

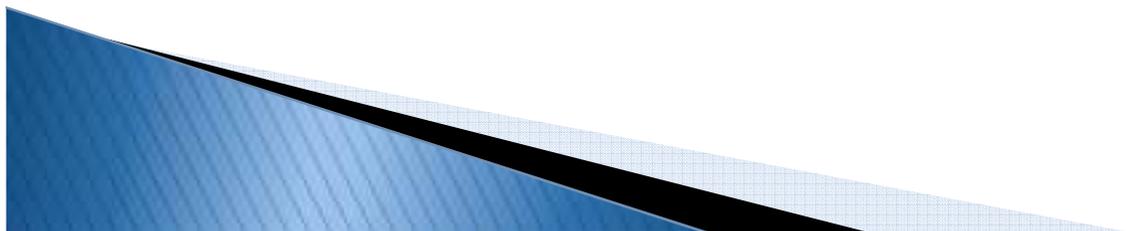
Psychological and Neuropsychological Impact of childhood cancer



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Outline

- ▶ The Psychological Support Team -who are we and what do we do?
- ▶ Consider the psychological impact of a diagnosis and then survivorship for families.
- ▶ Consider the cognitive consequences of childhood cancer.
- ▶ How we can help.



Psychological Support Team

- ▶ 2 Clinical Psychologists -1 working in the Brainbow team
- ▶ 2 Counsellor Practitioners
- ▶ 1 Assistant Psychologist working only in the Brainbow Team

- ▶ Working closely with the MDT team including Clic Sargent and wider teams in East Anglia

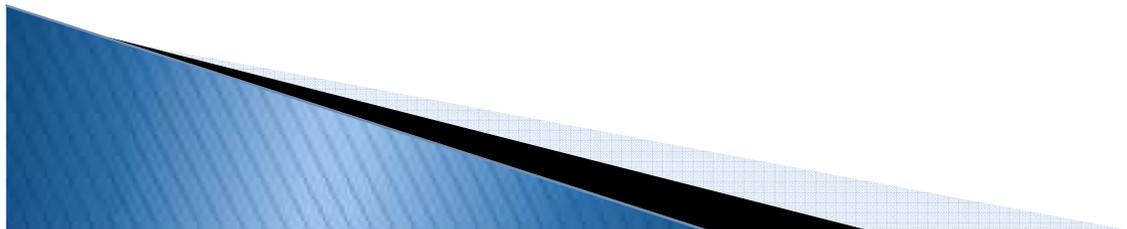
What do we do?

- ▶ Work with families, parents, children, siblings and groups.
- ▶ Joint working to facilitate family therapy, couple work or family work.
- ▶ Offer different approaches such as integrative counselling, Cognitive behavioural therapy, trauma focused therapy, systemic therapy, neuropsychological assessment and rehabilitation.
- ▶ Work with families from pre diagnosis to beyond end of treatment and bereavement.
- ▶ Support to address difficulties such as trauma, low mood and anxiety, coping, adjustment to illness, relationships, school difficulties, self esteem, social difficulties, cognitive impairment, grief work.

- ▶ Help Families cope with uncertainty
- ▶ Normalise feelings at all stages of their journey.
- ▶ identify those that need more help and refer to local teams.

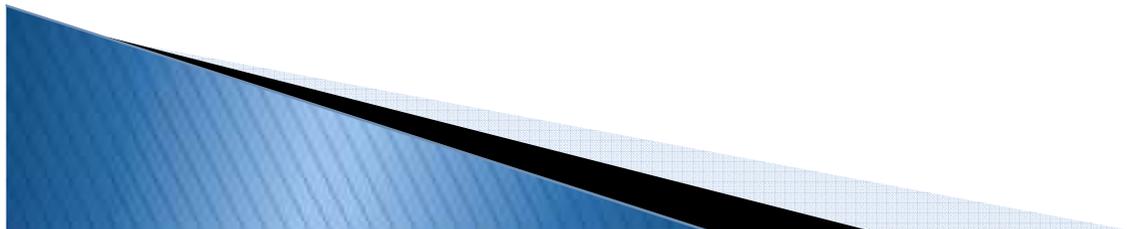
Impact of Diagnosis

- ▶ For the child with the condition and the family, there is uncertainty and concern about:
- ▶ The future in general and the condition in particular – will my child die?
- ▶ The long course of treatment, invasive procedures, surgery, chemotherapy and physical side effects - some maybe permanent
- ▶ Being away from home and other family support, missing school and friends
- ▶ Finances -how will we cope?



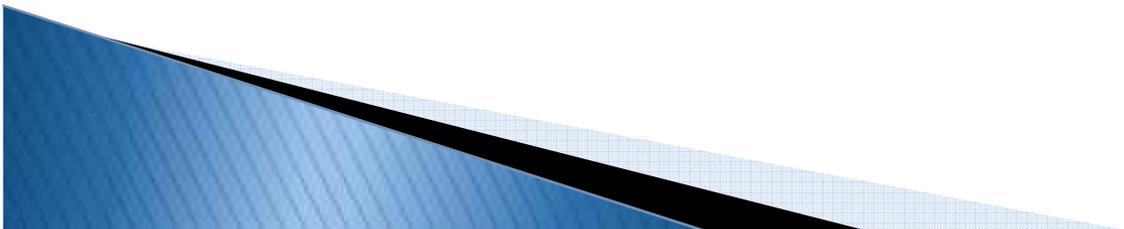
It's a family affair

- ▶ Childhood cancer is a non normative life event and an unnatural disaster in a family's development (Woznick and Goodheart 2002)
- ▶ A family's ability to cope is connected to it's ability to navigate the transition from the pre diagnosis 'old world' to the cancer dominated world being experienced. (Robinson Carroll and Watson 2005)
- ▶ The work:
- ▶ Undergoing treatment – curative – in the thick of it – turmoil, side effects. Often very physical rather than engaging with emotional.
- ▶ Maintenance / post curative – relief treatment has ended – emptiness gap –daring to hope they are safer. Facing what has changed
- ▶ Relapse – hopefully trial treatment – insecure future
- ▶ Pallative and end of life.



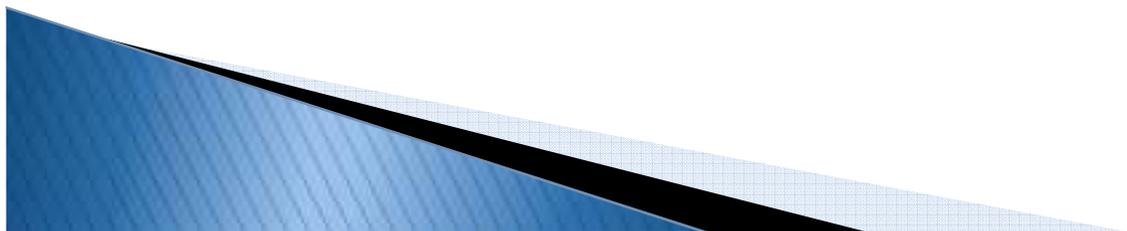
Challenges facing parents

- ▶ The challenges of adapting and surviving can make family members at risk to secondary trauma and other complications.
- ▶ With diagnosis begins the interrupted developmental flow of family life.
- ▶ It marks an abrupt transition from stability to a situation where previous 'rules' do not work.
- ▶ They can be shocked or stunned.
- ▶ Numb/cut off from feelings or what is going on – trauma block processing.
- ▶ Denial – unable to acknowledge what is happening
- ▶ After a few days they may have emotional reactions such as feeling: Scared, Angry, Guilty, Helpless, Sad, Tired



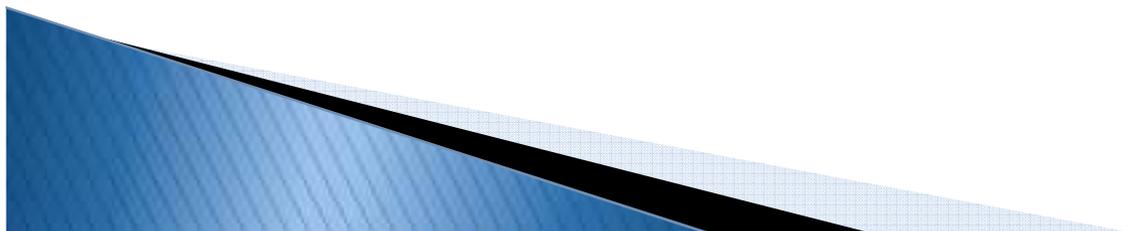
Research shows:

- ▶ **Rates of PTS: 68 % mothers, 57% fathers moderate to severe (Kazak et al 2005).**
- ▶ Feelings of uncertainty can be highest at the end of treatment
- ▶ Anxiety can continue up to 5 years post treatment
- ▶ Depression can continue for 5 years post treatment
- ▶ Post treatment rates of PTS can be between 10% to 42 %.
- ▶ Links between parental coping and child coping
- ▶ Importance of social support –and resilience
- ▶ What is asked of parents is much more than a normal parenting situation, careful not to pathologise parents reactions



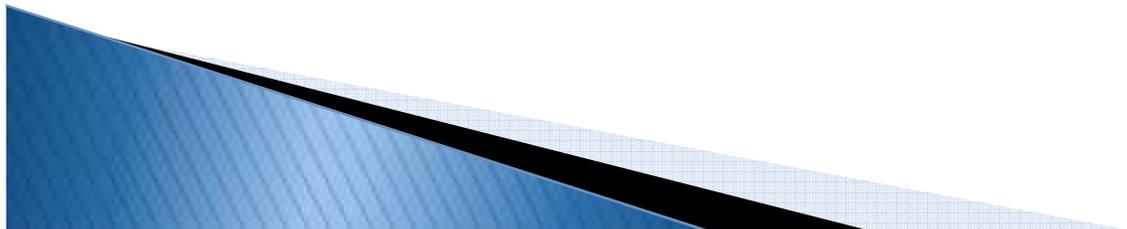
Impact on child or young person

- ▶ Coping with:
- ▶ Frightening and distressing, invasive procedures which happen almost immediately, surgery, recovery, may never have experienced staying in hospital before
- ▶ Witnessing parental distress
- ▶ Separated from siblings-can be long way from home
- ▶ Separation from friends and normal life
- ▶ hair loss
- ▶ Fear of dying
- ▶ Missing school

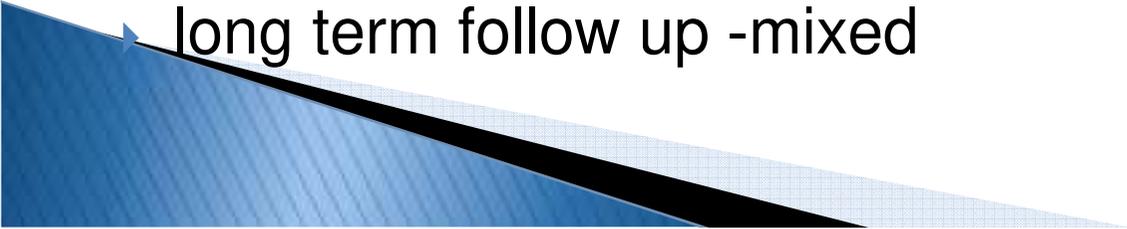


Child/young person emotional and behavioural responses:

- Resilience –
- Regression – how can they express painful feelings – make it easier for them
- Sleep disturbance-nightmares
- Fear, anger, sadness, withdrawn. May hide feelings from parents-protect parents
- Guilt feelings about disrupting family life
- PTS symptoms
- Self image concerns –avoidance of school
- Concentration and attention issues-prolonged



Impact on siblings

- ▶ Often separated from family for prolonged periods, never sure if parent will be at home
 - ▶ May not always have the information to help them make sense of what is happening
 - ▶ May face lots of playground questions
 - ▶ Feelings about loss of identity for sibling and also family identity changed.
 - ▶ significant subset experience post traumatic symptoms (shock, fear, worry, sadness, helplessness, anger, guilt) not consistent
 - ▶ School difficulties are also evident within 2 years of diagnosis
 - ▶ long term follow up -mixed
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Emotional impact? What helps?

- ▶ For children - support parents so they can support their children, access to play staff, Clinical Psychologist, Counsellors, groups, social media, friends.
 - ▶ School: keep in touch, support siblings, support, offering mentor or school counselling, good communication, buddy systems, time out card, homework- support separation anxiety.
 - ▶ About equipping them with information that can help them with illness. Giving time to acknowledge anxieties - both problem solving and providing information happens at stages various stages to help the turmoil.
 - ▶ How much to stay connected with outside world – end of treatment.
 - ▶ Practical support for families
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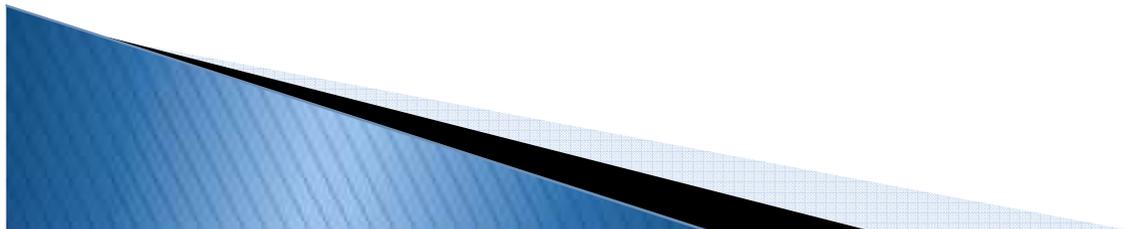
The Neuro cognitive impact of cancer

- ▶ Cognitive impact of a brain tumour
- ▶ Cognitive impact of other cancers
- ▶ How can we help?



Cognitive impact following a brain tumour

- ▶ Depends on site of the tumour, age at treatment, type of treatment.
- ▶ Radiotherapy effects can be seen from 1 year. Evidence that for younger children it is immediate and for older there is a delay of about 2 years.
- ▶ Research suggests a slower rate of knowledge acquisition. So they can still learn but not at the rate they previously did.
- ▶ What is effected?
 - ▶ General problem solving ability.
 - ▶ Attention and concentration
 - ▶ Memory-working memory, verbal memory deficits, both encoding and retrieving information.
 - ▶ Processing speed (do simple cognitive tasks speedily)
 - ▶ Executive functioning –planning, organising, initiating, emotional regulation



▶ **Attention and concentration**

- being easily distracted
- finding it hard to focus on a task -sustained attention
- difficulty switching attention





- **Memory**
- verbal memory -both storing and/or retrieving information
- working memory-auditory -cannot remember instructions, maths sums, this can effect reading, spelling skills and reading comprehension.

Executive functioning

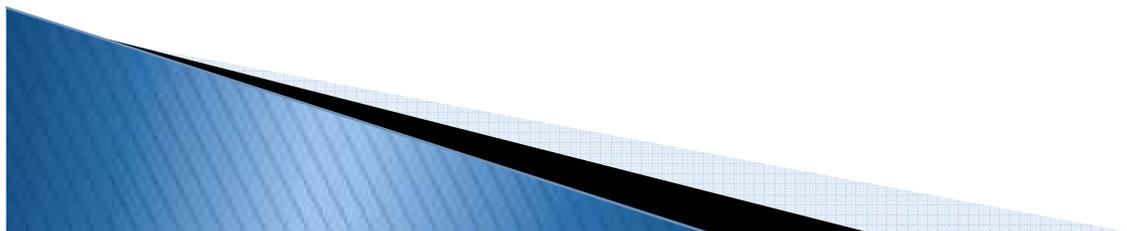
- Planning tasks, regulating emotions, multi tasking, applying previously learnt information.
- Difficulties organising belongings
- Inability to shift from one task to the next

Information processing speed

• processing speed ability: e.g. can't copy down information in time, follow teacher's instructions or manage the information required for a more complex task at speed. Sometimes a child's ability can be underestimated as they just need longer to think and complete. Can also cause difficulties with peers.

Impact on cognitive ability for children with other types of cancer

- ▶ Studies have explored the impact of leukaemia on cognition.
- ▶ Some studies have found evidence that some children have cognitive difficulties following treatment such as:
 - ▶ Auditory verbal attention deficit and verbal learning
 - ▶ Working memory
 - ▶ Processing speed



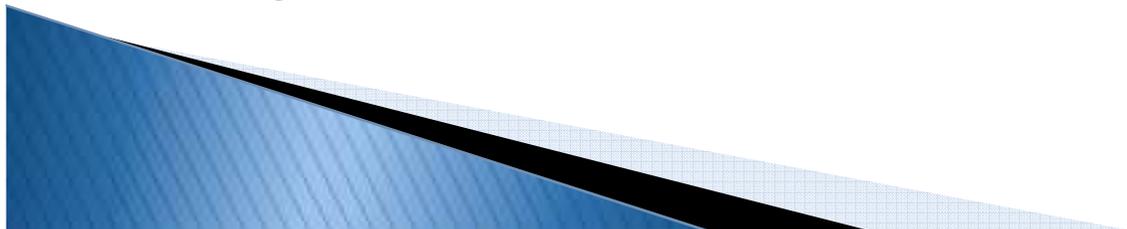
How can we help?

- ▶ Evidence suggests early intervention? Continuation of education –hospital teachers vital
- ▶ Assessment-identify the problems
- ▶ School can help promote academic development during treatment.
- ▶ **Helping with Attention problems:**
- ▶ Seated at the front
 - Breaks -comfort breaks
 - Reminders to stay on task (prompts, visual)
 - Breaking down tasks into small manageable steps-can use tick charts
 - Older children and more able children may be able to learn self monitoring skills.
 - Visual prompts can be helpful for both memory and attention difficulties



Memory issues

- ▶ What sort of memory issue? Encoding, Storage or retrieval, what about recognition memory? Rate of learning? Working memory?
- ▶ Encourage use of memory tools such as diaries, checklists, memo boards, dictaphones,
- ▶ Repeat information frequently –instructions and on task prompts
- ▶ Teach to all sensory modalities
- ▶ Back up verbal information with written instructions, or pictures if you can give them a copy of the lesson that will be shown on the board.
- ▶ Take away extra demands on cognitive processes such as copying, writing, reading?
- ▶ Use mindmaps –pictures to record and learn
- ▶ Break down complicated pieces of work-help them plan the stages
- ▶ More able children –encourage them to develop their own strategies



Problem solving difficulties

- ▶ Identify if a child has non verbal or/and verbal reasoning difficulties
- ▶ Present information in both verbal and visual ways
- ▶ Continue 'hands on' learning
- ▶ Move from concrete to abstract



Information processing

- ▶ Give more time
- ▶ Expect less volume of work but not necessarily less quality
- ▶ Give the child other ways of recording information eg scribe, computer, copies of lesson plans, creative ways.
- ▶ Give more time to answer questions
- ▶ Help with social skills-provide training

Processing speed

- ▶ Reduce the need for copying and multi tasking
- ▶ Allow child to use a computer -teach computer skills
- ▶ Creative ways to present work -
- ▶ Expect less quantity but not quality.

Can we improve cognitive functioning?

- ▶ Brain training?
- ▶ Cogmed
- ▶ Exercise programmes



Improve self esteem

- ▶ It is not all about academic achievement
- ▶ Find activities the child enjoys and nurture –
- ▶ Encourage extra curricular activities
- ▶ Nurture friendships
- ▶ Be sensitive to cancer related information
- ▶ Look out for signs of low mood and anxiety



School is vital

- ▶ School is one of the stable parts of family life
- ▶ Provides an essential role for the whole family
- ▶ Provides routine
- ▶ Support from the child's peers
- ▶ Support from the teachers
- ▶ Communication to other families about the situation
- ▶ Support for sibling during school term
- ▶ Support patient when back in school

