

CHILDHOOD LEUKEMIA: A FAMILY AFFAIR

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BLANK CHILDREN'S CANCER AND BLOOD DISORDERS CENTER**

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**WE HAVE NO
DISCLOSURES.**

OBJECTIVES

IDENTIFY

- Identify ways in which families are impacted by a diagnosis of Acute Lymphoblastic Leukemia

DESCRIBE

- Describe supports available to children and families when a child has cancer

SHIFTING MEDICAL AND PSYCHOSOCIAL TREATMENT PERSPECTIVES

1960-1970's

- Survival
- Coping with death

1980's

- Preservation of cognitive functioning
- Utilization of behavioral strategies and more humane approaches to chemo administration

1990's

- New, more aggressive therapies widely used
- Recognition of limits of psychological interventions
- Focus on children at risk for significant and long term difficulties

Present

- Standardized treatment approaches organized by COG
- Genetic advances
- Focus on medical and psychosocial late effects of treatment

LEUKEMIA IN CHILDREN

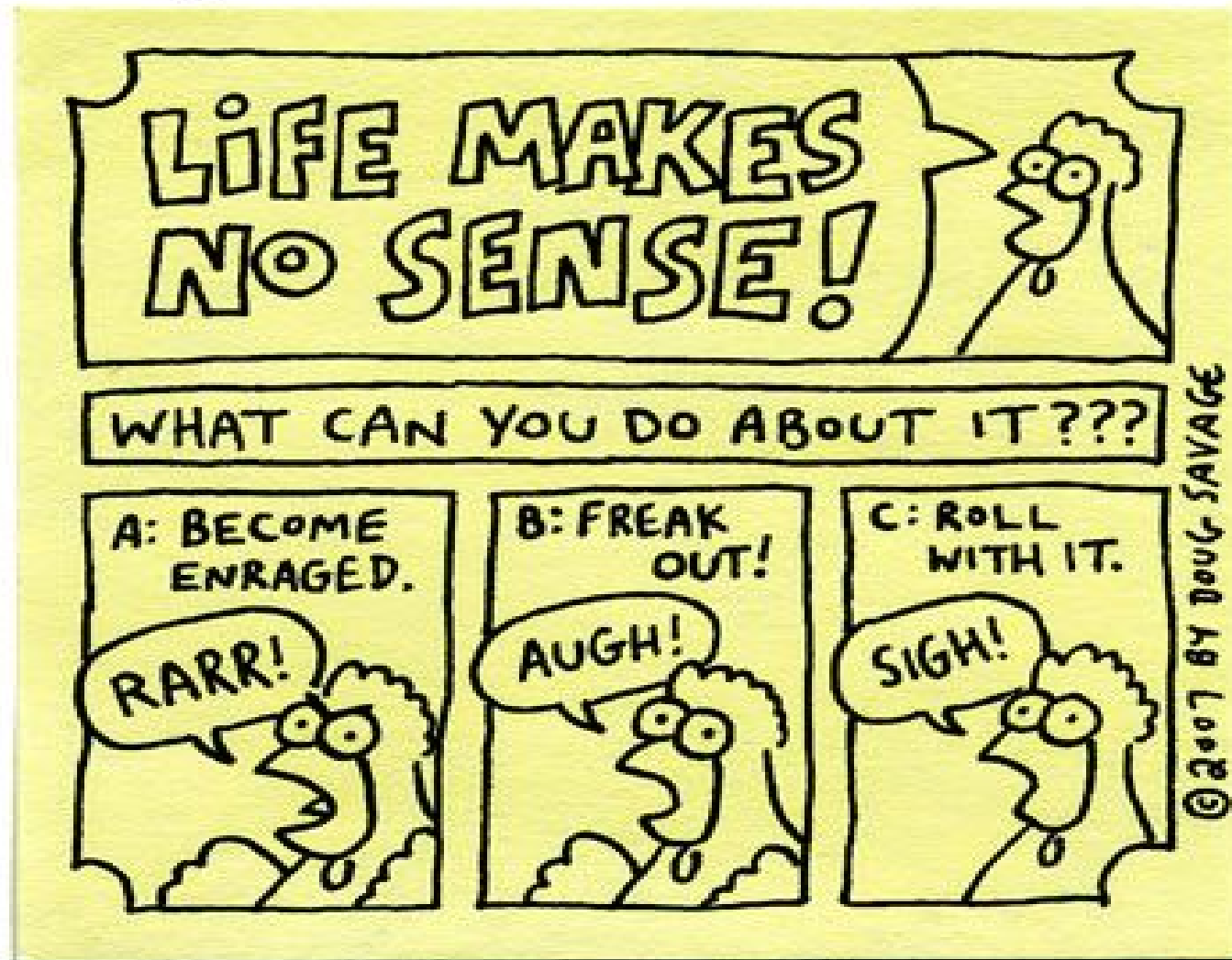
- Acute Lymphoblastic Leukemia (ALL) is the most common form of leukemia found in children.
- Accounts for 30% of all pediatric cancer.
- About 3,000 cases of ALL in children and youth up to age 21 each year in the USA.
- ALL has one of the highest cure rates of all childhood cancers.
- ALL affects the immature forms of white blood cells, (lymphocytes).
 - B-lymphocytes
 - T-lymphocytes
- Their immature forms are the source of the two corresponding subsets of ALL, T-ALL and B- or pre-B ALL.

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**"YOUR CHILD
HAS LEUKEMIA."**

Savage Chickens

by Doug Savage



THE PUNCH LINE

- Children and families are resilient! (Phipps et al, 2014)
- Many children and family cope well with basic supportive services.
- Report growing in positive ways as a result of the experience.
 - Many families experience both PTSS AND PT growth!
- One study examined 39 families with a child newly diagnosed with ALL compared to 49 families of healthy children. (Sawyer, Antoniou, Toogood, et al., 2000)
 - Higher distress immediately following diagnosis but it decreased over 4 years and was no longer evident.

IMPACT OF PEDIATRIC CANCER

INFANCY-PRESCHOOL AGED

- Adjustment to treatment with limited cognitive understanding
- Loss of control
- Fears of abandonment/separation
- Developmental regression/interruption
- Behavioral reactions
- *Coping*: problem-focused, action-oriented, distraction
- *Tools*: Storytelling, fantasy play and puzzles

SCHOOL AGED

- Understand seriousness
- Awareness of physical changes/feeling different
- Loss of control
- Isolated from peers
- Miss school
- *Coping*: development of emotion-focused
- *Tools*: Medical play, relaxation



IMPACT OF PEDIATRIC CANCER

Adolescent and Young Adult

- Disruptions in school & social activities
- Isolation
- Difficulty identifying with care-free friends
- Self-image problems
- Sense of invulnerability (adherence issues)
- More intense emotional reactions, distress, existential issues
- Independence-dependence struggle
- May have to postpone college, work, marriage, family
- *Coping*: use of social support, emotion-focused, cognitive strategies, information-seeking
- *Tools*: participate in medical decision making

PARENTAL ADJUSTMENT

- Impact of diagnosis often more intense & distressing for parents (trauma).
- Fears & worries about child's acute & long-term survival.
- Guilt.
- Marital distress.
- Overprotection.
- Financial distress.
- Re-negotiation of roles.

PARENTAL ADJUSTMENT

- Better short and long-term adjustment:
 - Employed.
 - Have social support from family, friends, and health care team members.
 - Experience lower levels of parenting stress.
 - View their children's quality of life positively.
 - Have positive expectations for treatment outcome.
- Poorer parental adjustment:
 - Low parental expectations for positive outcomes.
 - Feelings of helplessness, uncertainty, and anxiety.
 - Low levels of social support.
 - Negative interactions with health care team members.
 - Negative assessment of the child's quality of life.

(Grootenhuis & Last, 1997 and Dockerty, Williams, McGee et al., 2000)

SIBLING ADJUSTMENT

Normal Reactions:

- Loneliness / Isolation
 - Jealous of patient's attention
 - Acting out/negative-attention seeking
 - Responsibility for disease
 - Sadness & anger
 - Wish to be sick
-
- Assessment of their needs equally important!
 - Distress greater around time of diagnosis.
 - Research to suggest age of siblings important variable.

Alderfer, Long, Lown et al., 2010

FAMILY IMPACT

- Roller coaster of emotions
 - All the feelings!
 - Grieving the loss of their Before Cancer life
 - Questions of faith, fairness and blame
 - Challenges to normalcy and stability
- Physical upheaval
 - Role and responsibility changes
 - Employment
 - Education and activities
 - Finances
 - Sibling care
- Divide and conquer
 - Accept help
 - Point person
 - Social media
 - Prioritize
 - Delegate
- Forever changed: for better, for worse?

IT'S A JOURNEY

- While children and family tend to adapt and develop healthy coping mechanisms shortly after diagnosis, the cancer journey is often a bumpy ride.
 - Finding new normal.
 - Transitions stressful.
 - No definitive end to the “traumatic” situation.
- Encourage family to maintain as many daily routines as possible.
- Maintain expectations of child.
 - House rules should be minimally changed.
 - Encourage independence and autonomy.



COOPER AND CO.



CASE BACKGROUND

- Cooper was a healthy twin male until diagnosis of B cell Acute Lymphoblastic Leukemia at 8 years-old in July 2016.
- Twin brother has diagnosis of ADHD.
- Parents college educated and employed full time within a large financial company.
- Cooper in the 3rd grade at time of diagnosis and history of high academic performance.



TREATMENT AND ACUTE IMPACT

- Initially treated on AALL0932 and AALL08B1 for induction therapy.
- Day 29 bone marrow showed MRD of 0.11%.
- He is enrolled on AALL1131, VHR, and randomized to the control arm.
- Allergic reaction to PEG-asf.
- Multiple compression fractures secondary to chemotherapy, low bone density (wore brace for awhile).
- Physical therapy for tightness and vincristine associated neuropathy.

MOST COMMON COGNITIVE LATE EFFECTS

- Decline in intellectual functioning
- Memory problems (short-term)
- Attention/concentration difficulties
- Slower processing speed
- Visual-spatial/motor problems
- Arithmetic & other learning problems
- Problems in executive functioning

- Mulhern & Butler, 2006

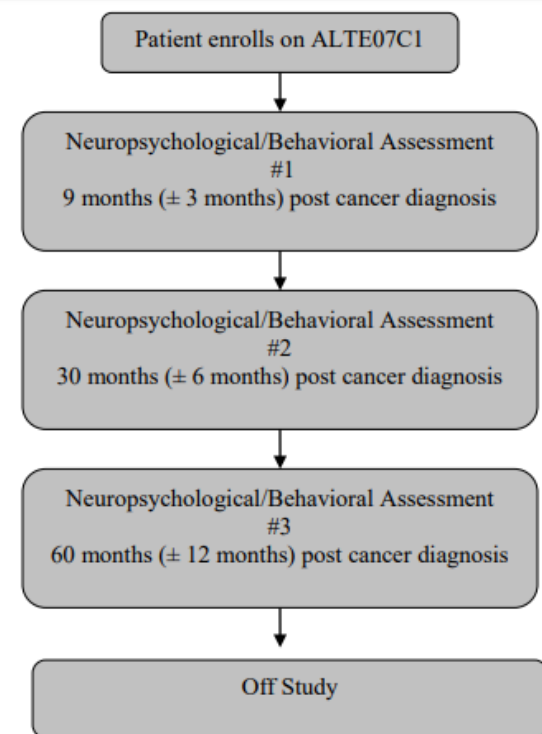
ALL AND CHEMOTHERAPY ONLY

- Neurocognitive deficits involving processes of:
 - Attention
 - Speed of information processing
 - Memory
 - Verbal comprehension
 - Visual-spatial skills
 - Visual-motor functioning
 - Executive functioning; global intellectual function is typically preserved.
- Does NOT appear to reduce global IQ after treatment with chemotherapy alone.
- Arithmetic performance can be impacted.
- Risk factors for poor neurocognitive outcome are younger age and female gender.

Campbell, Scaduto, Sharp, et al., 2007

NEUROCOGNITIVE STUDY

- ALTE07C1-Neuropsychological, Social, Emotional, and Behavioral Outcomes in Children with Cancer
 - Brief (1 ½ hour) assessment in COG studies.
 - Focused on critical functional domains empirically demonstrated to be affected in these conditions.
 - 9, 30 and 60 months post-dx



COOPER'S TEST RESULTS

Measure	T1: May 2017	April 2018	T:2 April 2019
WISC-V FSIQ (SS)	99	102	-
WISC-V Visual Spatial	100	94	-
Visual Puzzles	10	8	-
Block Design	10	10	7
WISC-V Fluid Reasoning	109	94	-
Matrix Reasoning	10	6	-
WISC-V Working Memory	97	112	-
Digit Span	11	13	8
WISC-V Processing Speed	95	98	103
CMS – Dot Locations – Learning	5	9	11
Total Score	6	10	12
Long Delay	7	12	13
CMS – Stories – Immediate	14	13	17
Delayed	14	13	15
Recognition	14	12	14
CMS – Faces – Immediate	12	16	17
Delayed	12	14	18

IMPLICATIONS

- A decline in functioning is assumed due to history of above average academic scores.
- Possible decline in reasoning, visual spatial and auditory attention abilities.
- However, no concerns regarding memory, learning or processing speed.
- Family sought out tutoring services which have been helpful in improving his test performances.



COOPER'S TREATMENT BY THE NUMBERS

- 3 emergency department visit
- 9 hospitalizations
- 22 radiologic scans
- 28 days spent in the hospital
- 48 telephone calls
- 70 office visits
- 78 infusions

COOPER'S FAMILY IMPACT

- Roller coaster of emotions
 - Appropriate and “normal”
 - Intermittent symptoms began 2 months prior (guilt, anger, regret)
- Physical upheaval
 - Parents shared burden of obligations
 - Parents maintained full-time employment with FMLA support
 - 504 plan; bracing ; Positive Party; Spring Break
 - Co-pays and deductibles; loss of pay
 - Sibling care
- Divide and conquer
 - Child Life for tough conversations
 - Psychology for emotional and educational support
 - Social Work for financial support and community resources
 - Community support
- Forever changed: For better!
 - Resiliency
 - Waukee Asst. Coach, ISU Kid Captain, Camp Heart Connect, Charity Gold Classic
 - Make-A-Wish trip to Aulani
 - Sports involvement (basketball and baseball) continue
 - New community of support (Momcology, Cancer Connection, other)



FAMILY SUPPORT

- Mother indicated that while the health care team was great, what she truly appreciated was the connection with other parents.
- She appreciated the encouragement to connect with others due to the benefits to knowing you aren't alone.
- Facebook group, CCC, etc. but no formal process.

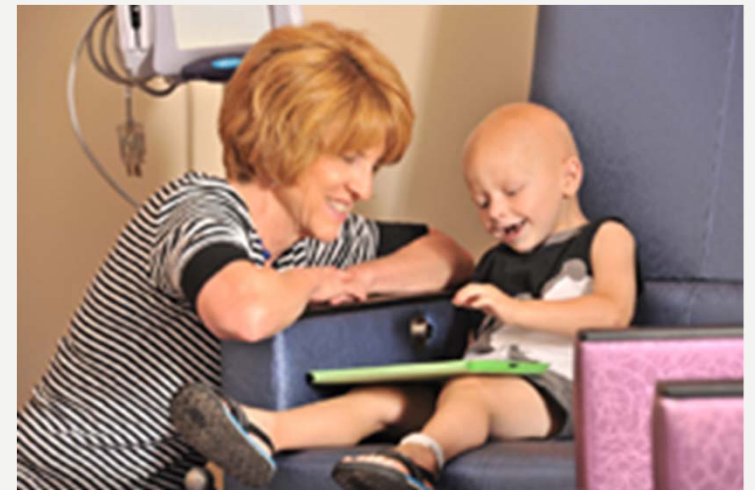


RESOURCES TO SUPPORT PATIENTS AND FAMILIES

- Psychosocial support team
 - Social work, child life, psychology, school-liaison, palliative care, chaplain, music and art therapy
 - Advocacy, education, supportive and therapeutic interventions
- School Re-entry program
- Local and National Charities
 - Children's Cancer Connection
 - Kid's Living Brave
 - Team Kelsey Foundation
 - Pinky Swear Inc
 - Family Reach Foundation
 - National Children's Cancer Society
 - Disease specific
 - Need Specific

PSYCHOLOGICAL INTERVENTIONS

- Cognitive-behavioral therapy (CBT)
 - Acceptance and Commitment Therapy (ACT)
- Eye Movement Desensitization and Reprocessing (EMDR)
- Mind/body or relaxation-based strategies
 - Biofeedback
 - Self-hypnosis
 - Mindfulness
- Behavioral management strategies (for parents)
- Supportive therapy
- Cognitive Remediation Strategies (??)



COOPER AND CO. SUPPORT

- Supportive services for both Cooper and brother.
- Cooper struggled on treatment due to losses (sports, school).
- Brother struggled with worry and jealousy and so short term therapy was provided.
- Both received short term psychotherapy services.
- Cooper has been able to resume participation in sports.
- Family is finding their current “normal.”



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THANK YOU!

QUESTIONS????

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