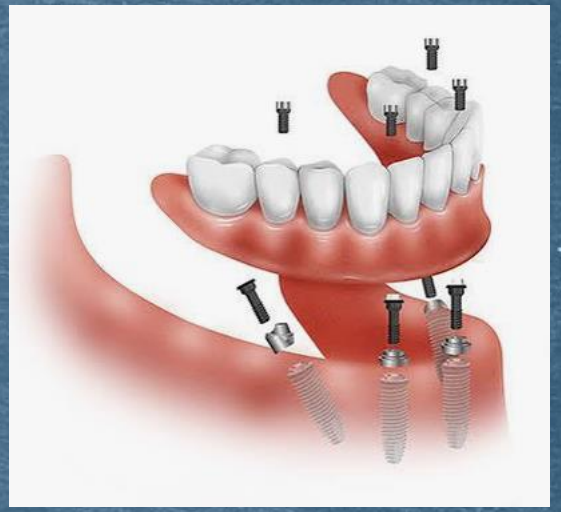
*You are the expert on how your body feels. Always tell the dentist what works best for you so the dentist can adapt to your needs*

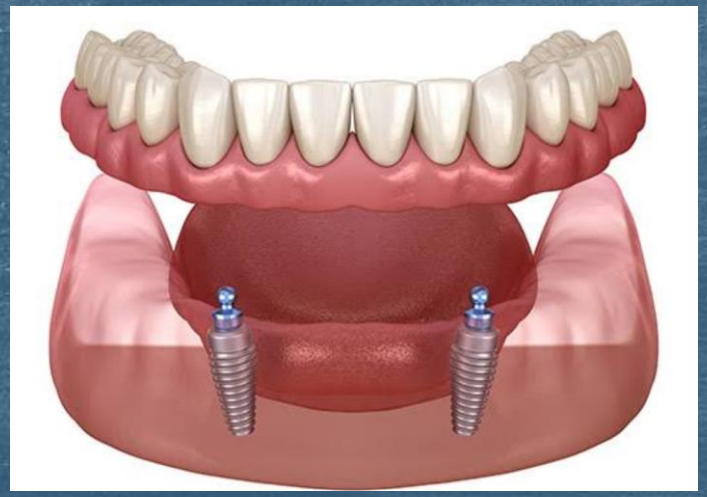
# Epidermolysis Bullosa – Risk and recall by type




Krämer S, et al Oral health care pathways for patients with epidermolysis bullosa: A position statement from the European reference network for rare skin diseases. J Eur Acad Dermatol Venereol. 2025 Jun;39(6):1080-1090

# ‘Advanced Care’: Dental Implants





# ‘Advanced Care’: Dental Implants

Implants can give fixed teeth that don’t rub the gums as much

Same clinical considerations for EB people

No evidence of increased rate of implant failure in people with EB

**Considerations**

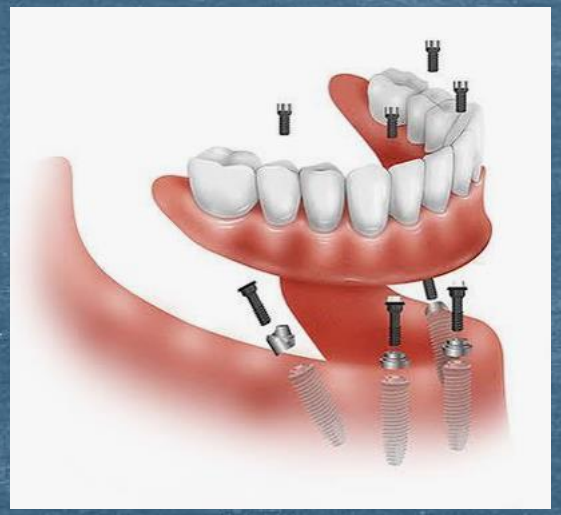
Home care

Microsotomia

Maintenance

Cost

What next!



**Implant treatment is complex and should be done by experienced teams**

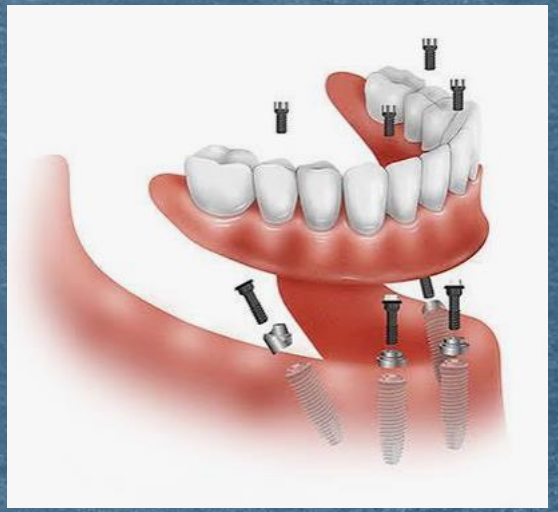
# ‘Advanced Care’: Complex care

**The more extensive the dental need, the greater the complexity of care.**

**The greater the complexity, the greater the maintenance needs**

**The more challenging  the complications**

**The more challenging the treatment**



**LESS IS OFTEN MORE**

Hugh Trengrove

htrengrove@adhb.govt.nz