

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”

