

# First Responder Information

## Cri Du Chat Syndrome (5p-)

Cri du Chat Syndrome is the result of a loss of genetic material on the short arm of the fifth chromosome at conception. **Because 5p- is a spectrum disorder, it varies greatly from person to person, and can include a range of intellectual and developmental disabilities, from severe to moderate.**

### QUICK FACTS

- Cri du Chat affects 1 in 50,000 children.
- Individuals typically have difficulties in verbal and non-verbal communication.
- Individuals are very friendly, social and trusting, and may not distinguish who is a stranger, engaging them in conversations.
- Individuals can be small in stature and have difficulty gaining weight. They are eating and burning what calories they are consuming; they most likely are not being deprived.
- Some individuals with Cri du Chat Syndrome are tube fed.
- There is no medical cure for 5p-

### RESOURCES

**National Support Group:** 5p- Society  
**Main Web:** [www.fivepminus.org](http://www.fivepminus.org)  
**Email:** [director@fivepminus.org](mailto:director@fivepminus.org)  
**Phone:** 888/970-0777

## 5p- BEHAVIORS

*A Child/Adult with 5p- may...*

- Have verbal and auditory limitations.
- Repeat something over & over.
- Not be potty-trained.
- “Stim” Or self-stimulate (rock back & forth, flap hands, flick fingers, hyper laugh, etc).
- Head-bang, hit, bite, pinch, pull hair, pick skin until it bleeds.
- Have no eye contact.
- Not respond to their name, or questions.
- Seem deaf or defiant.
- Be unable to understand social cues.
- Have extreme sensitivity to light, sound and/or touch.
- Demonstrate low to no sensitivity to pain, or oversensitivity to pain.
- Have no fear of real danger.
- Have odd fears.
- Be attracted to water, traffic, or have extreme obsessions with certain ideas, objects, places, or people.
- Run or bolt from stressful situations.
- Enter another person’s home without understanding consequences.
- Be impulsive or aggressive when scared.
- Communicate through a picture system.
- Act intoxicated, high, or suspicious.
- Have the cognitive ability of child.
- Be inflexible to change.
- Have extremely narrow food preferences, or ingest non-food substances (Pica.)

*(more)*

## PARENT BEHAVIORS

### *The Parent of a child/adult with Sp- may...*

- Have unusual security patterns in the home: Locks on both sides of door, nailed-down windows, chain locks, makeshift locks, barricades (fire safety may be secondary to parents of elopers.)
- Have walls with holes and dents.
- Have unusual foods in the fridge.
- Have home windows blacked out, or car windows covered.
- Have unusual sleeping arrangements (Mom/Dad may sleep next to child's bed.)
- Have weighted blankets, vests and other weighted materials.
- Allow child/adult to wear odd clothing depending on tactile sensitivity.

## TIPS ON INTERACTION

- Check child For ID – It may be on the shoe or in a pocket.
- Reduce stimuli (bright lights, loud noises, commotion)
- Avoid giving complex directions, use simple phrases
- Don't assume the child understands.
- Provide communication aids if possible.
- Use techniques to ease anxiety, such as first/then & fill-in-the-blank. For example...  
First, we are going to get into the white car, and then you can have a cookie.  
Instead of: What is your phone number? Try: "My phone number is \_\_\_\_\_."  
Follow up all actions with praise: "Great job!"

## AS VICTIMS, INDIVIDUALS MAY:

- be easily victimized and targeted for victimization
- be less likely or able to report victimization
- be easily influenced by and eager to please others
- think that how they have been treated is normal and not realize the victimization is a crime
- think the perpetrator is a "friend"
- be unaware of how serious or dangerous the situation is
- not be considered as credible witnesses, even in situations where such concern is unwarranted
- have very few ways to get help, get to a safe place or obtain victim services or counseling

## AS SUSPECTS, INDIVIDUALS MAY:

- not understand their rights but pretend to understand
- not understand commands, instructions, etc.
- be overwhelmed by police presence
- act upset at being detained and/or try to run away
- say what they think officers want to hear
- have difficulty describing facts or details of offense
- be the first to leave the scene of the crime, and the first to get caught
- be confused about who is responsible for the crime and "confess" even though innocent