

THE CHARGE ADOLESCENT: FOR THE PHYSICIAN

Kim Blake, M.D.

IWK Grace Health Centre, 5850 University Ave., Halifax, Nova Scotia B3J 3G9, Canada
kblake@is.dal.ca (902)420-6499

The adolescent period is a stage of change and offers its own challenges for all families but especially to those with CHARGE teens.

Behavioral problems can be a big issue. These may be outbursts, tantrums, self-abuse, and defiance.¹ For a non-CHARGE adolescent unruly behavior is more likely due to psychological concerns than from medical ones. With the CHARGE adolescent a medical cause needs to be considered first especially if these outbursts occur without any provocation or warning and are waking the adolescent from sleep³.

There are certain co-morbid psychological conditions that can occur with CHARGE. These may be detected before adolescents and these include:

- Attention deficit disorder (ADHD)
- Pervasive developmental disorder (PDD)
- Obsessive compulsive disorder (OCD)
- Anxiety
- Depression
- Learning difficulties

If it is suspected that the CHARGE adolescent has one of these co-morbid conditions secondary to the CHARGE diagnosis, it is important to have a full psychological evaluation including a detailed home and school profile. The psychologist should have understanding of adolescents with sensory deficits. It is important to take care of the above labeled diagnosis as it is easy to overlook sensory deficits i.e. hearing and visual loss.

Drugs used to treat these co-morbid conditions may be required in smaller doses than for non-CHARGE adolescents. Before starting medication, it is best to treat the adolescent not the label. Any of the listed diagnoses often gives rise to adverse behaviors but so do frustrations in not being able to communicate or frustration in this non-CHARGE world. It is important to observe when these types of behavior are occurring and to try behavior modification techniques along with a very structured day.⁴ Planning a daily routine and preparing the adolescent for any change may be a good strategy. Positive rewards for good behavior and a routine are a very good start to a behavioral modification program. The adolescent with CHARGE responds like many other non-CHARGE adolescents and would benefit from having a set of rules about behavior that is and is not acceptable,¹ e.g. The parent may tell their teen they can touch a person's hand, shoulder and arm, but that they are not allowed to touch peoples breasts.¹

Observations about behavior in CHARGE adolescents directly from a handout from Veronika Bernstein¹ are as follows:

- ✓ *Denotes behaviors which can occur in any adolescent.*
 - ✓ mood disturbances
 - ✓ marked irritability
 - ✓ emotional lability
 - ✓ anxious
 - ✓ depressed

- ✓ insomnia
- ✓ excessive sleepiness
- ✓ eating problems
- diminished taste
- changes in cognition
- ✓ changes in concentration
- deterioration in vision and hearing related to not paying attention
- slowing of mental processing
- ✓ diminished initiative
- impaired memory
- ✓ increased impulsivity
- repeating same sign or phrase over and over
- obsessive-compulsive rituals
- tics starting with facial grimaces to major muscle groups
- ✓ increased aggression
- increase in self-injurious behaviors
- increase in sensation seeking
 - ✓ novel experiences
 - ✓ intense experiences
 - ✓ increase in risk taking behaviors
 - ✓ violation of well learned rules
- ✓ increase in thoughts of invincibility and telepathic powers
- interest in sexually related behaviors:
 - increase in masturbation
 - increase in staring at others (inappropriate)
 - increase in touching others (inappropriate)
- ✓ hate to be corrected
- ✓ hate to be told what to do
- ✓ hate to be bored
- ✓ hate to be bothered
- ✓

The above could describe any typical adolescent - with or without CHARGE.

If the adolescent is experiencing regression in behavior or cognition (mental processes - memory), it is important to rule out an underlying medical deterioration i.e. hypothyroidism, heart disease, regression in hearing and vision.

REFERENCES.

1. Bernstein, Veronika, 1995, *CHARGE Adolescence Is it Behavior? Is it Communication? Handout.*
2. Blake, K., et al., 1998, *CHARGE Association: An Update and Review for the Primary Pediatrician*, Clinical Pediatrics, pp. 1-16
3. Blake, K., *CHARGE into the year 2000*, presentation handout.
4. Blake, K., 1997, *CHARGE Association Workshop "Growing Up with CHARGE"*.
5. Oley, C. A., M. Baraitser, and D. B. Grant, 1987, *A reappraisal of the CHARGE association.*

THE CHARGE ADOLESCENT: PARENT INFORMATION

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Two key things to remember about your adolescent:

Their success and performance will vary from day to day. Just because they accomplished something yesterday, don't look down upon them because they can't do it today.¹

There is no miracle strategy for dealing with your adolescent. Just keep trying new things until you find something that works with your teen.

MEDICAL ISSUES:

An important aspect of your child's adolescents is the onset of puberty. Both males and females with CHARGE may require hormone replacement therapy. If a deficiency in sexual hormones is suspected, an appointment with an endocrinologist is suggested.⁵ Many families forget the "sex hormone" issues and are either never referred to an endocrinologist or go too late.

In males, androgen replacement therapy (male sex hormones) may cause significant growth in the penis. The psychological boost derived from this treatment is very significant and sufficient reason for considering this therapy. Males also tend to have poor growth of facial hair, which may be alleviated by this therapy⁵.

Females without hormone replacement therapy tend to enter puberty late and have irregular periods. They may also have no breast development without estrogen replacement therapy.²

As more CHARGE children enter adolescents there is an increased awareness of problems and how to approach these. Skeletal curvature (scoliosis) is of concern and was brought to our attention when conducting a survey at the 997 Family College Association Conference.⁴ If there is concern, ask to see an orthopaedic surgeon. This scoliosis may increase during the growth spurt of the adolescent (13-20 years). The growth spurts in CHARGE adolescents occur later than the documented norms for growth. This puberty pattern reflects the potential for later growth and for a normal adult stature.

As many CHARGE children obtain milestones late (walking, running, communicating), it is not unreasonable to suspect that many of them crave for more learning opportunities later in life. These need to be respected and as some of our adolescent case studies show it is not reasonable to expect the adolescent to be happy doing "basket weaving" or other menial tasks.

REFERENCES.

1. Bernstein, Veronika, 1995, *CHARGE Adolescence Is it Behavior? Is it Communication? Handout.*
2. Blake, K., et al., 1998, *CHARGE Association: An Update and Review for the Primary Pediatrician*, Clinical Pediatrics, pp. 1-16
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