



Centre for Appearance Research



Online vs Face-to-Face Support for People Affected by Visible Differences

Online workshop led by

**Diana Harcourt, Pippa Tollow, Ella Guest &
Abbi Mathews**

**On behalf of the VTCT Foundation
Research Team**

8 June 2022

Welcome!

- Please introduce yourself – your name & the organisation you are from – in the chat



Pippa Tollow



Ella Guest



Abbi Mathews



Di Harcourt

Areas of focus

- What do we currently know about the provision of online and face-to-face support for people with (and/or affected by) visible differences?
- What can we learn from each others' experiences of providing online and face-to-face support?
- What do you want to know from those who could/do use your services, about their preferences for the provision of support?

Workshop plan

- Introductions
- Your practice & experiences to date
- Online vs Face to Face Support – what does the research literature tell us?
- Example 1: A project with Children's Burns Trust
- Comfort break
- Example 2: A project with Caring Matters Now
- What do we gain or lose by going online?
- What do you need to know from those who do/could use your services?
- Going Forwards

Participation

- Interactive – share your thoughts/ideas
- 'Raise hand'
- Mute mic when not speaking
- Menti - Go to www.menti.com

How are you feeling today?



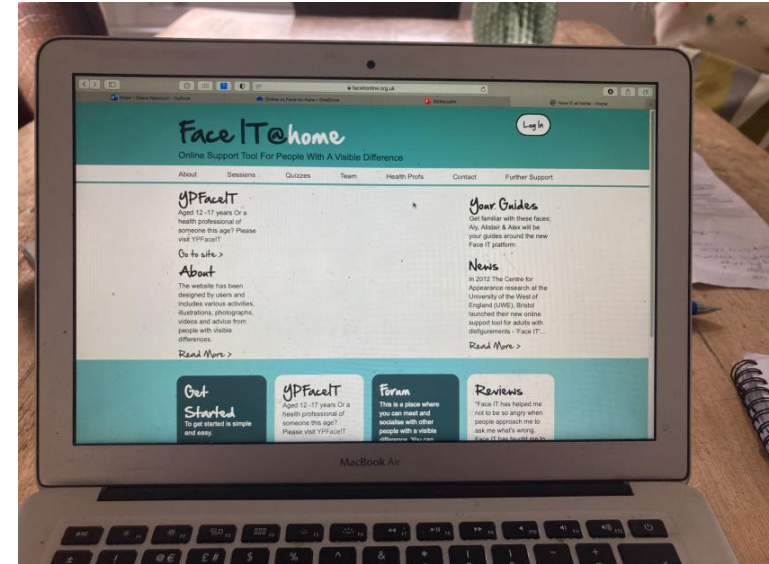
Go to menti.com

What does the literature tell us?



Visible Difference interventions

- **Face IT**
- Randomised Controlled Trial: Face IT vs standard CBT delivered face-to-face vs control group
- Face IT & face-to-face CBT - significant reductions in anxiety, appearance-related distress, depression & fear of negative evaluation
- Benefits maintained at 6 month follow up (but some indication that in person was preferable)
- (Bessell et al, 2012)



Visible Difference interventions

- YP Face IT
- RCT of YP Face IT vs care as usual
- Compared with care as usual, YP Face IT - significant reductions in social anxiety
- (Zelihic et al, 2022)



Online/digital & face-to-face similarly effective:

- Rehab for burns patients (Rouzfarakh et al., 2021)
- Social phobia (Andrews et al, 2011)
- Symptoms of depression (Wagner et al, 2013)
- Stress/resilience amongst trainee HPs (Mayor-Silva et al, 2021)
- Student counselling (Lerardi et al, 2021)

Body image & eating disorder interventions:

- Attendance – better in person (Paxton et al, 2007)
- Geographical barriers reduced online (Gollings & Paxton, 2006)

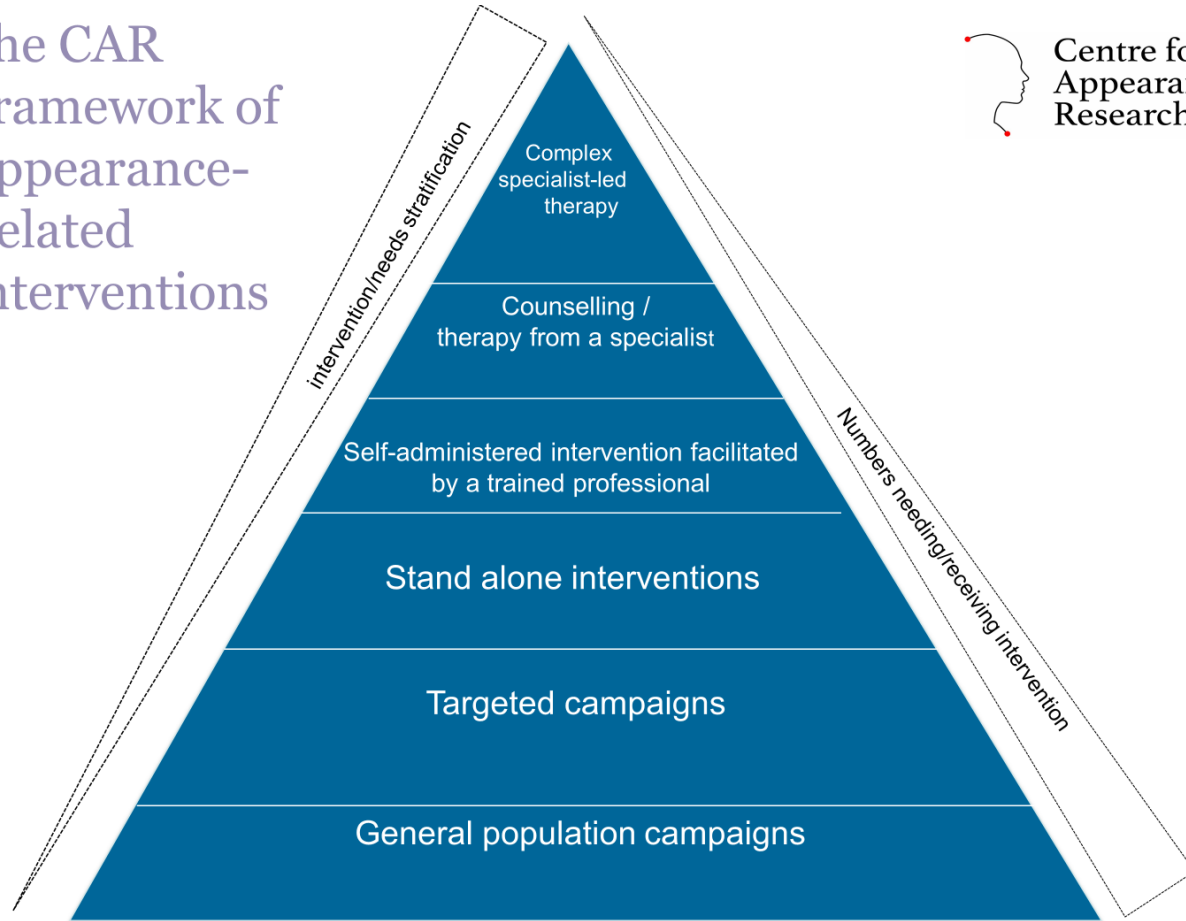
A need to consider individual needs

- Level of concern (intensity)
- Nature of concerns/need
- Expectations
- Previous experience
- Other support available to them

ONE SIZE
DOESN'T FIT ALL

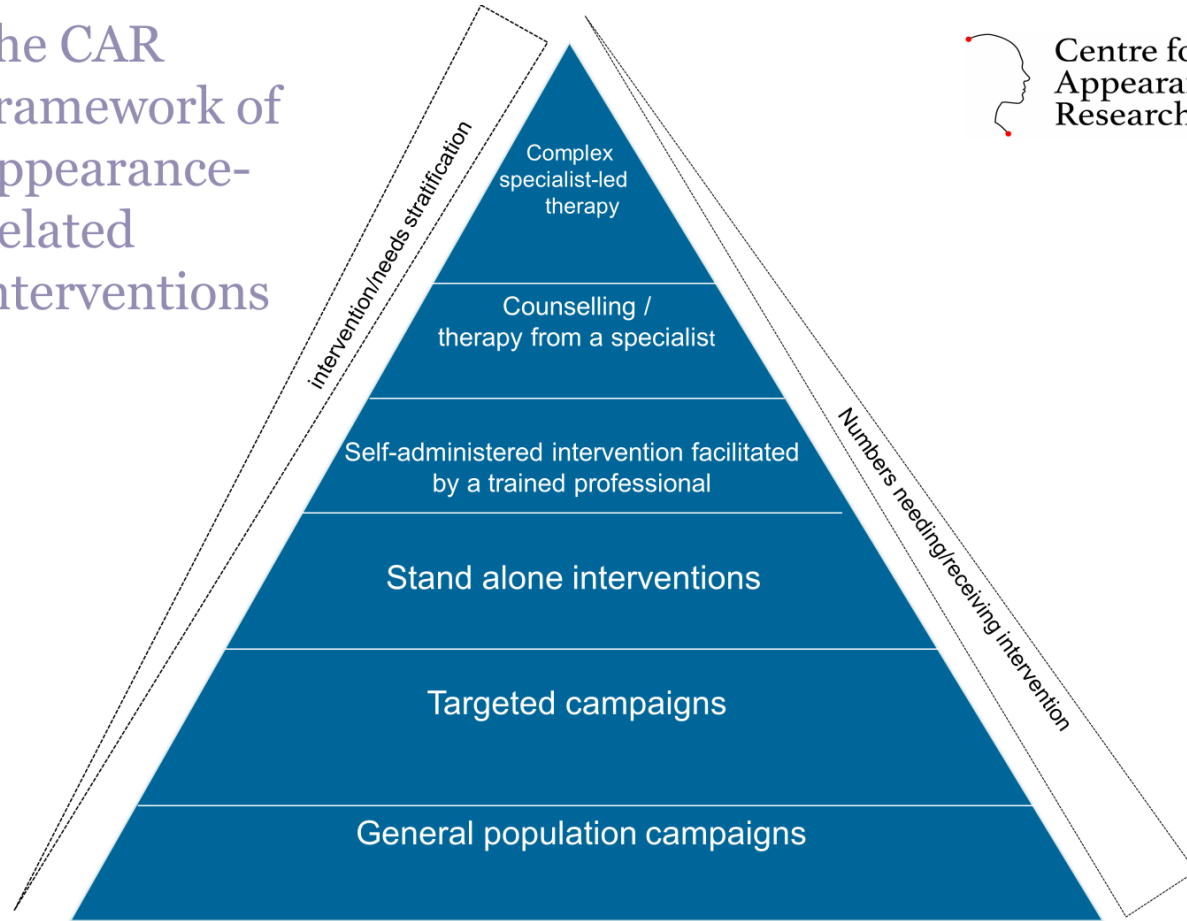


The CAR Framework of Appearance- Related Interventions



Centre for
Appearance
Research

The CAR Framework of Appearance-Related Interventions





Centre for
Appearance
Research



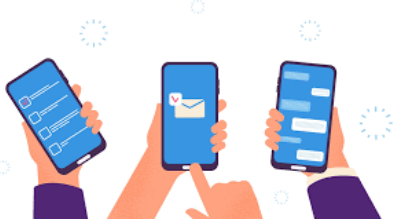
E.g. Clinical
Psychologists

Appearance
Collective
charities?

A toolbox of interventions & strategies



Face-to-Face		Stand-alone online
		
<p>Camps Support groups Events Clinical Psychologists</p>		<p>Web-based Apps Podcasts</p>

Face-to-Face	In person via online/blended	Stand-alone online
		
<p>Camps Support groups Events Clinical Psychologists</p>	<p>Peer support online Events Clinical Psychologists</p>	<p>Web-based Apps Podcasts</p>

Examples of supportive interventions developed by members of CAR

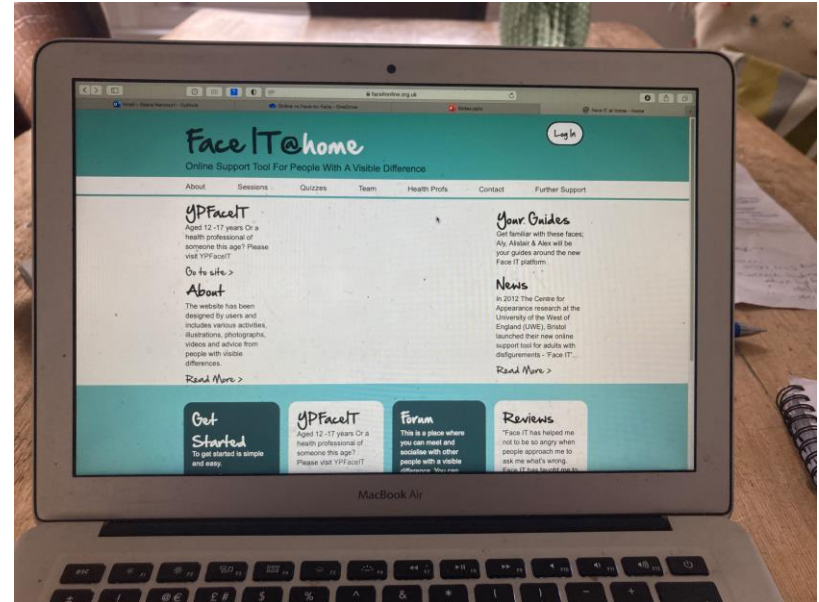
YP Face IT (www.yfaceit.co.uk)

- Accessible now, for free.
- YP aged 12-17 years with any visible difference
- 8 sessions
- Incorporating cognitive behavioural therapy (CBT) & social skills
- **Online standalone** (sometimes with HP input)
- Parental support is key to success
- Evaluated in a body of research evidence



Face IT (www.faceitonline.org.uk)

- Accessible (contact alyson.norman@plymouth.ac.uk)
- Adults (18 yrs+) with any visible difference
- 8 sessions
- Incorporating cognitive behavioural therapy (CBT) & social skills
- **Online standalone** (sometimes with HP input)
- Evaluated in a body of research evidence



Support for parents

- <http://supportingchildrenwithburns.co.uk>



Online – website

Parenting Toolkit



Online - interactive workbook

Act It Out

- Based on Acceptance & Commitment Therapy (ACT)
- **Online** - App-based intervention
- For adults with any appearance-altering condition
- Developed by Fabio Zuchelli
- Will be freely available when evaluation is complete



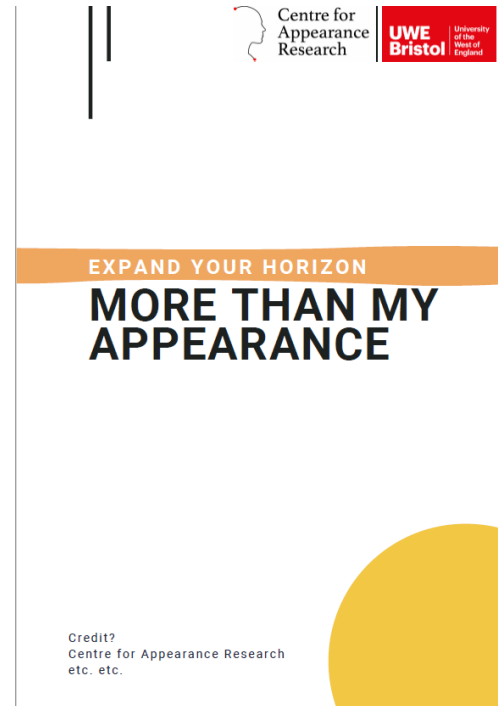
Visible Difference & Intimacy

- Support with concerns around intimate relationships
- Based on Acceptance & Commitment Therapy (ACT)
- **Online** - Podcast format
- For adults with any appearance-altering condition
- Developed by Nick Sharratt & Maia Thornton
- Will be freely available when evaluation is complete



More Than My Appearance

- Online functionality-based writing programme
- Five writing tasks completed over the course of one week
- COMING SOON!



Learning from your experiences

Support for children with burn injuries and their families: Experiences of moving support online (and back again!)

Jo Myers (Children's Burns Trust) and

Dr Pippa Tollow (Centre for Appearance Research,
UWE Bristol)



Background

- Family Weekends offer an opportunity for children and their families to meet others with similar experiences and learn about topics such as scar management and managing anxiety.
- Research suggests benefits include **increased confidence and coping** (Gaskell, 2009), as well as **reduced isolation, improved social skills**, and **acceptance of an altered body image** (Kornhaber *et al*, 2020).
- COVID-19 pandemic meant re-evaluating how to provide this support.

Face to face events

- Since 2005
- Three events each year
- In collaboration with; Firefighters Trust , Northern Burns Network and London & Southeast Burns Network
- Supported through a grant
- 3 day/2-night event
- 6 families
- 10-14 burn care professionals/volunteers

Including sessions for parents on: *scar management, psychosocial wellbeing.*

Including sessions for families: *swimming, farm visit, walking llama's, reptiles, music therapy, craft sessions*

Including the following sessions for children's: *children's storyteller, children's tea party, activity/playtime in gym*

Moving support online

Face-to-face activities had to be suspended in March 2020 due to the COVID-19 pandemic.

Explored alternative methods of providing support – 'online family event'

Online family-event



Events took place in January 2021 and May 2021

Including sessions on: *scar management, lived experience, psychosocial wellbeing, music workshop and crafts.*

Pre-recorded webinars: *impact of a burn injury on young children, managing questions on your child's burn injury, parent wellbeing, and supporting siblings.*

Return to face-to-face

Post pandemic desire to return to face-to-face as soon as we could....impact of lockdown for all.

Three family events in 2022 will take place in April, September and November.

CAR/CBT collaboration

Collaboration between CBT and researchers at CAR to provide an independent evaluation of the online family event/family weekends.

Aim to **evaluate the experience and impact of both types of support, with both parents of children with burn injuries and staff.**

Evaluation methodology

Independent mixed-methods evaluation, including:

- **online qualitative survey with staff**
- **online surveys with families (with 10-week follow-up)**
- **qualitative interviews with families (online event only)**

19 families attended the online family-events and 9 families (47% of those who attended) completed the evaluation.

6 families attended the April 2022 face-to-face weekend and five families completed the evaluation.

Quantitative findings

Online

78% rated their **overall experience as 'very good'**

22% rated their **overall experience as 'good'**

89% suggested they would **attend similar events in the future and recommend this event to others**

Face-to-face

100% rated their **overall experience as 'very good'**

100% suggested they would **attend similar events in the future and recommend this event to others**

Qualitative findings

Online

Feedback focused on:

- Sharing experiences
- Opportunity for learning
- Accessibility of event

Face-to-face

Feedback focused on:

- Sharing experiences
- Meeting other families and forming connections
- Positive experiences for children

“to bring people together quickly with no expense, and to see different hospitals and different people from different backgrounds, that's really brilliant, all we needed to do was log in and it was there” - Parent

“it was so nice to hear other parents that feel the same and know that we are all just doing are [sic] best and not bad parents. I came away from the weekend feeling completely different about the accident that left my son with a burn.” -

Parent

Evaluation conclusions

Online alternative to Family Weekends was seen as **highly acceptable** by families and staff. Parents and staff suggested a **role for both face-to-face and online events in the future.**

Feedback from return to face-to-face suggests the **two types of events may have different strengths.**

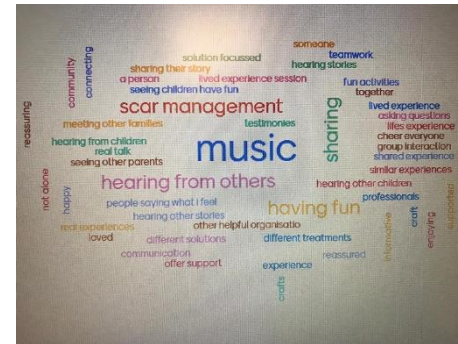
- online events offered accessibility, opportunity to share experiences, and chance for parents to learn about burns treatments/care.
- face-to-face events offered opportunity to meet others, for children to have fun together, to learn about burns treatment/care, and to form meaningful connections.

Children's Burns Trust (CBT) experiences

Face to Face

They are all valuable & all well evaluated

Parent conference



Online event

What's next for CBT?

Listen to the feedback.....

- Review evaluation following 2022 family weekends
- Review CBT strategy and priorities: prevention, rehabilitation, support
- Consider national picture with regards to provision of family support
- Cost
- Impact

Acknowledgements

Thank you to the **VTCT Foundation** for funding this ongoing collaboration between Children's Burns Trust and the Centre for Appearance Research, as well as to all the families and staff for taking part and sharing their experiences with us.



Thank you for listening!

Jo.Myers@cbtrust.org.uk
@CBTofficial

Pippa.Tollow@uwe.ac.uk
@PippaTollow



Comfort break

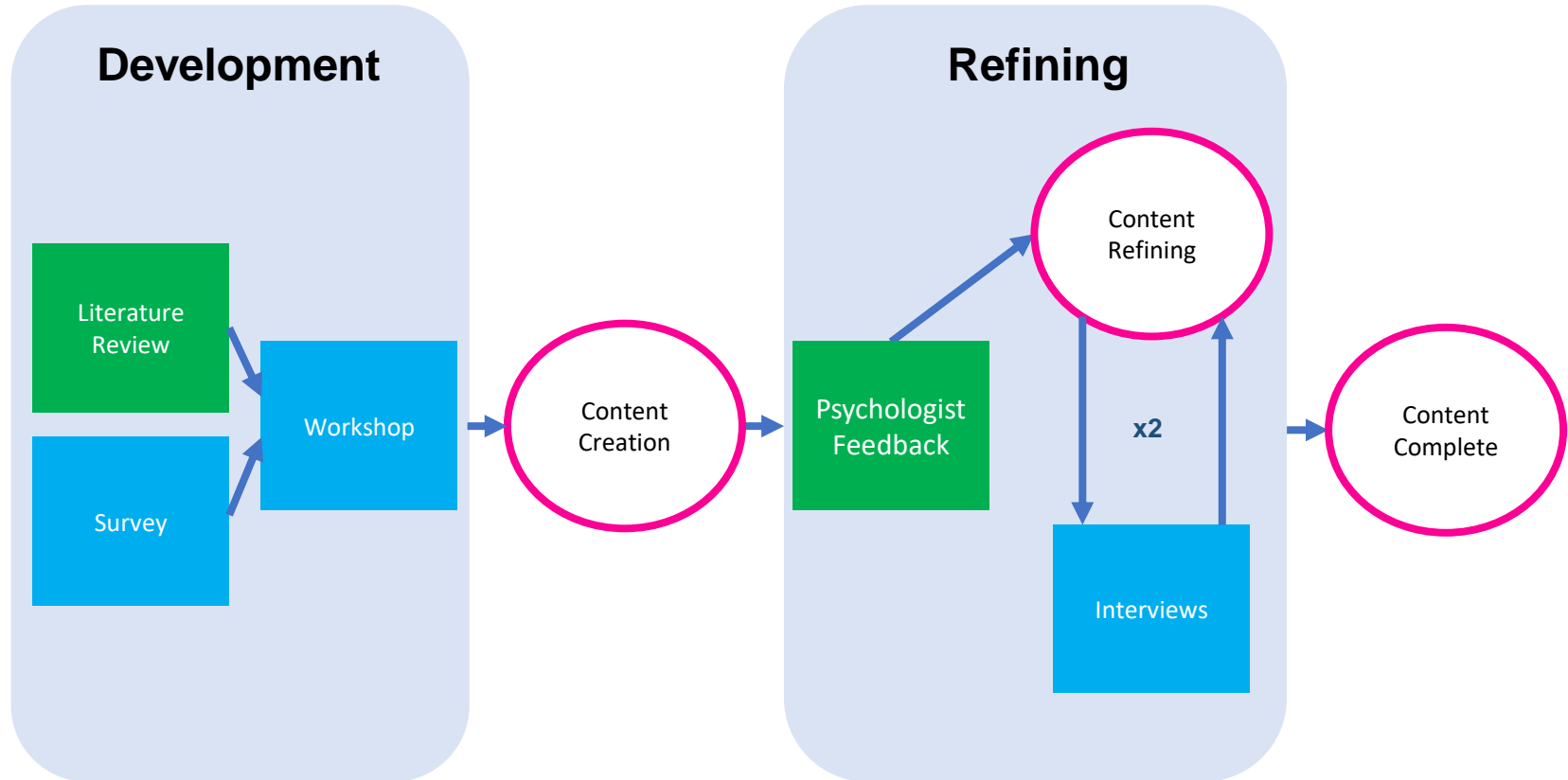


Caring Matters Now Collaboration

- Congenital Melanocytic Naevus (CMN) – birthmark condition and visible difference.
- Self-esteem, social consequences, low mood and anxiety.
- No support available specifically for young people with the condition.
- Aim of current project: **to develop and produce a psychoeducational resource for young people with CMN.**

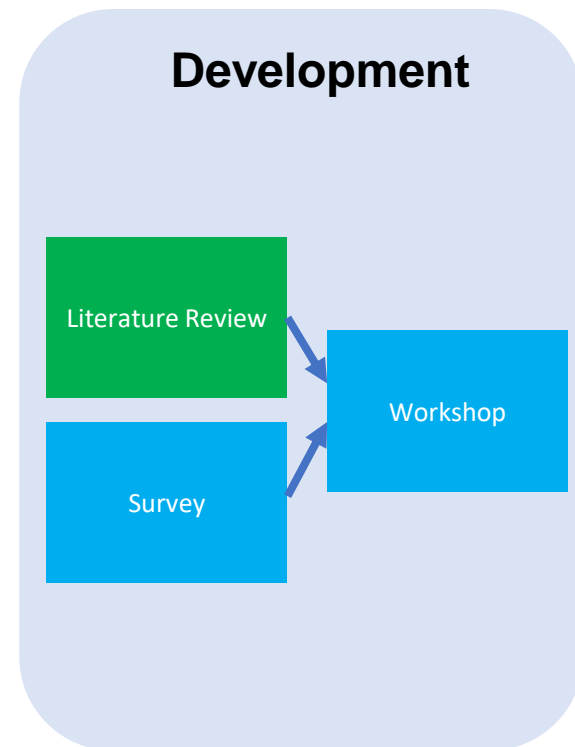


Project overview



Development

- **Literature Review:** CBT, psychoeducation, social skills training were effective for young people.
- **Questionnaire:** found young people wanted help with their confidence, mood, and self-esteem.
- These both fed into the **Workshop:** Introduced and trialled some techniques, discussed in more detail what was important to young people with CMN.



Pages of the resource



Feeling more confident



Social Situations



Starting Something New



Social Media

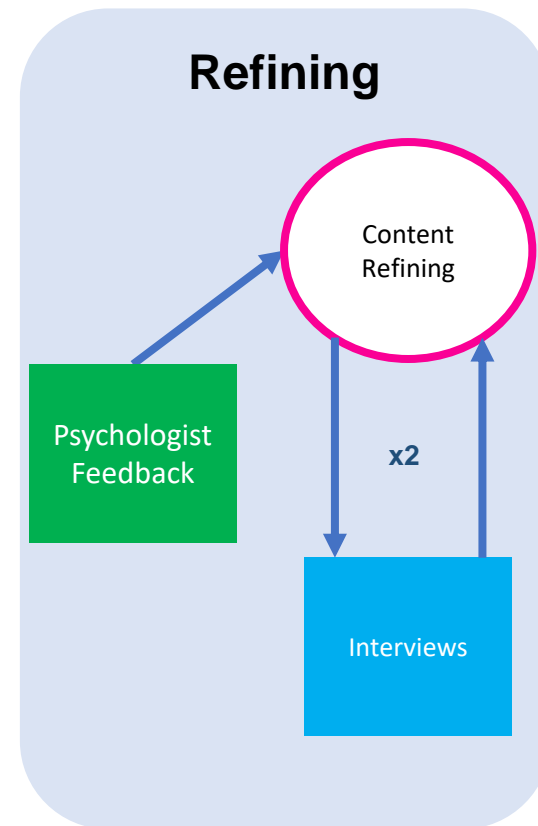


Toolbox



Refining

- **Psychologist input:** A qualified psychologist with expertise in helping children and young people with visible differences gave feedback on content and presentation for this age group.
- **Think Aloud interviews:** Shared the resource and gained feedback from young people with CMN about the suitability of the format and content.
 - **Stage 1:** raw content in word files (*content*)
 - **Stage 2:** content uploaded onto draft website (*website usability/appearance*)



The resource

- Freely available on the Caring Matters Now website
- Mix of text, video content, activities, images
- Representation



Listen below for more advice from another one of our young ambassadors, Nik:

[Click here to read more stories from our young ambassadors](#)

ANXIETY


Anxiety is a natural response to stress that humans have had for hundreds of thousands of years. Many years ago, there were threats from predators that humans had to react to in order to survive. When they saw a threat, a chain reaction was set off which caused a hormone called **adrenaline** to quickly pump through their bodies. This gave them a burst of energy, which was needed to either fight or flee (run away) from an enemy. This is called the **fight or flight response**.

In society today, we rarely see threats in our everyday lives that would need all this energy and activate fight or flight. However, we still have this response, and it can be triggered when we perceive threats. It can even be triggered when these threats are just imagined. When things worry us and feel threatening, like deadlines, exams, and social situations we still have the same adrenaline response in our bodies. However, none of these things require us to put up a fight or run away.

ACTIVITY

What are some of YOUR warning signs that you are experiencing anxiety? Remember, you might only experience a few of these effects, but it can be helpful to know which are your warning signs so that you can identify them when you are feeling anxious. You might even experience some sensations that aren't on the list below.

SHAKING
SWEATING
HEART RACING
HEADACHE
TENSE MUSCLES
NEEDING TOILET

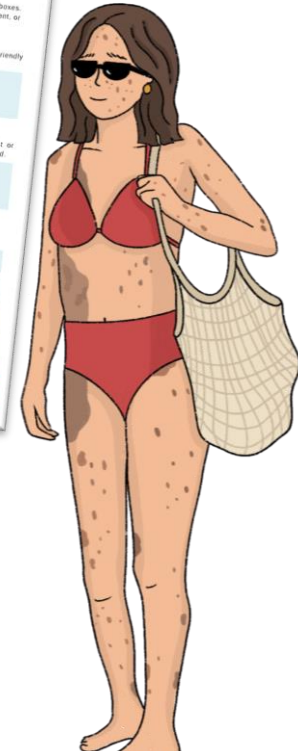
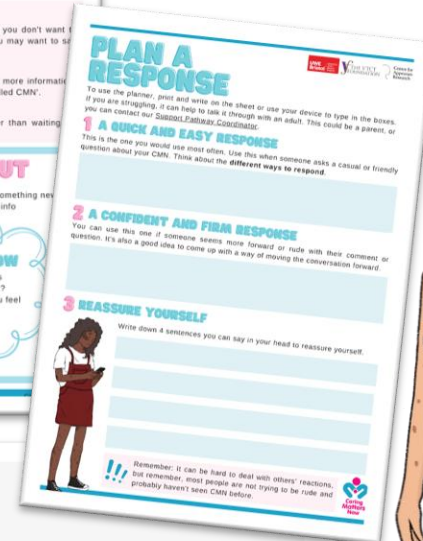


DRY MOUTH
SHORT BREATH
DIZZY
TREMBLING
CHEST PAIN
BUTTERFLIES



Using the resource

- Support available from Hannah



NEED HELP?

If you are struggling with this or would like some advice on how to use this resource, please contact our Support Pathway Coordinator, [Hannah](#), who will be able to help you.

Email Hannah

Hannah –

- My role as Support Pathway Coordinator
- How does this resource fit into Caring Matters Now's Support Pathway?



Child to Adult Support Pathway



0-3 YEARS

As a charity we educate medical professionals to aid early diagnosis, with particular focus on partnering with midwives and dermatologists across the UK & Ireland. We provide specialised early years support and information for parents caring for babies born with CMN.

4-11 YEARS

We support families throughout the primary years by providing age-specific support literature, school resource packs, parent support contacts, family friendly regional gatherings, and support events for parents, children and siblings.



12-16 YEARS

When a child member turns 12 years old, they will start to receive direct support from our Teens Contact Team. Katie Arends specifically supports members aged 12-16 years. Teenage members will be invited to participate in the Young Ambassadors Programme and our teen support events. We provide Parent Support Guides for those caring for teenagers living with CMN.



17-24 YEARS

When a teenage member turns 17 years old, they will start to receive direct support from Katy Jackson who specifically supports members aged 17-24 years and assists them in transitioning from a child member to an adult member. Our 17-24 year old members will be invited to participate in the level two Young Ambassadors Programme and to attend our young adult support events.



18+ YEARS

When a teenage member turns 18 years old, they will start to receive support from the Adult Contact Team. 18+ members will be invited to register with Caring Matters Now as an adult member, rather than their membership continuing under their parents registration. 18+ members will be invited to attend our adult support events and participate in adult-focused research studies.



12-16 YEARS



When a child member turns 12 years old, they will start to receive direct support from our Teens Contact Team. Katie Arends specifically supports members aged 12-16 years. Teenage members will be invited to participate in the Young Ambassadors Programme and our teen support events. We provide Parent Support Guides for those caring for teenagers living with CMN.

17-24 YEARS

When a teenage member turns 17 years old, they will start to receive direct support from Katy Jackson who specifically supports members aged 17-24 years and assists them in transitioning from a child member to an adult member. Our 17-24 year old members will be invited to participate in the level two Young Ambassadors Programme and to attend our young adult support events.



18+ YEARS



When a teenage member turns 18 years old, they will start to receive support from the Adult Contact Team. 18+ members will be invited to register with Caring Matters Now as an adult member, rather than their membership continuing under their parents registration. 18+ members will be invited to attend our adult support events and participate in adult-focused research studies.



Case Study

- Christmas 2021 Mum of a 16 year old girl with a large CMN on her leg made contact with Caring Matters Now.
- Her daughter had been under the care of a dermatologist until she was 10 years old and then had "fallen off the system.' CMN had taken a back seat and the family 'tried not to make a big deal of it.'
- However, the older she became the more conscious she was of her CMN and she would wear '200 denier tights, even on the hottest day...never wearing anything that reveals it.'
- Despite having a good relationship at home, her daughter had kept her feelings bottled up for some time and had developed an eating disorder.
- This young person had been referred to CAHMS and was on a very long waiting list.
- Mum wanted to know if there was anyone she could talk to about her birthmark so that she could learn to accept and embrace having CMN.

Catch it, Check it, Change it

Anxious thoughts can lead to uncomfortable feelings and cause us to behave in certain ways. Catch it, Check it, Change it is a method for noticing these unwanted thoughts, considering whether they are true or justified, and help us to replace a new, more balanced and helpful thought.

- Catch it** What is the thought that is causing you trouble?
- Check it** Is it justified? What is the evidence for/against it?
- Change it** What is a more reasonable or balanced thought?

Remember: Practice makes perfect! You may find this process difficult, but keep using it until you're happy. Have a go at discussing with someone you trust. **Look at the next page for some examples!**

Catch it, Check it, Change it

Fear Ladders

1. At the top of the ladder next to number 9, put your goal. For example, "We're shorts to the beach".
 2. At the bottom next to number 1, put the closest thing to your goal that doesn't currently give you anxiety. For example, "Go to the beach with trousers on".
 3. Gradually build up small steps in between for 2-8, being careful not to make any jumps too big. You don't have to use all 9 steps.

Remember! When you use a ladder, the most important part is having someone you trust hold it steady for you. Fear ladders work best when you have someone who knows you are trying it and you can check in with.

Fear Ladders

Plan a Response

Print this sheet out or use your device to write in the boxes.

A quick and easy response

This is the one you would use most often. Use this when someone asks a casual or friendly question about your CMN.

A confident and firm response

You can use this one if someone seems more forward or rude with their comment or question.

Things to consider

- How much do you want people to know about your CMN?
- How visible is your CMN? How likely are you to get questions about it?
- Who else is around?
- How do you feel right now?

See 'starting new' page for more info.

Plan a Response

REACHOUT

Use this sheet to remember your social skills toolkit. <https://www.uwebristol.ac.uk/caringmattersnow>

Remember
 3 people are always around you, you could try to reach out to them. Try saying something like "Hi, my name is..."

Eyeing, eyeing and eyeing
 If it feels like there's someone who's looking at you, you could try to reach out to them. Try saying something like "Hi, my name is..."

Eyeing, eyeing and eyeing
 Let others know how you are feeling and what you need from them. This might include standing up for yourself if someone is being rude. Remember to stay calm and not get aggressively.

Confidence
 Be confident even in difficult situations. This can be really tricky, see Fear Ladders for help with overcoming worries and fears with confidence.

Humour
 Making jokes is not always of your own volition. Try to be light-hearted, make a joke and see the funny side of things. This will help to make other people comfortable and help you to feel positive.

Clear thinking
 Think of ways to deal with stress by focusing on what you can do. Try starting a conversation about something else. It could be about school, film or TV, hobbies. Start by asking a question.

Understand
 It can be frustrating but try to remind yourself that others often do not know how to deal with the situation and most of the time, you are not trying to be unfair.

Be confident
 Don't give up and don't let bad experiences stop you from trying again. See Catch it, Check it, Change it for help with anxious thoughts.

REACHOUT

Relaxation Techniques

Sometimes we need something in the moment which can help us to take a step back, breathe and calm ourselves down. Try some of these relaxation techniques and see which one works best for you.

Counting
 Counting is a way of bringing us away from our anxious thoughts and back into the present. It helps to distract our minds and make us feel more in the moment. Try one here, and see if you can identify.

- 5** Things you see
- 4** Things you hear
- 3** Things you feel
- 2** Things you smell
- 1** Thing you taste

Square Breathing
 This is a breathing exercise to help you slow down and get control of your breathing. It's useful for calming, but for a 4x4 square, hold for 4 seconds for 4, and hold for 4 seconds for 4, and hold for 4 seconds for 4, and hold for 4 seconds for 4.

Body Scan
 Body scans can help to relax our minds, make our thoughts and focus on the present in our bodies. Take deep breaths, and then focus your mind on different body parts and describe how they feel to you. Close your eyes, if you can. Tighten, hold, relax, unclench and and with your face. Use help to close your eyes.

Relaxation Techniques

Supporting a young person with CMN

Why have I been given this?
 You have been given this advice because you are or will be supporting a young person with CMN.

What is CMN?
 CMN is a birthmark condition and a visible difference. Young people with CMN have birthmarks on their body which can appear in their, connect, freckles, and placement. Some people with CMN have small birthmarks, but it is also common to have more 'spotted' CMN.

How can I support someone with CMN?
 Unfortunately, anyone who has a visible difference such as CMN can be more likely to experience teasing and bullying from peers. It is important to discuss with the young person how best to support them, but everyone will want to be supported in the same way.

Where can I go for more information?
 Caring Matters Now is the leading UK charity supporting those with CMN. Please see the website for more information about CMN and further support, including a teachers' guide to promoting acceptance of appearance diversity in the classroom.

www.caringmattersnow.org.uk

Supporting a Young Person with CMN

Support guide for school staff promoting acceptance of appearance diversity

From speaking with teachers, it is clear that there are many reasons why teachers do not have the best experience of supporting young people with appearance diversity. This brief guide aims to support teachers to be better equipped to discuss the topic and successfully promote appearance diversity in school.

This guide has been developed with qualified primary school teachers. All information in **italics** are direct quotations from teachers.

"I think it's a big thing I imagine, for everybody, especially nowadays when we're all talking to it very publicly, serious and being offending people that think knowing what language is appropriate and what you can and can't say, so, the best way to explain things to the children (and) just give them like a story or do it to be really helpful."
 - Teacher

"We haven't had any official training. I think it would have been helpful and I think in the future it will be helpful because there's always a worry that you know when you're addressing more sensitive topics - particularly if you don't have experience of something yourself."
 - Teacher

"It's such an important topic area. I think for the children to be involved in it and engaged in it."
 - Teacher

"It would just be better to be advised properly on what to say and how to teach the children."
 - Teacher

"I think the main thing for me is the language. I think I'd personally feel a lot more comfortable having these discussions if I knew in my head that this is how I should respond and this is the language that should use."
 - Teacher

"I think it should be part and parcel of education, full stop."
 - Teacher

Teachers' Support Guide

Thinking Traps

There are a variety of traps that we can fall into with our thinking. Use this sheet to help to identify which traps your thoughts might have been caught by.

We aren't magical!

Mind reading
 Your thoughts might tell you that you know exactly what someone else is thinking.

Future telling
 Or your thoughts might be reading the future.

Don't be so hard on yourself

Labelling
 Attaching a negative label to yourself instead of realising it was a single event.

Filtering
 Only focusing on the negative and ignoring all the positives.

Black-or-white
 Only seeing things in black or white - all or nothing, success or failure - not anything in between.

Proving
 One bad experience is not 'proof' of what will happen in the future.

Catastrophising
 Thinking about the worst thing that could possibly happen.

Thinking Traps

Catch it, Check it, Change it

Anxious thoughts can lead to uncomfortable feelings and cause us to behave in certain ways. Catch it, Check it, Change it is a method for noticing these unhelpful thoughts, considering whether they are true or justified, and help us to recreate a new, more balanced and helpful thought.

1. Catch it What is the thought that is causing you trouble?

2. Check it Is it justified? What is the evidence for/against it?

3. Change it What is a more reasonable or balanced thought?

Remember: Practice makes perfect! You may find this process difficult, but make sure you keep trying. Have a go at discussing with someone you trust.

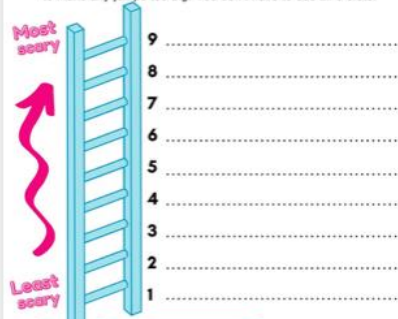
Look at the next page for some examples!



Fear Ladders




1. At the top of the ladder next to number 9, put your goal. For example, 'Wear shorts to the beach'.
2. At the bottom next to number 1, put the closest thing to your goal that doesn't currently give you anxiety. For example, 'Go to the beach with trousers on'.
3. Gradually build up small steps in between for 2-8, being careful not to make any jumps too big. You don't have to use all 9 slots.



Remember!

When you use a ladder, the most important part is having someone you trust hold it steady for you. Fear ladders work best when you have someone who knows you are trying it and you can check in with.



Catch it, Check it,
Change it

Fear Ladders

Thinking Traps

There are a variety of traps that we can fall into with our thinking. Use this sheet to learn to identify which traps your thoughts might have been caught by.

We aren't magic!

Mind reading
Your thoughts might tell you that you know exactly what someone else is thinking

Fortune telling
Or your thoughts might be reading the future



TOOLBOX

Don't be so hard on...

UWE Bristol THE VTCT FOUNDATION Centr. Appl. Research



A hybrid approach—

- As a side note; Online Communities
- Impact on members meeting for first time at Alton Towers 25th birthday
- A visual aid
- Going forward-
 - A Teens resource which we can come back to,
 - Development of an Adult Resource



Any questions?



Learning from your experiences



Go to [menti.com](https://www.menti.com)

Moving forwards

- What would you/your organisation like to know, from those who could benefit from/use support, about their preferences and experiences for online vs face to face support?
- Potential for a survey to gather this info for your organisation
- (small groups)

Looking ahead....

- VTCT Foundation funding Phase 2 – from September 2022
- 2 streams of work:
 - Supportive interventions (inc. signposting to suitable interventions)
 - Social media
 - Generic or condition-specific??



Looking ahead...

Intimacy and romantic relationships

- Evidence-based intervention developed to focus specifically on concerns about romantic relationships and intimacy
- Content and format of intervention informed by input from health professionals and individuals with lived experience
- Looking for individuals to provide feedback on the content and format
- Maia Thornton will be in touch with information
- Any questions: maia.thornton@uwe.ac.uk



Final comments & questions

- Feedback -
https://uwe.eu.qualtrics.com/jfe/form/SV_5sWYIACuzdT6tX8



Centre for
Appearance
Research

Thank you – to you and...



- *Vocational Training Charitable Trust Foundation*
- *Appearance Collective, Amanda Shepard*
- *Caring Matters Now, Hannah Cree*
- *Children's Burns Trust, Jo Myers*
- *Participants in research*



Further information:



www.uwe.ac.uk/car



@CAR_UWE



@AppearanceResearch



@car_uwe



Appearance Matters: The Podcast



CAR@uwe.ac.uk