

When your Child has an Appearance Difference

Information for parents and carers



This leaflet aims to provide some helpful information for parents and carers of children with appearance differences. Trying to have a positive attitude, even when this feels difficult at times, can feel stressful for parents or caregivers. However, portraying a positive attitude and positive language towards your child's appearance difference can really help in reducing any shame or discomfort your child may feel about their appearance difference and can teach them to think well of themselves.

Finding out about my child's appearance difference

It can be challenging to find out about your child's appearance difference and often the amount of information can be overwhelming. Here you can find some guidance on how to approach the challenges of finding out information.

Getting the most out of your medical appointments

It can be quite unsettling to understand the amount of medical terminology and possible treatments. It can also be difficult to retain new information and know the right questions to ask during an appointment.



Some parents find it helpful to take a systematic approach to finding out information. The more information you have, the more in control you might feel.

Top tips for information gathering:

Have a list of all your questions

- If your child is old enough, they can also write down any questions they might have.

Review your questions

- The day before your appointment, you might want to highlight the questions you want to prioritise.

Don't be afraid to ask for clarification

- Medical professionals often use medical terms that you might not understand. Don't be afraid to ask for an explanation or to use language that you understand.

Tips on having a conversation with your child

Carers and parents often worry about upsetting their child by talking to them about medical conditions and treatments. We know it's normal for children around the age of 8 years old to start questioning why they look different. Involving your child and talking to them in a calm and reassuring way may help them to:

- build confidence in themselves and their self-image
- answer questions from other people
- reduce anxieties or fears.

Top tips on having a conversation:

Talk in a positive way

- Normalise similarities and differences in your child's environment.
- Their appearance difference is just another part of who they are – just like a personality trait or the colour of their hair.
- Focus on the whole person and their good qualities.

Use appropriate language

- Think about the language you use when talking about people's appearance and try to choose words that are neutral and factual.
- Be open and honest and use language you feel comfortable with.

Listen first and offer solutions later

- Pay attention to any difficulties or anxieties your child is having without judging them or offering them solutions on how to cope.

Encourage family discussions

- Having a conversation about body image or appearance when it pops up on TV or social media can be a good way to have a chat about how what is shown on TV or online doesn't always reflect how people look in the real world.
- Don't let bullying be a taboo subject – encourage your child to talk to you about any incidences and share experiences that you or other family members might have also had at their age.



How to cope with other people's reactions

Because of your child's appearance difference, your child (and you) may receive unwanted questions or comments about their appearance. How you respond to other people's reactions can teach your child to react in similar ways, as children often look to adults for how to behave.

Top tips on responding to unwanted attention:

Plan your response

- Having a prepared response can help when questions are asked off-guard.
- It is up to you how much (or how little) you want to give away about your child's appearance difference.
 - You can say that you don't want to discuss it at all.
 - You can give a short description.
 - You can give a longer description.
- When planning your response, you might want to consider:
 - Who you are talking to – is it a close friend or a stranger?
 - How you are feeling – are you feeling confident or having a bad day?
 - What situation you are in – are you in a busy environment where other people might overhear your conversation?

Explain – Reassure – Divert

1. **Explain** the appearance difference, say as much or as little as you like.
2. **Reassure** the other person (they might be worried) or reassure yourself that they are just curious.
3. **Divert** attention away from your child.

Example:

“It’s called alopecia. It doesn’t do them any harm. We’re on our way for lunch, what are you doing now?”

Managing stares

- People are often curious. Sometimes people look at something for longer without realising it when they see something different. Most people do not intend this to be hurtful or inconsiderate. Knowing this can often help reassure yourself and your child.
- There are different ways you can respond to staring:
 - Acknowledge the staring by looking back, smiling or nodding. This can help break the ice and most people tend to smile or nod back and then look away.
 - You can decide not to respond at all or move away. This does not mean that you are “letting them get away with it”, because it is your choice to ignore the staring.

Looking after your mental health as a parent

As a parent or carer of a child with appearance differences, you may experience extra worries that can have a strain on you and your family. You might feel like you have to push your own feelings aside to take care of your child, but it is important that you look after your own mental health as well.

If you ever feel like you are struggling to manage, you might want to reach out to your GP for support.

Top tips for improving my wellbeing:

Plan and prioritise activities you enjoy

- Put some time aside every week to do your favourite activity.
- Find a few minutes each day to do something pleasurable for yourself – whether this be reading a chapter of a book or going for a walk to get a nice coffee.

Learn to say no

- Don’t feel guilty for taking time for yourself.
- Be honest about your feelings and reach out to loved ones when things feel overwhelming.

Try to keep a balanced diet

- Drinking plenty of water and keeping your body fuelled with nourishing food can have a positive impact on your gut and mind.

Reflections and being mindful

- Reflect on your current coping strategies and identify what has been helpful and unhelpful.
- Pay attention to what your body needs and take the time to take care of yourself.

Talk to someone

- It can be helpful to talk to someone about your feelings (whether this is a friend or a professional).

Identify what helps you relax

- There are different ways to relax. Some people enjoy reading a book, whereas other people like to go for a jog. This is something that is individual to you and your preferences.

Use the links or scan the QR codes below for videos on helpful relaxation techniques:

Breathing techniques can be beneficial to practise in the long term (e.g. breathing in to the count of 4, holding for 4, and breathing out for 4).

www.youtube.com/watch?v=1Dv-ldGLnIY



Progressive muscle relaxation is helpful when your body is feeling tense. It is a technique used to help you relax your muscles (e.g. you could try and tense your major muscle groups for 5 seconds and then let go).

www.youtube.com/watch?v=GZ9PHsbm4



Grounding techniques can help promote mindfulness and refocus our attention on the present. Take a calming breath and try and name 5 things you can see, 4 things you can hear, 3 things you can touch, 2 things you can smell and 1 thing you can taste.

www.youtube.com/watch?v=30VMIEmA114



Siblings

When a child has an appearance difference, it can have an impact on other people in the family too.

Brothers and sisters may notice or resent the attention that their sibling's appearance difference attracts. They may misbehave to get attention or feel like they always have to be on their best behaviour. They can also be aware of the stares or comments made and may get asked questions which can worry them.

Top tips on helping siblings:

- Help them learn about the appearance difference and get them involved in family discussions.
- Depending on their age, you can help them understand more about their brother or sister's appearance difference.
- Check in with them and talk about any worries they might have about their sibling, or about themselves.
- Help them plan a response to any questions they might get.

Paediatric Psychology and Liaison Service, Royal Hospital for Children and Young People
With Thanks to the Changing Faces Charity

