

Psychosocial Issues in Survivors of Childhood Malignancy.

KAREN D

NHL, Chemo, Chest XRT, CXRT

Health Issues:

- Growth
- Thyroid
- Fertility
- Cardiac

Social:

- Work
- Relationship
- Pregnancy – discuss outcome

JOHN B

AML, Age 11yrs, BMT

Health Issues:

- Acute complications and long

Social:

- Family Issues
- Fertility and Relationship Issues

JOSH MC

H.D age 12 years, high dose XRT and chemo

Health Issues:

- Thyroid
- Fertility
- Cardiac
- Lung function

Social:

- High achiever
- Relationship
- Impact of diagnosis and career

KIM B

Brain tumour, surgery, high dose XRT and chemo

Health Issues:

- Schooling
- Social

MH

HD at age 9yrs. Now 40yrs, chemo and XRT, relapse after 3 years, further chemo

Work – pharmaceutical Industry

Health Issues:

- Hormonal
- Panic attacks
- Cosmetic

Peter D

RMS orbit age 9yrs, now 40yrs. Lost eye, XRT to eye and neck, chemo

Work – varied, on pension

Health Issues:

- Hormonal
- Dental

Social:

- ETOH
- Nutrition
- Relationship

SEB O

Wilms Tumour age 18 months, surgery/chemo

Health Issues:

- Thyroid
- Osteoporosis
- Growth
- Lungs

Social:

- Second tumour (varicoele)
- ↓school performance/truanting (at private school)
- Extreme anxiety
- Relationship with parents (divorced), close to mother. Mother made urgent appointment with LEC because of his concern regarding second malignancy and ↑anxiety.
- "At risk" behaviour (S,D,R+R)
- Medical ?BP
- Parental difficulty with adolescence – "control"

NICK M

? ALL ?MB, Chemo + CXRT, TBI

Health Issues:

- Growth
- Hormonal
- Hair

Social:

- Education
- Family Expectations

MARK D

Brain tumour age 14years, surgery, CXRT, chemo

Health Issues:

- Hearing
- Associated genetics
- Osteoporosis

Social:

- Very isolated, family dislocation
- CRS involvement
- Mental health

PETER L

Testicular tumour 5 years, surgery, chemo

Health Issues:

- Fertility

Social:

- High achiever
- Cultural (Role of GP)
- Relationship pressure (because of infertility) not interested in counselling.

Educational Issues

- Missed schooling (critical periods)
- Social Aspects
- Learning Difficulties (CXRT intrathecal MTX)
- Complications during treatment – seizures
- Participations
- What the kids want

Body Image

- Surgery eg. Loss of limb/eye
- Hair loss
- Asymmetry
- Local radiation effects
- Feeling that “body has failed one...”
- Body shape and growth

Psycho-Social Issues

- Parent-child dynamic
- Loss of autonomy/age appropriate independence
- Friends and participation in sport etc
- Sibling relationships
- Survivor guilt
- Fear of recurrence
- Concept of “post traumatic stress disorder” – intrusion/avoidance/hyper arousal
- Concept of “thriving” – greater appreciation of life
- Aspects – more mature, more “purpose” in life, closer family relationships

Quality of Life Complicated

- Is it (a) “being happy” ?hopes for the future
(b) Freedom from Physical symptoms
(c) Relationships
(d) WHO definition – complete physical, mental and social wellbeing
- Influences – culture and value systems

Lifestyle Indicators

- 1. Academic Success and Achievement
- 2. Employment and Insurance
- 3. Marriage and Attitudes to parenting
- Varying studies on lifestyle indicators:
 - Less likely to go to university
 - drive
 - ↑numbers in special ed program
 - No difference in involvement competitive sports
 - Active social life
 - Diagnosis at young age → more educational issues
 - Discrimination in workforce in 10% (USU unfounded) armed forces
 - Insurance rates (difficult issue)
 - Genetic information
 - Family distress and coping has a major impact

What can we do?

- Little evidence regarding interventions eg. Reinterpret the cancer experience → ↓feelings of stress
- Healthy lifestyle and prevention strategies
- Patient passport

Overall vulnerable groups

- Brain tumours
- Young age at diagnosis
- Poor communication in family
- Fertility Issues – a minefield

Neuro Cognitive

Late Effects related to:

- Aggressiveness of CNS therapy
- Age at diagnosis
- Time since diagnosis
- Socio economic status
- Neurologic problems

Specific Problems:

- Working memory
- Executive functions

Anatomy:

- Diffuse/multifocal white matter abnormalities
- Demyelination
- Microvascular occlusion
- Calcifications eg. Basal ganglia

Parental Effects

- Long lasting
- Some negative some positive
- Need to “mourn” losses
- Ongoing uncertainty, anxiety, loneliness
- May “conceal” marital problems
- Control issues
- Ability to express emotions
- “Normalise”