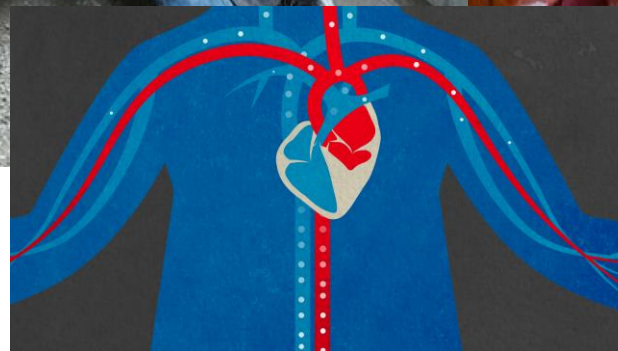


Supporting the 7–11-year-old child affected by a single ventricle



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Supporting the 7–11-year-old child with a single ventricle

11.00 am	Introduction and group agreement
11.05 am	Looking after ourselves
11.15 am	Understanding the 7–11-year-old
11.25 am	Setting the Scene
11.40 am	Comfort break
11.45 am	General suggestions
11.55 am	Treatment Adherence
12.00 pm	Exploring feelings of difference
12.15 pm	Discussion/questions/thoughts

Supporting the 7–11-year-old child with a single ventricle



Agree to keep to time



Challenge the idea not the person



Listen while others are speaking



Create a safe sharing environment



Respect confidentiality (excluding risk). Share ideas not the person



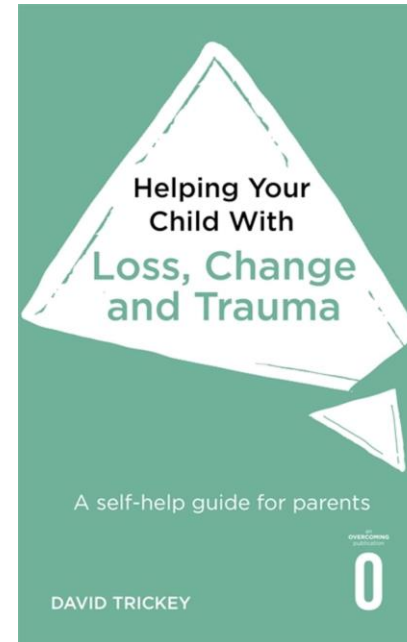
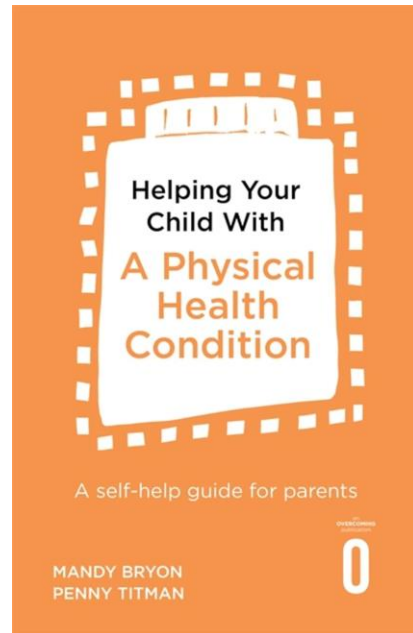
Avoid interruptions (mobile phones) etc



Keep screen on and sound off (unless speaking)

Supporting the 7–11-year-old (difference)

Suggested reading if helpful:

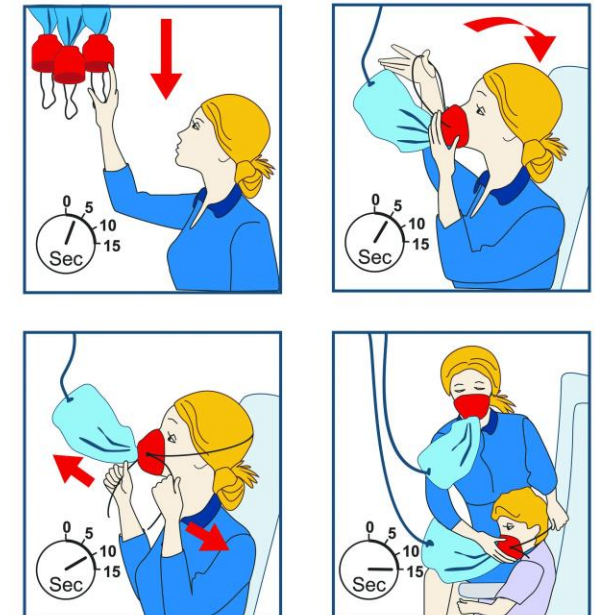


Supporting the 7–11-year-old child with a single ventricle

-looking after ourselves

David Trickey et al.....looked at 64 studies which had assessed more than 30,000 children in total following potentially traumatic events. By combining the results, they were able to predict why some children developed PTSD and how severe their symptoms of PTSD were.

They found that the 'trauma severity' was exactly the same size risk factor as the carer's mental health



read a book...for pleasure

exercise

say NO to activities or people who drain you

take a class

talk to friends on the phone

schedule time to do nothing

take a bath

take a walk in nature

meditate

listen to music that makes you happy

spend time with people you love or like

buy fresh flowers

use positive self-talk

eat good food

Supporting the 7–11-year-old child with a single ventricle

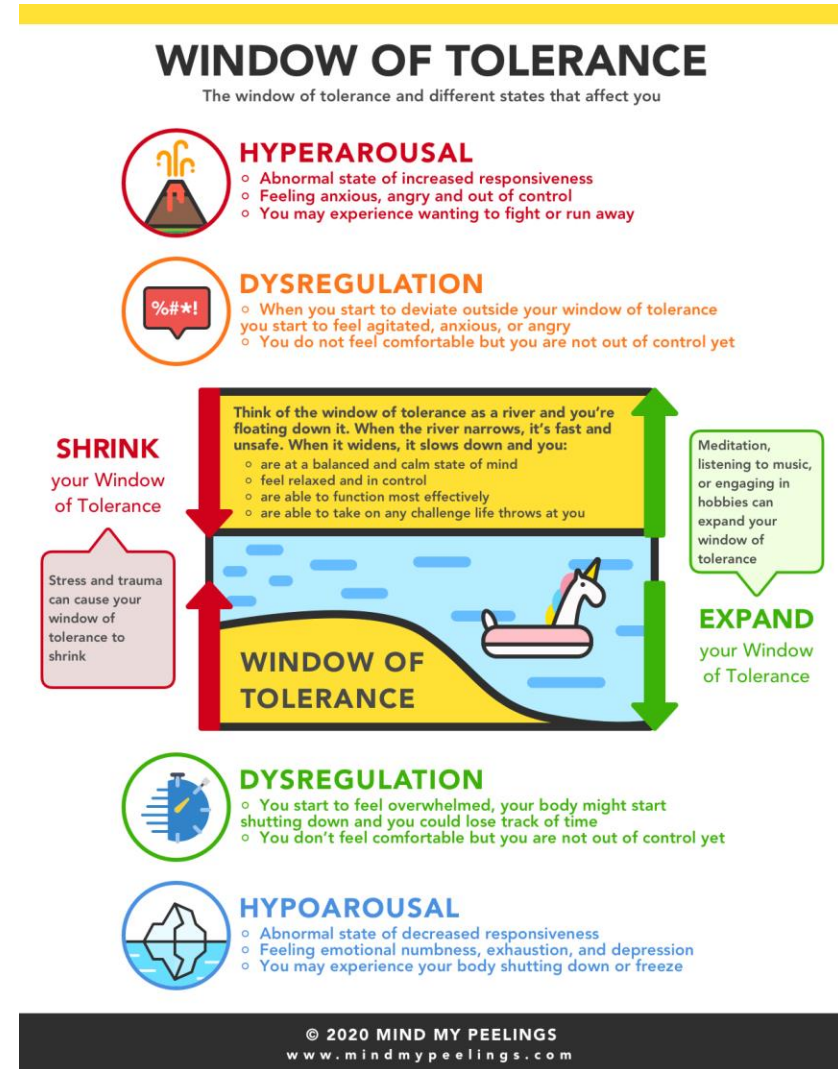
Looking after ourselves

Basics

- Eat well
- Sleep
- Exercise
- Take prescribed medication
- Take time to stop
- Write things down (on phone or paper)

Supporting the 7–11-year-old child with a single ventricle

- *How can you feel safe?*
- ✓ Understanding health and other care
- ✓ Finances
- ✓ Housing
- ✓ Keep things as routine as possible at times of challenge



Supporting the 7–11-year-old child with a single ventricle

How can you feel calm?

- ✓ 'Mind you mind'- notice what you are thinking and what you are feeling. Maybe acting as a 'concerned friend' or act like an alien who is exploring your thoughts



Supporting the 7–11-year-old child with a single ventricle

- *Work on feeling connected*

People who help *you* as you help your child

-nurture your own support system with partners, family, friends, colleagues, neighbours etc who are part of your healthy and positive connections



Supporting the 7–11-year-old child with a single ventricle

- *Try to feel hopeful*
 - make plans for things to do that you and our family will look forward to

- *Reach out for support if you need it*



Supporting the 7–11-year-old child with a single ventricle

Understanding the 7–11-year-old affected (i.e. patient and siblings etc) by SV

- Developmental/cognitive stage
- Intersectionality
- Neurodevelopmental issues/ Intellectual disability/ ADHD/autism
- Physical health and relationship to health care
- Emotional well-being /Resilience

Supporting the 7–11-year-old child with a single ventricle

DEVELOPMENTAL STAGE

When talking to children aged 7–12 it is important to understand:

- Children can now see themselves as different to others and understand that other people have different needs and perspectives.
- Children still think about things from their own perspective so will be influenced mainly by that.
- They have an understanding that illness can be lots of different symptoms, and that lots of things go on inside their body which they can't see.
- They understand that medicines and following doctor's advice can help them get better but still need a lot of help and prompting to follow advice.
- They are more able to understand concepts of time and permanence, and will understand that illness and death happens to everyone and is permanent.
- Their peer's opinions begin to be much more important to them
- Can still have feelings of 'magical thinking'

Supporting the 7–11-year-old child with a single ventricle

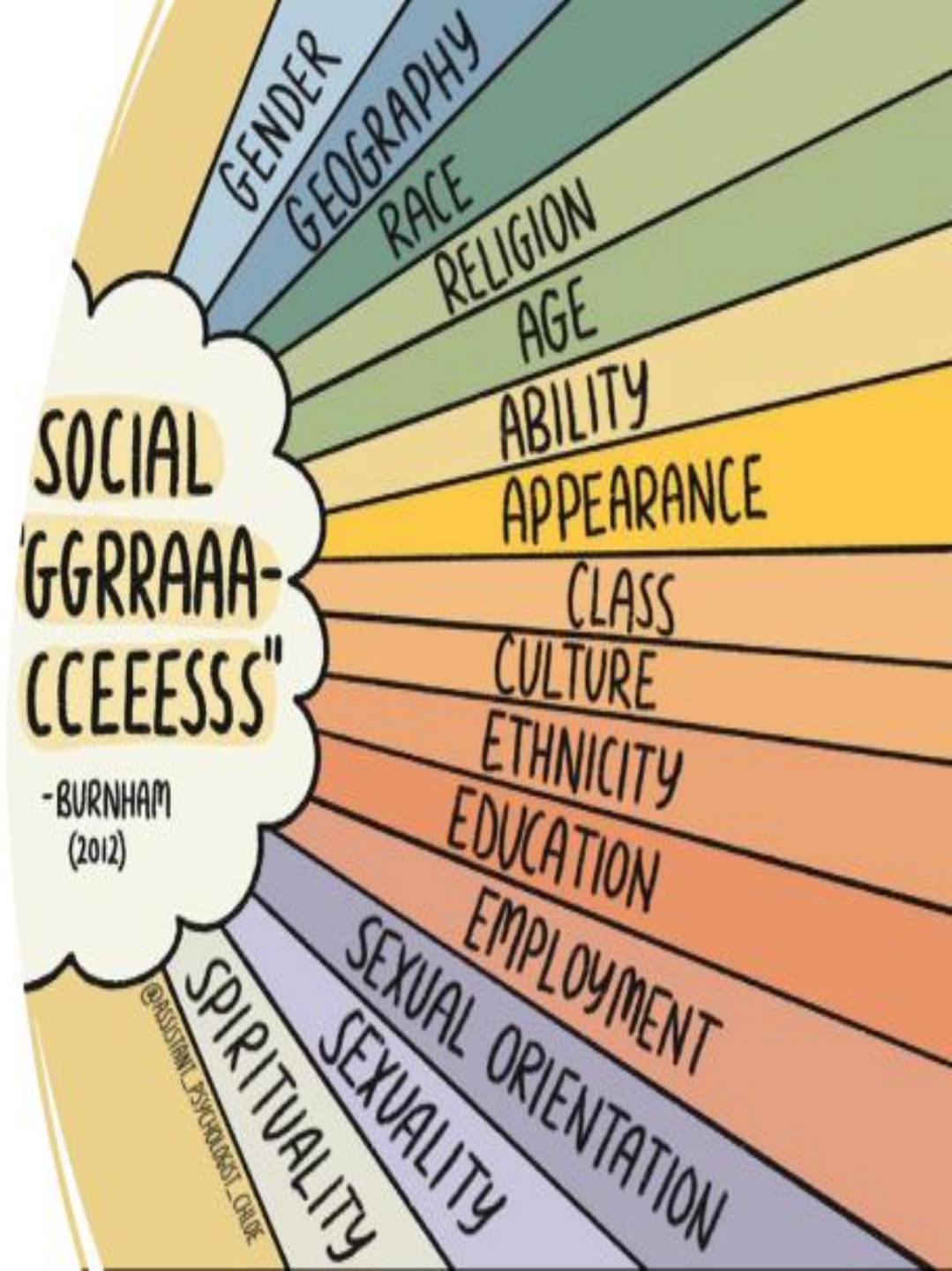
What they may do or say

Not wanting to voice concerns for fear of upsetting parents, friends or others.

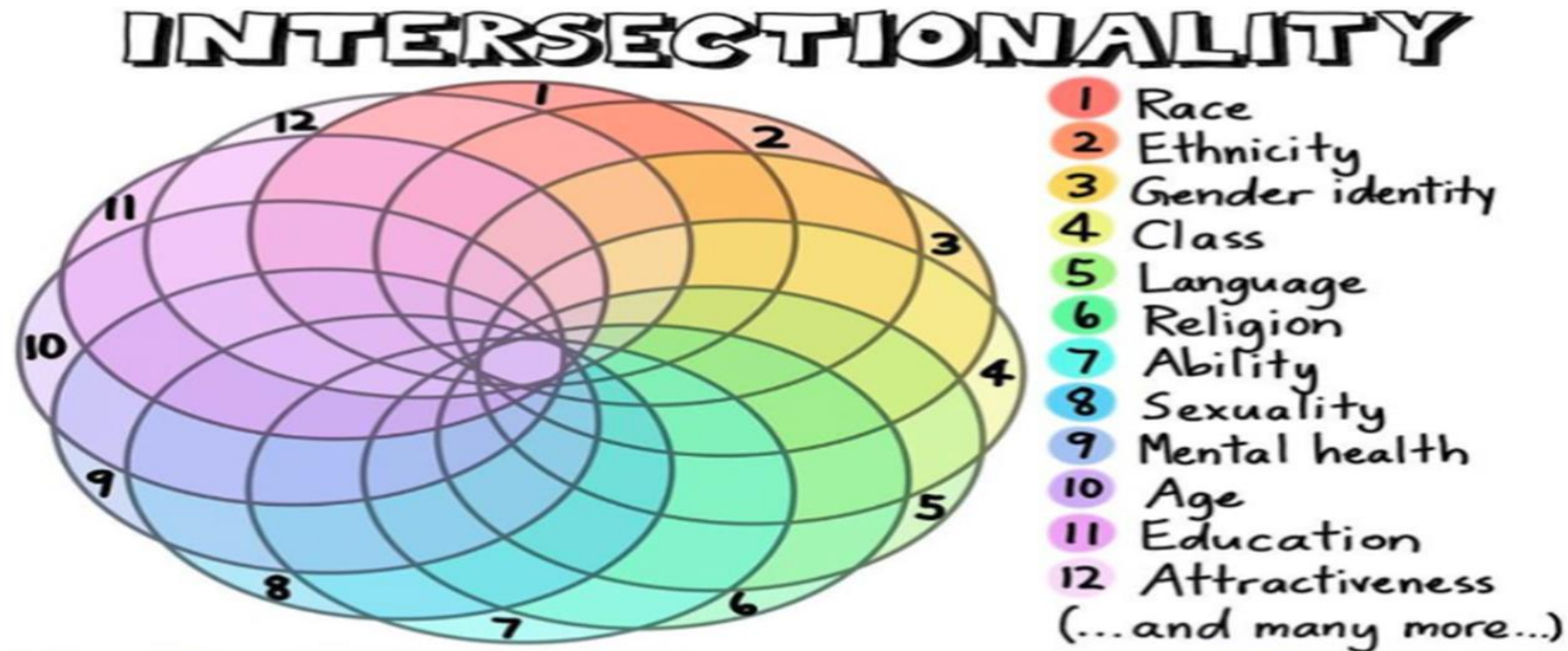
- Difficulty verbalising distress—may not know why they feel worried or stressed.
- They are more likely to experience stress as physical symptoms, like a headache, a stomach ache or wanting more physical contact.
- They will ask more questions about the impact on other people or on wider changes to life than younger children.

Social GRRRAACCEESSS (Burnham, 1993; 2012; 2018)

- Framework for understanding aspects of identity and how they shape our practices
- Visible and invisible
- Voiced and unvoiced



Supporting the 7–11-year-old child with a single ventricle



Intersectionality is a lens through which you can see where power comes and collides, where it locks and intersects. It is the acknowledgement that everyone has their own unique experiences of discrimination and privilege.

– Kimberlé Crenshaw –

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Supporting the 7–11-year-old child with a single ventricle -education

Key Stage 2 (KS2)

In England and Wales refers to the second phase of primary education, typically covering years 3, 4, 5, and 6, for children aged 7 to 11. It's a crucial stage where students deepen their understanding of core subjects like English, Math, and Science, along with other subjects like history, geography, and art.

Preparation for transition to secondary school

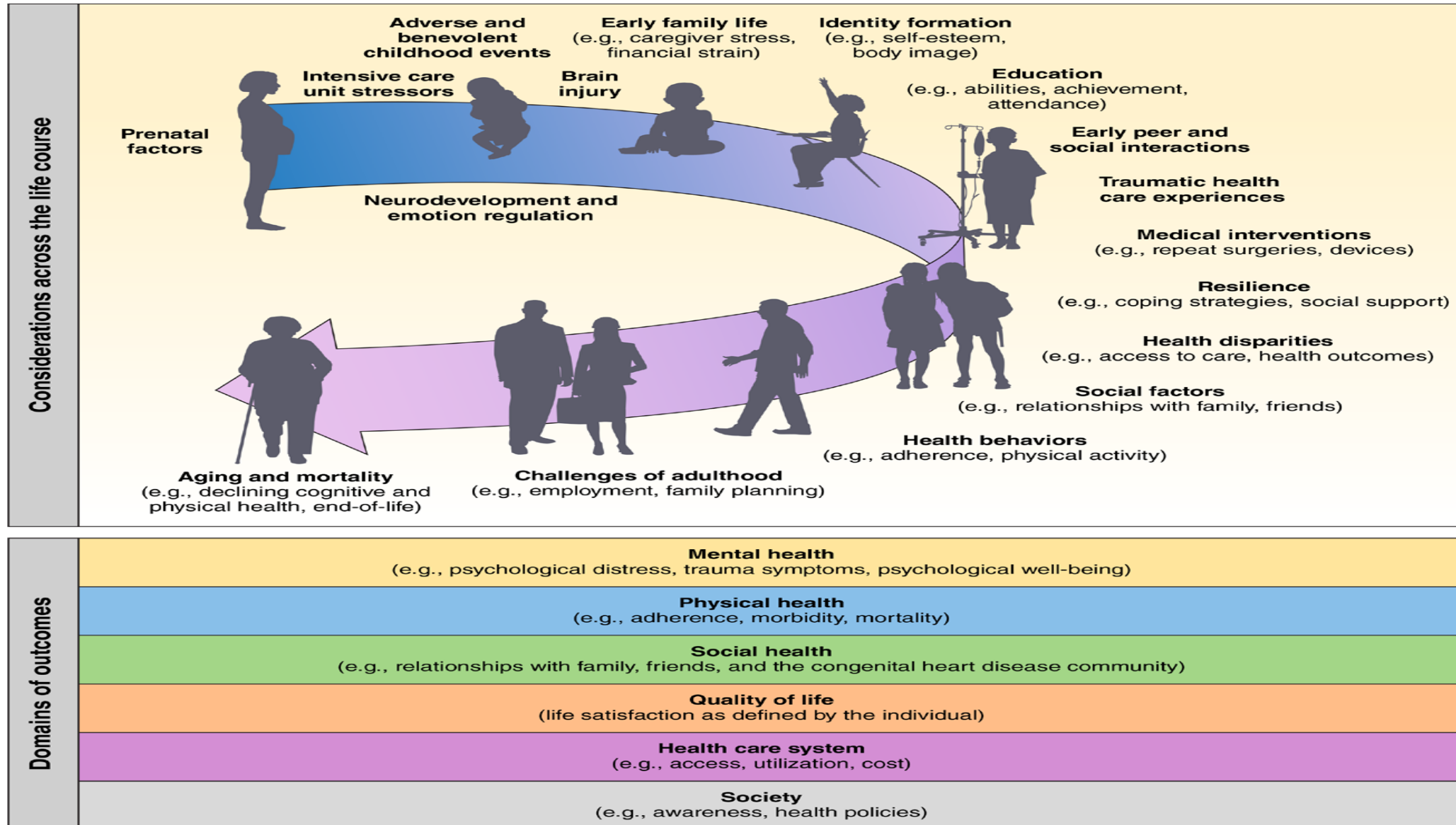
Supporting the 7–11-year-old child with a single ventricle

- Increased incidence of intellectual disability, autism and ADHD
- Challenges with attention and executive function (helps individuals plan, organize, and manage their actions, thoughts, and emotions, ultimately enabling them to achieve goals)
- Emotional well-being challenges more likely than for their peers

Supporting the 7–11-year-old child with a single ventricle -physical health



Supporting the 7–11-year-old child with a single ventricle



(Kovacs et al. 2022 *Circulation: Cardiovascular Quality and Outcomes*)

Supporting the 7–11-year-old child with a single ventricle



Supporting the 7–11-year-old child with a single ventricle

Adherence

At what age do you think that a child with SV should be expected to do their treatment?

What are your experiences of treatment adherence with your child(ren)?



Supporting the 7–11-year-old child with a single ventricle

Adherence to treatment- what are we talking about?

'the extent to which a patient's behaviour aligns with the agreed-upon recommendations from a healthcare provider, including medication, lifestyle changes, and follow-up appointments.'

For 7-11 year olds this also involves parents/carer

Research such as there is indicates that there is a relatively high level of adherence to treatment in children with SV

Aged 7-11 years

In most children they will do *most* of their treatment *most* of the time and this will fluctuate over time



Supporting the 7–11-year-old child with a single ventricle

- Suggestions:

Use '*protected time*' to explore understanding of health condition and reason for treatments

- This is a dedicated arranged time (15-20 minutes only) once or twice a week when you can be available to your child to discuss anything they want to (does not have to be SV or challenges- could be positives too like getting 'pen license' at school).
- This is an occasion, at which your child has your undivided attention (no phones etc.); at a time, they can anticipate.
- It is a technique used in case your child suddenly becomes very 'interested' in their health and that conversations about it appear to 'take over' your and/or their life temporarily. Alternatively, the opposite, your child could feel that at any time they are going to be 'expected' to talk about heart/health again. If your child tries to talk about health at times other than '*protected time*', you might find it helpful to tell them that the next '*protected time*' would be a good idea to discuss it – unless it is urgent.

Supporting the 7–11-year-old child with a single ventricle

- Manage your own thoughts and feelings to model calm and share clear expectations of your child's co-operation
- Treat as 'typical' – just what your child needs to do to get on with everyday life
- Use routines/ phone alarms and visual schedules
- Involve your child- let them track their meds or mark calendars etc
- Celebrate /notice small wins like remembering the dose
- Positive reinforcement (bribes) can work!
- Consider using the school / other trusted adults to support success
- Plan ahead to trouble shoot changes in routine/expectations
- Please do work with your teams – local or at specialist centre if you are struggling, you won't be the first family to experience challenges.....and if you are we *really* love to support this!



Supporting the 7–11-year-old child with a single ventricle



Supporting the 7–11-year-old child with a single ventricle

What are the reasons that a 7–11-year-old might be affected by the diagnosis of a 'little heart' (LH) single ventricle heart condition feel different?

1. Developmental
2. Visible (and invisible) difference
3. Hospital appointments/admissions/treatments
4. Activity limitations/feeling tired more easily
5. Cognitive/neurodevelopmental/emotional
6. Other

Supporting the 7–11-year-old child with a single ventricle

- Model coping/ calm yourself when with your child and others

If a comment or question is asked at a time that feels difficult (e.g. in a queue at a shop); or another person is asked questions by your child who does not know or think that it is helpful to answer (e.g. a teacher) they might find it helpful to say “that is a really important question and I want to give you an important answer so I am going to talk to (e.g. Mum) and we will come back and answer your question on _”

This can avoid saying something that is regretted later and/or allows you to consider how you would like to share the information asked for.

- Practise your response/ develop a range of strategies which work

So you say something you and your child are comfortable with

Supporting the 7–11-year-old child with a single ventricle

- Actively foster a culture with your family and friends of valuing difference and challenging society's unrealistic perfectionist ideals
- Take a proactive stance with new settings for your child (e.g. school)
- Help your child to develop an area of strength they can enjoy and feel proud about
- Help your child stay safe online from an early age
- Use age-appropriate story telling-use books, films, personal stories etc
- Encourage peer connections-camps, on line support etc
- Encourage- 'different but not alone' philosophy

Supporting the 7–11-year-old child with a single ventricle

- Where to ask for help- I acknowledge that talking therapy is often very hard to access. Resources can be found at schools, GP's, hospices, charities, community, faith groups as well as at the hospital.
- When you might need to ask for help:

Behaviour changes, school challenges, persistent sadness, other changes that seem difficult to change.



