

# Practical Strategies for coping with the effects of a Paediatric Brain Tumour

Dr Dianne Gumley  
Consultant Clinical Psychologist  
Great Ormond Street Hospital

# TOPICS

- Coping with news of diagnosis and treatment
- What does treatment mean for your child's future
- What are areas of difficulty your child may face
- Returning to school
- How can we help / rehabilitation
- Discussion

# Coping and Adjustment

- Diagnosis and treatment will be associated with changes in family life and experience
  - Decisions around treatment
  - Hospital visits – inpatient /outpatient
  - MRI Scans = increasing anxiety
  - Arrangements for other children
  - Financial effects – giving up work
  - Changes in child's appearance
  - Time off school

# Coping and Adjustment

- Balancing uncertainty and predictability
- Maintaining family life
- Talking to your child, other children in the family and the extended family
- There is no right or wrong way of coping

# Talking to Children

- There is more than one opportunity
- It is an ongoing process
- Children's concerns may not be the same as adults concerns
- Appropriate to child's cognitive level
- Adult concerns are separate and different from child concerns
- Too much too early not taken in.
- Conversation that needs to be updated and added to

# Parents

- Practice what you want to say by saying it out loud
- Focus on the child and what that child needs now and in the future.
- Age is a risk factor for impaired cognition which may impact on treatment decision making
- Emerging knowledge and process both for the child's continuing development and parents understanding of implications.

# Childhood Brain tumour Survivors

- More children are surviving through childhood into adult life.
- Treatment is associated with a range of adverse long-term side effects
- Children can suffer neuropsychological effects of both the tumour and the treatment
- Neuro-cognitive late effects are relatively common and can be debilitating if not supported
- Good outcome will affect child's future functioning

# Risk Factors for Impaired Intellectual Outcome

- Surgery alone : Surgical complications
- Tumour type and location
- Age - younger age at diagnosis and treatment
- Radiation effects : children treated with lower doses or reduced fields of cranial radiation demonstrate less impairment of intelligence than children treated with higher doses.

# Other factors which effect outcome

- Emotional
  - family factors and coping style
  - Child
- Adaptation to chronic illness
- Neurological effects
- Visual impairment,
- Hearing impairment
- Physical disabilities

# Long term effects

- Executive function
- Attention
- Self esteem
- Social functioning
- Memory
- Slow processing
- Difficulty acquiring new learning

# Cognitive outcomes

- Children have been reported to experience learning difficulties, including slowness, memory and comprehension difficulties, which impact on mathematics, reading, and spelling.
- Reported cognitive deficits can have a significant effect on the children's ability to function well in the school situation.
- There is not a uniform profile.
- Can lead to career goal restrictions

# Emotional / behavioural outcomes

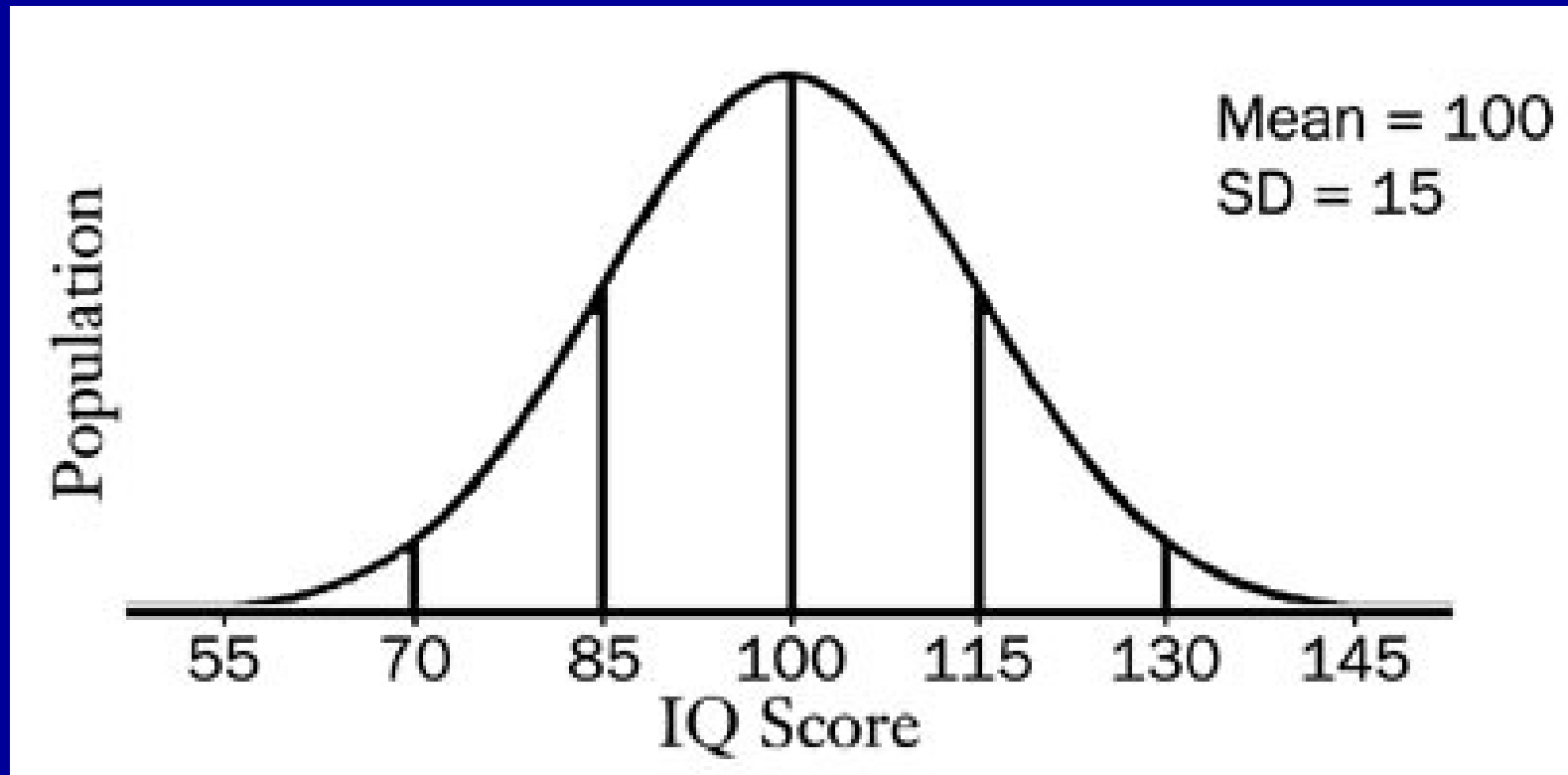
- Social functioning
- Peer relationships
  - Problematic relationships during childhood and adolescence impact on healthy emotional adjustment
  - Cognitive impairments
  - Social skill deficits
  - Physical appearance

# What is different about childhood outcomes

- Length of time since diagnosis is an important consideration, when assessing long-term effects.
- Pattern of neurological and cognitive impairment might not be stable.
- Vulnerable to continuing development.
- Social environment
- Emergence of new skills

- It can be difficult to separate neuro-cognitive effects of treatment from other non-biological matters such as time off school, loss of environmental and social stimulation for example.

# IQ Standardisation



**Borderline - Low Average - Average - High Average - Superior**

# Results – Complete Database

Assessment	Mean	Std. Dev.
Verbal Comprehension	97.28	19.28
Perceptual Reasoning	<b>92.73</b>	20.59
Processing Speed	<b>90.48</b>	17.79
Full Scale IQ	94.98	19.67
Mathematical Reasoning	98.53	19.90
Numerical Operations	95.68	18.67
Word Reading	99.74	19.52
Reading Comprehension	95.78	20.88
Spelling	98.33	18.20
Learning	<b>91.57</b>	19.67
Attention and Concentration	97.96	20.89
General Memory	<b>91.24</b>	20.32

# Educational Advice and Support

- Cognitive profile of child's strengths and weaknesses
- Linking behaviour to cognitive changes
- Classroom management and advice

# Rehabilitation

- School is the major source of both cognitive and behavioural rehabilitation
- Transition into school and from primary to secondary school – new difficulties may become more apparent
- Children who miss school at transition into secondary school are vulnerable

# Why is it important to think about rehabilitation

- A structured rehabilitation programme can help prevent the development of secondary problems such as academic or social/ behaviour problems
- It is important to anticipate potential areas of difficulty and be pro-active when considering rehabilitation needs of the child.
- Reintegration into school is very important process.

# Reintegration into school

- School re-entry is usually eagerly anticipated milestone
- Schools have a key role in securing and providing appropriate support and services for a young person.
- Thorough planning is vital to successful re-integration and inclusion into school.
- Difficulties can be subtle – child may not fulfil criteria for an assessment of special educational needs.

# Reintegration cont.

- Educational Provision tends to be based on evidence of failure rather than potential difficulty
- Problems emerge at unpredictable times
- Needs can increase over time
- Statement of Special Educational  
specific advice concerning impact of child's condition on opportunity for learning and maintaining appropriate links with peers

# Statement of Special Educational Needs

- Criteria for Assessment
- School factors
  - persisting special educational needs
- Child Factors
  - significant impairment
  - significant learning difficulty
  - Significant emotional and behavioural difficulty
- Resources
  - Educational needs may call for special educational provision

# Cognitive rehabilitation

- Mix of direct training, personal and environmental compensation
- Over learning may be necessary
- Should be appropriate to child's needs e.g. stage of recovery, developmental and chronological age.

# Cognitive Rehabilitation

- Specific approach = aims to improve particular cognitive skills
- Compensatory skills – use areas of strength to compensate for weakness
- Environmental manipulation – providing structure and cues in environment.
- Psycho-social or behavioural problems and cognitive problems are more likely than physical impairments to create long term difficulties.

# Environmental compensation/ manipulation

- Providing a calm, non-chaotic, quiet environment
- Structured routine
- Labelling doors etc
- Providing a visual timetable
- Specific places for personal items
- Using signs to designate areas
- Checklists

# Errorless learning

- Children with low self esteem, know they are different or have changing skills.
- Start tasks at a level where the child can succeed
- Give feed back.

# Fatigue

- Important consideration in all attempts to introduce rehabilitation for children who have an acquired brain impairment

# What is Processing Speed?

- Speed of thought
- Transferring thought into actions (i.e. writing quickly/completing work in timed conditions)
- Remembering things
- Difficulties 'getting thoughts out/down on paper'
- Anxiety/Panic
- Getting ready in the morning
- Decisions – over-thinking
- Perfectionism

# Processing Speed:

- How quickly and efficiently a person processes information in their head
- This can often result in slower physical responses due to slower translation of thoughts into actions
- Identified as an important domain of cognitive functioning
- An interplay between working memory, processing speed and reasoning

# Timed Training Tasks

- **Letter cancellation tasks**
  - From a series of random letters cancel out highest (or lowest) letter in alphabet ordering
- **Number cancellation tasks**
  - From a series of random numbers cancel out lowest (or highest) number
- **Comprehension task**
  - Read a story and answer questions as quickly as possible
- **Yellow pages search tasks**
  - Search for specified contact numbers from pages from a contacts directory
- **Handwriting tasks**
  - Make notes as quickly as possible from a tape recording
- **Listening Tasks**
  - Complete the letter or number cancellation tasks whilst listening to a tape of a story, random letters or numbers being read.
- **Homework tasks**

# Memory and learning problems

- Difficulty in learning and retaining new information
- Difficulty integrating new learning in existing knowledge
- Difficulty generalising new learning.

# Attention

- Failure to sustain attention
- Attention to non-essential details
- Inability to inhibit response to external details
- Inability to inhibit response to internal distractions
- Inability to do two things simultaneously
- Poor attention concentration and highly distractible behaviour – concerns about safety and learning

# Visuo perceptual and spatial problems

- Poor writing and drawing ability
- Difficulty acquiring written skills
- Poor sports skills
- Poor constructional skills
- Can lead to restricted output

# Physical / Sensory Impairments

- Physical changes can be obvious or hidden but will impact on the child's functioning and ability to access learning.
- Neurological effects – hemiparesis
- Visual impairment, including restricted visual fields, vision disturbances, blurred or double vision, light sensitivity
- Hearing impairment hearing disturbances, tinnitus (ringing in the ears), noise sensitivity, hearing loss

# Behavioural and Emotional Impairment

- Social interaction / social communication difficulties can be helped with social skills training using Social Stories, Comic Strip conversations
- Referral to CAMH teams

# Key points

- A Full Scale IQ within the normal range does not mean the child is free of cognitive impairments.
- School is the focus for intervention both educational and social
- Important to be proactive – child's learning and behavioural profile may not be stable

# Contact details

- [gumled@gosh.nhs.uk](mailto:gumled@gosh.nhs.uk)

# Cognitive outcomes

Children have been reported to be experiencing learning difficulties including:

- below average IQ scores
- poor concentration
- visual-motor integration difficulties
- reduced memory
- comprehension difficulties
- (mathematics, reading, and spelling)
- slow processing speed

(Shatz 2000; Steinlin 2003; Peers et al 2005; Anderson et al 1997)