It can be very difficult to assess pain in a person living with CDKL5 Disorder. Because they are non-verbal, and due to their intellectual disability, it can be very difficult to understand reasons for crying for example. We know that those living with CDKL5 Disorder can cry for extended periods of time and some parents / carers report that they believe it is for no reason. The FLACC Pain Scale is a system that can help parents, carers and professionals to assess pain levels in children and adults who have limited or no expressive communication.

It is important to note that the person might not necessarily be in pain. However, if you think they are, and the symptoms continue, then it is important you seek medical help as soon as possible.

THE FLACC PAIN SCALE

The FLACC Pain Scale is a system that can help parents and professionals assess pain levels in children who have limited or no expressive communication. The diagram shows the categories for scoring. Zero, one or two points are given to each of the five categories: Face, Legs, Activity, Cry and Consolability.

- **INTERPRETING THE BEHAVIOUR SCORE**

  Each category is scored on the 0-2 scale, which results in a total score of 0-10.

<table>
<thead>
<tr>
<th>CATEGORIES</th>
<th>SCORE ZERO</th>
<th>SCORE ONE</th>
<th>SCORE TWO</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Face</strong></td>
<td>No particular expression or smile</td>
<td>Occasional grimace or frown withdrawn, disinterested</td>
<td>Frequent to constant frown, clenched jaw, quivering chin</td>
</tr>
<tr>
<td><strong>Legs</strong></td>
<td>Normal position or relaxed</td>
<td>Uneasy, restless, tense</td>
<td>Kicking or legs drawn up</td>
</tr>
<tr>
<td><strong>Activity</strong></td>
<td>Lying quietly, normal position, moves easily</td>
<td>Squirming, shifting back and forth, tense</td>
<td>Arched, rigid, or jerking</td>
</tr>
<tr>
<td><strong>Cry</strong></td>
<td>No cry (awake or asleep)</td>
<td>Moans or whimpers, occasional complaint</td>
<td>Crying steadily, screams or sobs; frequent complaints</td>
</tr>
<tr>
<td><strong>Consolability</strong></td>
<td>Content, relaxed</td>
<td>Reassured by occasional touching, hugging or being talked to; distractable</td>
<td>Difficult to console or comfort</td>
</tr>
</tbody>
</table>