

# Sharing Photos Online; *A Gentle Guide For Goldenhar Families*

## **Empowered, Safe Choices For Families**



Goldenhar UK



# RELIGHT

## COUNSELLING

**Explore | Empower | Embody**

[www.relightcounselling.co.uk](http://www.relightcounselling.co.uk)

# 1. You're Not Alone in These Feelings



Many parents of children with Goldenhar Syndrome, or any visible difference, feel this tug-of-war (I know I did for many years).

You're not the only one lying awake wondering if posting a photo might make your child a target or fearing that keeping them hidden might make them feel different.

These thoughts don't make you paranoid or negative.

They make you a **thoughtful, loving, human parent** doing your best.



# 2. The Common Worries, & Why They Make Sense



**“What if someone says something cruel?”**

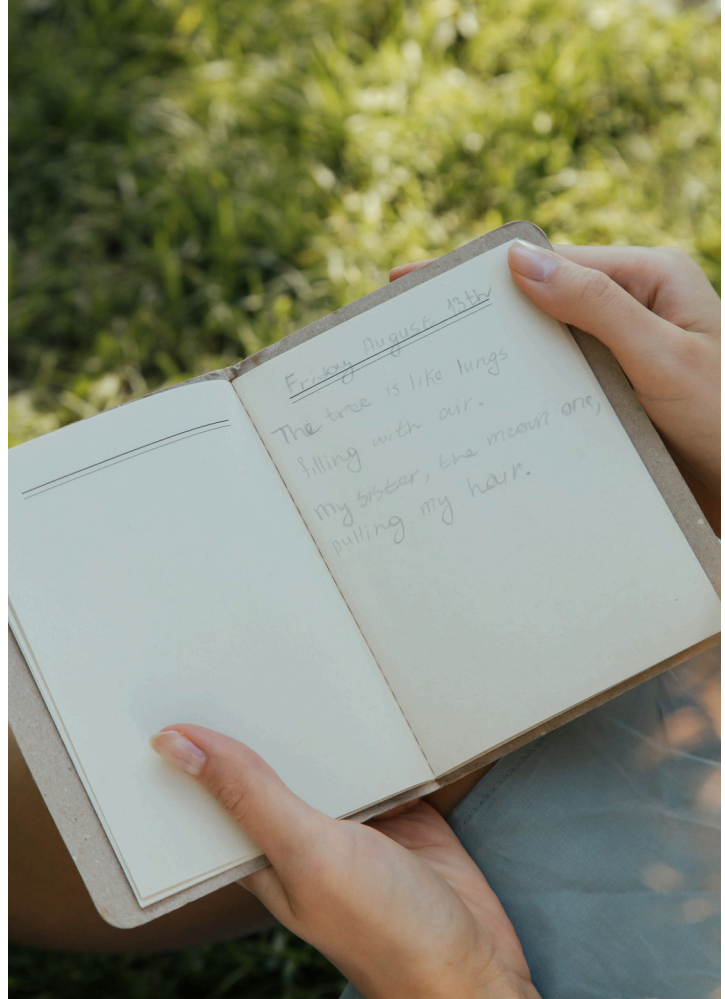
It’s a real fear. The internet isn’t always kind, and neither is the world. But you can choose safe spaces. You can choose what you share and who sees it.

**“What if school shares their photo without asking?”**

UK schools usually require photo permissions. You can give limited consent (e.g., for use inside school only, not social media). You have rights, and it’s okay to set boundaries.

**“What if they grow up and don’t understand my decision?”**

That’s a valid fear. One way to help is to keep a record of your reasons. More on page 9.



## 3 REFLECTION JOURNAL PROMPT

Take a quiet moment and ask yourself:

- 1) What am I afraid of when it comes to sharing photos of my child?
- 2) What do I want them to know about the choices I made?
- 3) What message do I want to send them—and the world—when I share?
- 4) What feels like the most loving, respectful way to share their story right now.

# 4.DECISION-MAKING CONSIDERATIONS



- → **Do I feel confident about sharing this?**
- • Yes → Proceed with intention and check privacy settings.
- • No → Pause. Explore what's making me unsure.
- → **Will my child feel respected if they see this in the future?**
- • Yes → Is this moment meaningful to share?
- • No → Consider saving it privately or journaling instead.
- → **Am I sharing from a place of love or pressure?**
- • Love → Go gently, share meaningfully.
- • Pressure → Pause, reflect, wait.

# 5. THERE'S NO PERFECT DECISION

There's No Perfect Decision, Just the Best You Can Do.

You can never be 100% certain how a choice will play out. And this goes for everything in life!

But if you're making it with care, thoughtfulness, and love, it counts for a lot, and our children will understand in time.

It's okay to say, "This is what feels safest and kindest for my child today." It's okay to change your mind. Or not.



# 5. REVIEW YOUR DECISION OVER TIME



Our kids grow. We grow too

You might feel differently in six months, or not until years later. That's okay.

You could set a simple yearly reminder:  
“Do I still feel okay about how we’re sharing photos?”

Some families do a “values check-in” around their child’s birthday or in the new year. It’s a gentle pause to reflect and tweak if needed.

**Deciding to review regularly can help to take the pressure off**



# YEARLY CHECK-IN PROMPT



At the start of each year (or on a date that feels meaningful), ask yourself:

- How do I feel about what I've shared about my child so far?
- Does anything need adjusting?
- Are there new tools or language that can help us explain our choices to our child?
- What would feel like a kind next step for our family?





# ANNUAL LETTER TO YOUR CHILD

Each year, you might write a letter to your child, building a loving record of your parenting journey.

## **Include:**

- What you noticed and loved about them this year
- Any big decisions you made and why (including your decisions about sharing photos or not sharing)
- How you've grown as their parent
- Wishes and hopes for their future

**You could keep these in a journal or box to one day gift your child when the time feels right.**



# REAL STORIES FROM GOLDENHAR PARENTS



I would love if we could fill this section with some personal insights here from Goldenhar parents to support this guide (this will of course be anonymous, unless you would specifically like to be named)

**If you would like to add to this section, please get in touch with myself or Suzanne from Goldenhar Uk.**



# A PERSONAL NOTE



When I had my son, I was so consumed by worry. His future, the future operations, the “what ifs” and the “what will they say?” It all weighed so heavily that I wasn’t fully present in those early baby days.

And now, if I’m honest, I miss that time. I miss the moments I could have spent just *being* with him, not planning and protecting every second.

That’s why I want to encourage you, let’s make a decision for *this* life stage. What feels right right now? You can always reassess later.

I also want to encourage you to seek emotional support if you need it, as a psychotherapeutic counsellor and a Goldenhar parent I offer up to 8 free counselling sessions as part of Goldenhar UK, visit [www.relightcounselling.co.uk](http://www.relightcounselling.co.uk) or scan the QR code. Alternatively, you can speak to your GP to signpost you to supportive services.



# A REFRAME: SHARING ISN'T ALL OR NOTHING

Here are ways to honour your child's presence without putting them on display:

- Side or back-view photos
- Images of hands holding, favourite toys, shadows, or nature walks together
- Caption the joy,
- Create photo books or private online albums for close friends/family,
- A family WhatsApp group to share photos
- Famelio is a subscription, where you can upload photos and messages which are printed monthly in the style of a newspaper, perfect for grandparents or loved ones who don't use social media

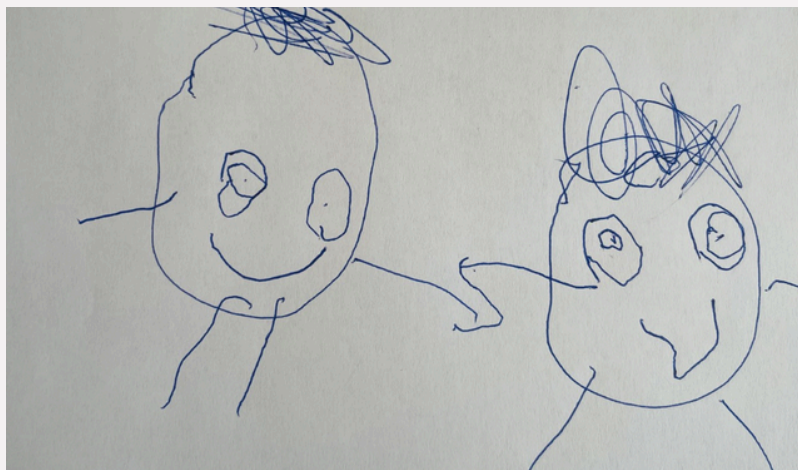


# BEYOND DIFFERENCES



As parents, we naturally want to celebrate our children and share their beautiful moments with the world.

When it comes to children with Goldenhar Syndrome, and truly, all children, it's important to remember that they are still growing into who they are.



Many children, as they get older, may feel differently about what has been shared about them.

This isn't just about facial differences; it's about protecting their story, their sense of self, and giving them the choice to share their journey when they're ready.

With love and thoughtfulness, we can honour both their today and their future.

# CHILD-FRIENDLY WAYS TO EXPLAIN PRIVACY

## Here are some gentle phrases:

- “We’re we waiting until you were old enough so that you can decide, your own autonomy is important to us.”
- “We love sharing about you in ways that feel safe. The internet isn’t always a safe place.”
- “Some families post lots of photos. We do things a little differently, and that’s okay.”





# PLEASE REMEMBER



Please remember, if others don't understand your decisions, that really doesn't matter.

It's your understanding and your child's that matter the most.

**IMPORTANT**



# SOCIAL MEDIA SAFETY CHECKLIST



If you choose to share online, consider:

- Set your account to private and check your followers regularly.
  - Use watermarking apps if concerned about image misuse.
  - Disable comments if you're worried about negativity.
  - Share in closed, trusted groups instead of public timelines.
  - Know how to report and block if needed, and trust your instincts!
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# FINAL THOUGHTS

**There's no one size fits all answer.**

Just a series of small, thoughtful choices.

Whatever you choose, if it's rooted in **love and care**, it will be enough for your child.

Take a look at my blog section for more goldenhar related topics



**From one parent to another**

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*Psychotherapeutic counsellor.*



I would love to hear your thoughts on this resource.

Feel free to contact me.

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