



Appearance Collective workshop

Support for parents of children with a visible difference

Dr Maia Thornton
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THE VTCT
FOUNDATION



Centre for
Appearance
Research



UWE
Bristol | University
of the
West of
England

Overview:

- **Introductions**
- **Parent/carer challenges discussion**
- **Update on the literature**
- **What support is available?**
- **Parent support development at CAR**
- **Upcoming research**



Workshop participation:

- Interactive – share your thoughts/ideas
- ‘Raise hand’
- Use the 'chat' function on Teams
- Mute mic when not speaking
- Menti - Go to www.menti.com

Menti code 3231 4777



Introductions



Dr Maia Thornton
Research Fellow



Clare Clement
PhD student



Funded by



**Workshops delivered to members
of the Appearance Collective**

What are the challenges faced by parents & carers in your communities?



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What does the research say?

In addition to typical parenting challenges....

We know parents and carers can experience emotional and practical challenges related to their child's condition or injury.

Both condition-specific and cross-condition research.



What does the research say?

Initial diagnosis or injury event can be a stressful and anxious time.

Parents talk about feelings of guilt related to the cause of their child's condition.

Social stigma , such as unwanted attention or social exclusion.

Anxiety about social challenges e.g., making friends, starting or moving schools, dating, employment.



What does the research say?

Additional healthcare needs:

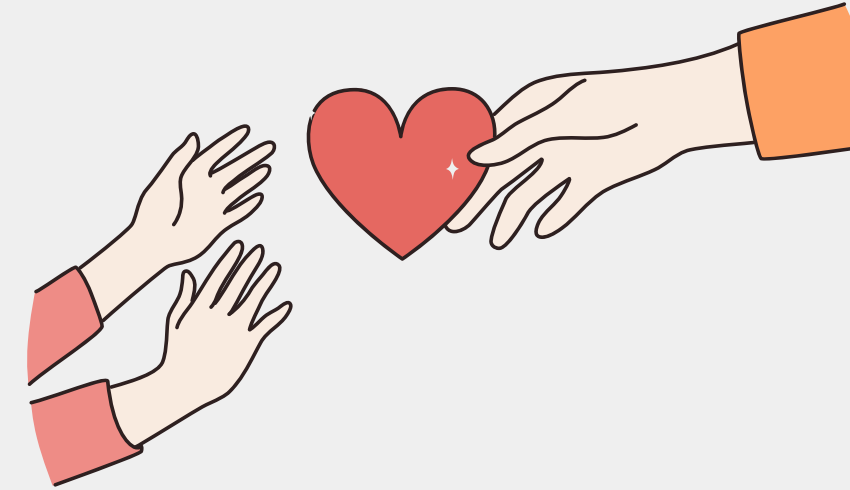
- **Diagnosis process**
- **Treatment decision making**
- **Attending hospital/GP appointments**
- **Carrying out treatment regimes**

Other functional differences:

For example:

- **Craniofacial: Feeding, speech, hearing**
- **Skin conditions: bathing, treatment**
- **Burn injuries: Scar management**

What does the research say?



Parents report they struggle to find the balance.

Providing emotional and practical support.

Speaking to their child about their appearance difference.

Equipping them with the skills to manage independently.

Not wanting their parent-child relationship to only be about their child's condition or injury.




What does the research say?

Some parents and families adjust really well.

- **Appreciation of difference.**
- **Empathy for others.**
- **Awareness of resilience.**





What does the research say?

Overall, parents are driven to support their child.

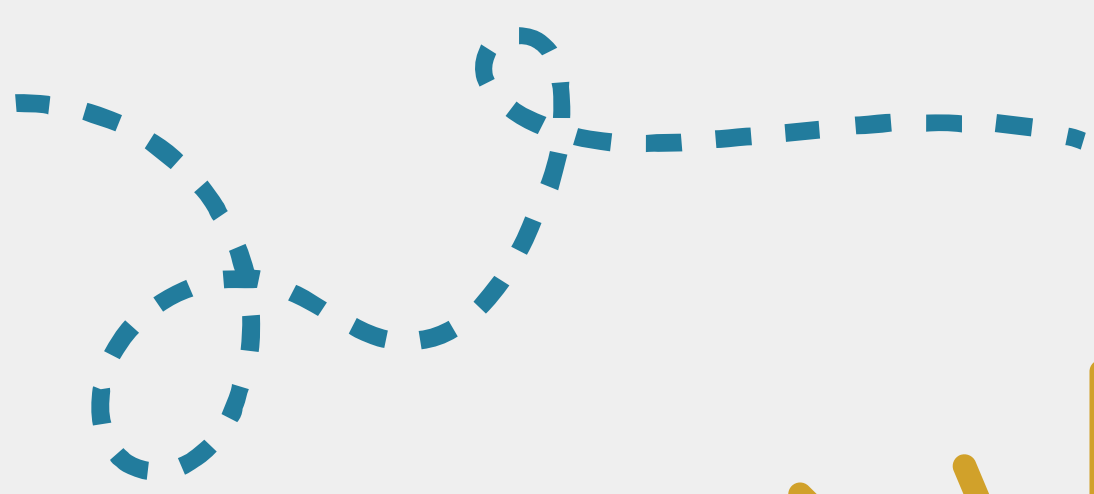
Aware of the need to prepare their child to manage independently.

But sometimes lack confidence in how to best approach this.

Highlight a gap in support for parents and carers.



Break



What does parent support mean for your communities?



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The Parenting Toolkit

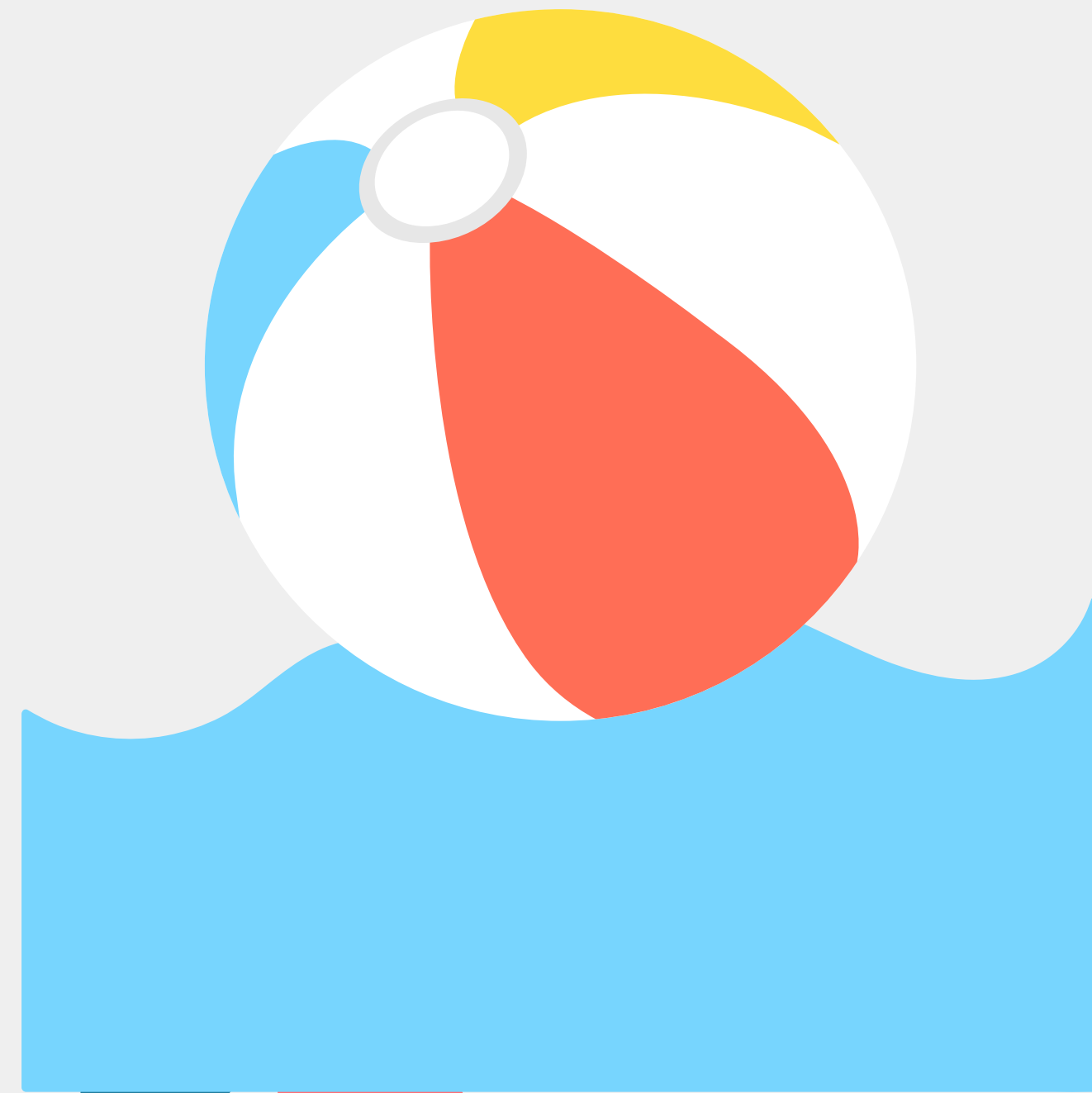


Acceptance and Commitment Therapy = ACT

- **Mindfulness with a Purpose**
- **Related to Cognitive and Behavioural Therapy**
- **Focuses on how you act, to do more of what makes life fulfilling**



The Parenting Toolkit



Difficult experiences can make us feel like we want to avoid or control a situation

ACT teaches us to attend to these experiences in a curious, open, and accepting way

The Parenting Toolkit

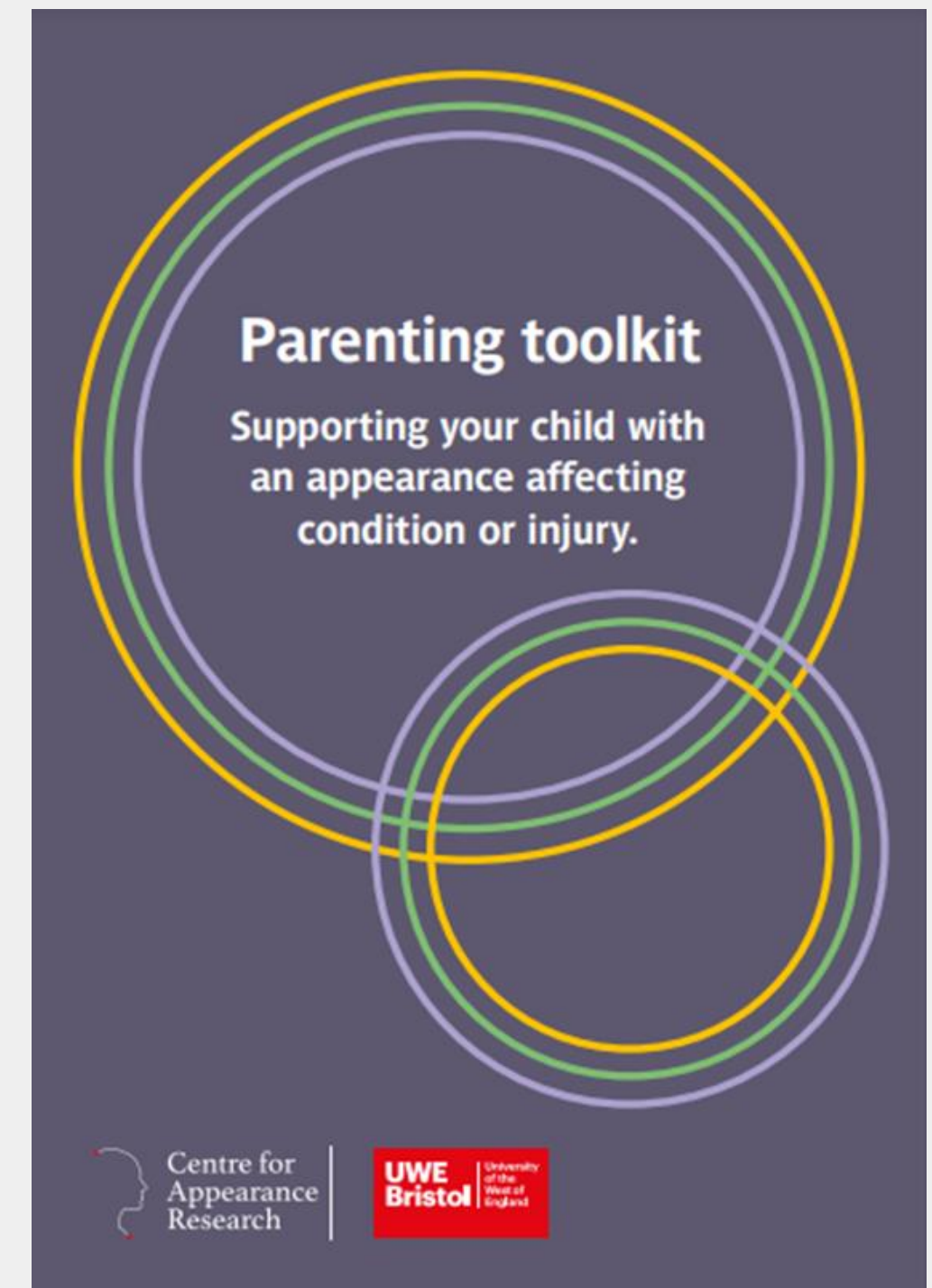
Working alongside parents with lived experience and clinical advisors.

Evidence-based e-workbook intervention aimed at promoting psychosocial wellbeing in parents

Section 1: Managing difficult thoughts and feelings for parents.

Section 2: Practical advice and guidance to help parents support their child

- Managing reactions of others
- Talking to your child and others
- Managing appointments
- Advocacy for your child



Parenting toolkit

Supporting your child with an appearance affecting condition or injury.

Knowing your values

My values, doing what is important to me and my family

As we discussed earlier on, we want to be able to act in a way that is in line with what is important to us in life.

When we are at the crossroads where we make decisions about how we behave, it is helpful to know what is important in family life. For example, what matters to you as a parent and a family? Is it quality time together? Or being able to speak and share things openly? Or taking part in shared interests or hobbies?

Whatever it is that is important to you as a parent, we hope that this toolkit will help you to move in the direction of these values.

What are values?

Values are our deepest desires for how we want to act, how we want to treat ourselves, others, or the world around us. Values can be described in one word e.g. **loving, caring, fairness, enthusiasm, honesty**. Or in a sentence: "I want to live my life with courage and kindness", or "I want to prioritise those I love, or I want to act with loyalty or courage."

Values are not surface-level qualities like attractiveness, you cannot act with attractiveness. Nor are they feelings like happy or relaxed, because it's much easier to choose how to act than how to feel.

Think back to your journey on the bus. When you are driving your bus, your values act as a compass, or SatNav, that we can use to direct us in life.



To figure out what is important to you and your family, it might be helpful to spend a bit of time thinking about this and completing the values exercise on the next page.

Exercise: What is important to me and my family?

Take a look at the values below. Are there any that represent what is important to you and your family? Select the ones that you feel are important. There is also space to add your own values on the next page, so you can pick some of the examples or come up with your own.

Compassion: Act with kindness and compassion	Adventure: To seek, create or explore	Self-awareness: Be aware of my own thoughts, feelings and actions
Acceptance: Be open and accepting of myself and others	Respect: Be respectful to myself and others	Honesty: To be honest and truthful with myself and others
Co-operative: Co-operate and work together with others	Creativity: Create and explore together	Flexibility: To adjust and adapt to changing situations
Equality: Treat others equally	Fun: Fun-loving, seek and engage in fun activities	Spirituality: To grow spiritually

The Parenting Toolkit



Initial feedback

22 parents

- Content relevant and they identified closely with the topics
- Presentation and layout was clear and accessible



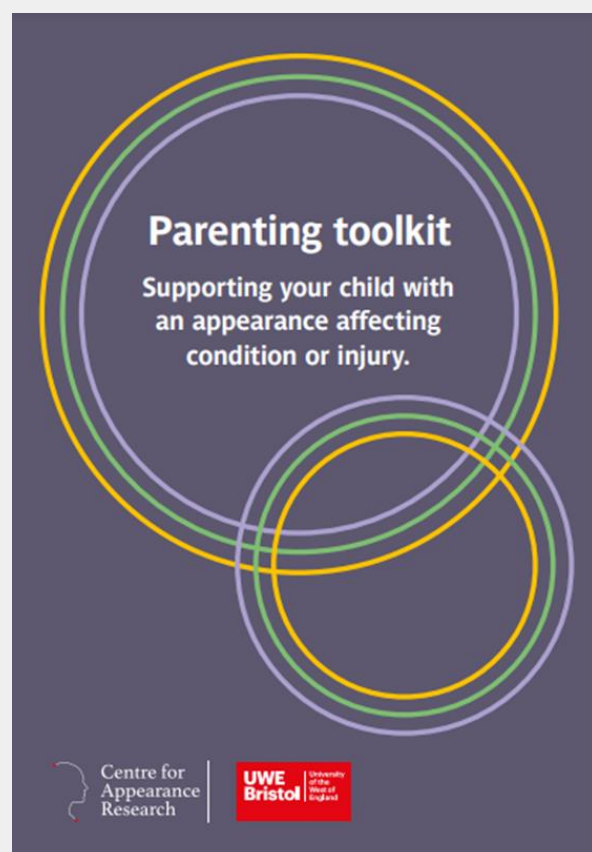
Participants rated their overall experience with The Parenting Toolkit as either “Good” (32%) or “**Very good**” (64%)

Participants said they would be either “Likely” (18%) or “**Very likely**” (78%) to recommend The Parenting Toolkit



The Parenting Toolkit

How effective is this support?



- Full access to PDF copy
- 3 surveys over 2 months
- Option to take part in an interview
- Shopping vouchers for survey responses and interview
- Due to launch in the next couple of weeks.
- Contact Maia.Thornton@uwe.ac.uk with any questions or to find out more.



Upcoming research at CAR



CREATING AN EVIDENCE-BASED TOOL TO IDENTIFY THE SUPPORT NEEDS OF ADULTS AFFECTED BY VISIBLE DIFFERENCES (TIDES)

CLARE CLEMENT, PHD PROJECT



BACKGROUND AND AIM

People with a visible difference can experience negative psychosocial impacts without adequate support.



There are many ways in which people with visible differences can be supported.



However, currently, there is no way to identify adults' support needs.

The PhD aims to develop a user-focused tool to identify the support needs of individual adults with visible differences and the level of support required.

HOW WILL THE TOOL BE DEVELOPED?

Phase 1 – identifying what people's support needs are

- Interviews and focus groups to find out about people's experiences with having a visible difference and support needs.

Phase 2 – developing the tool with service users

- A series of workshops with adults with a visible difference and support providers to develop a tool in partnership with the researcher.

Phase 3 – assess acceptability and usability

- People using the tool and providing feedback to the researcher about their experiences and thoughts about it.

HOW CAN I FIND OUT MORE?

Contact Clare at
clare.clement@uwe.ac.uk
or 07902246225

Follow the study on
Twitter @tidesstudy

Experiences of LGBTQ+ youth with a visible difference

Qualitative study exploring the lived experiences of LGBTQ+ youth (15-24 years old) with visible differences.

Online survey with option to opt-in for follow-up 1:1 photo-elicitation interview (in person, telephone, or video)

Seeking input from a) those working with LGBTQ+ youth; b) those working with youth with visible differences; c) youth advisors on questions such as:

Is the study relevant?

What should be the focus?

Are the terminology and recruitment strategies appropriate?

What should be covered in the survey and follow-up interviews?



Siblings research



- Research due to start September 2023
- Experiences of non-affected siblings of children with a visible difference
- Interviews with non-affected siblings (11-18 year olds)
- Understand what support needs of siblings
- Thank you to all who provided letters of support!



healthtalk.org



A new form of online support for people affected by burn injuries is coming soon.

Join our free live webinar to learn more.

DATE
Friday 26th May

UK TIME
12:00 - 13:00



SPEAKER
Christia Huntington
PhD Student



SPEAKER
Prof Diana
Harcourt



SPEAKER
Dr Abi McNiven

Scan the QR code to register to join the webinar, or go to:

www.gck.fm/ttjgf





Any questions?





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Thank you!

**Please look out for a feedback
survey in your emails.**

