

## Tell me where it hurts

Many individuals with CHARGE syndrome have complex medical needs. In addition, it is now recognised that they can experience intense pain. This may be related to migraines (including abdominal migraines), constipation, chronic otitis media, sinusitis, reflux, dental problems and other issues. For some this pain can be chronic (long term) and may lead to the individual developing a higher degree of pain tolerance as they accommodate the pain they are experiencing.

Challenging behaviours can increase with pain, and can be especially manifested in aggression and self-injury and Hartshorne et al (2017) identify pain as a potential trigger for challenging behaviour.

Unfortunately, many parents and professionals have reported that individuals with CHARGE can struggle to locate the source of the pain being experienced and to explain what they are feeling. Below are some suggestions for how it might be possible to support these individuals to express this more easily.

### Medical check up

Whenever there is a marked change in behaviour, the first step should be to check for pain and the individual's sensory status, as this change in behaviour can often be an indicator of pain. This should include getting a medical check undertaken.

### Learning about my body

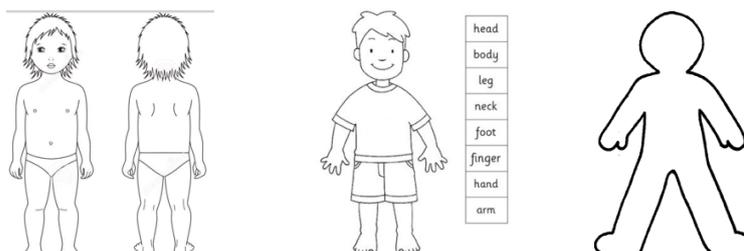
Many individuals with CHARGE have poor body awareness as a consequence of their sensory impairments, poorly modulated/stimulated proprioceptive sense and vestibular dysfunction. Some activities to help raise their body awareness include:

- Regular engagement in large movement activities
- Action songs/rhymes that include naming body parts
- Massage
- Paired yoga
- Massage stories



### Naming body parts

- Games to point to parts of the body (e.g. Simon Says)
- Pointing to our eyes, nose, mouth etc. when drawing a face, and then extending to other body parts
- Learning to point to our corresponding body parts shown on a diagram. For example:



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### How much does it hurt

Using a scale to help explain how much something is hurting. Initially the adult may need to interpret the level of pain being experienced to model how to use the chart. So, for example, a small bump on the knee may be a 1 while an ear infection might be a 4.



### Individuals at an early developmental level

For some individuals at any early developmental level, it will be too difficult to undertake these activities, although massage, massage stories and paired yoga are likely to be helpful for all.

The CHARGE Non-Vocal Pain Assessment (CNVPA) was developed by Stratton and Hartshorne (2012) for use with those who find it difficult to explain where it hurts. This assessment could be undertaken when the child or young person is known to be feeling well to provide a baseline. When there is any marked change in behaviour and it is suspected they are experiencing any pain, this can be used to identify what changes in behaviour have occurred. In the future if these behaviours are observed, it is likely that an increase in pain is being experienced.

The use of brushing protocol may be introduced to support the child or young person who is experiencing sensory integration difficulties (often thought to be inherent in individuals with CHARGE). This can be adapted to be used in the same way of rubbing something better, and in time the child or young person may be able to then use the brush themselves to rub where it hurts, thus showing where the pain is.

### References

Hartshorne TS, Stratton KK, Brown D, Madhavan-Brown S and Schmittel MC (2017) Behavior in CHARGE syndrome. *American Journal of Medical Genetics* Vol.175C pp.431-438

CHARGE Non-Vocal Pain Assessment (CNVPA)

<https://www.chargesyndrome.org/wp-content/uploads/2016/03/non-vocal-pain-assessment.pdf>

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