

Practical strategies for managing the effects of an adult brain tumour

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Impact of diagnosis

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Normal reactions can include:

- Shock – numb
- Some people even feel relief when diagnosed
- There is no RIGHT way to respond to a diagnosis
- Some people want a lot of information, others don't
- Other emotions that people may experience and types of reaction include, but are not limited to:
 - Fear and uncertainty
 - Anger
 - Blame, guilt, resentment
 - Withdrawal and isolation

Types of problems

- Depression which interferes with demands of treatment
- Depression relating to prognosis
- Depression relating to negative thoughts about self-worth / appearance
- Anxiety associated with clinic attendance / treatment
- Avoidance of discussion about cancer and its impact
- Anger and irritability with family / friends / staff
- Problems with continuing daily routine
- Sexual problems

Helpful strategies

- Simply being able to talk can reduce distress
- Being able to 'manage' other people's responses
 - *You must be positive*
 - *You must fight it*
- Awareness of the possible problems
- Knowing how to access appropriate information
- Feeling able to ask questions
- Knowing that you don't *have* to be depressed
- Being allowed to have hope
- Getting professional support

Helpful strategies for family members

- Learn how to listen
- Take your lead from your family member
- Know that you won't *create* a problem by asking a question
- Avoid trying to 'fix it' – you can't
- Look after yourself
- Have your own support
- Try not to feel guilty about needing your own space, feeling upset or getting cross

Psychological issues relating to treatment and tests

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- Anxiety about going for treatment
- Anxiety about the type of treatment
- Uncertainty about the outcome of treatment
- Anxiety about side effects
- Difficulties with the process of treatment
 - Needle phobia
 - Seeing a different person every time
- Fear while waiting for scan / test results

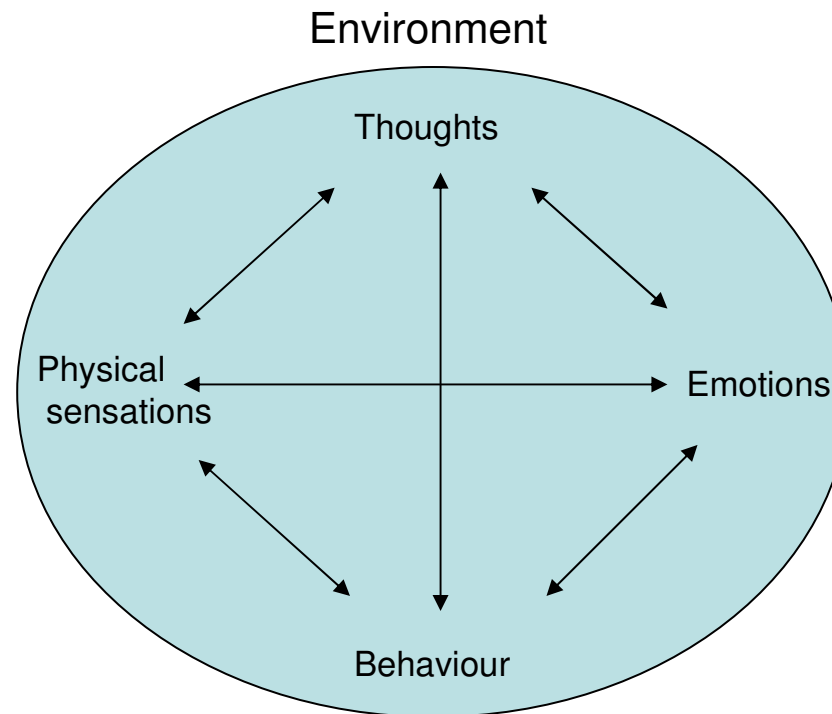
Panic attacks



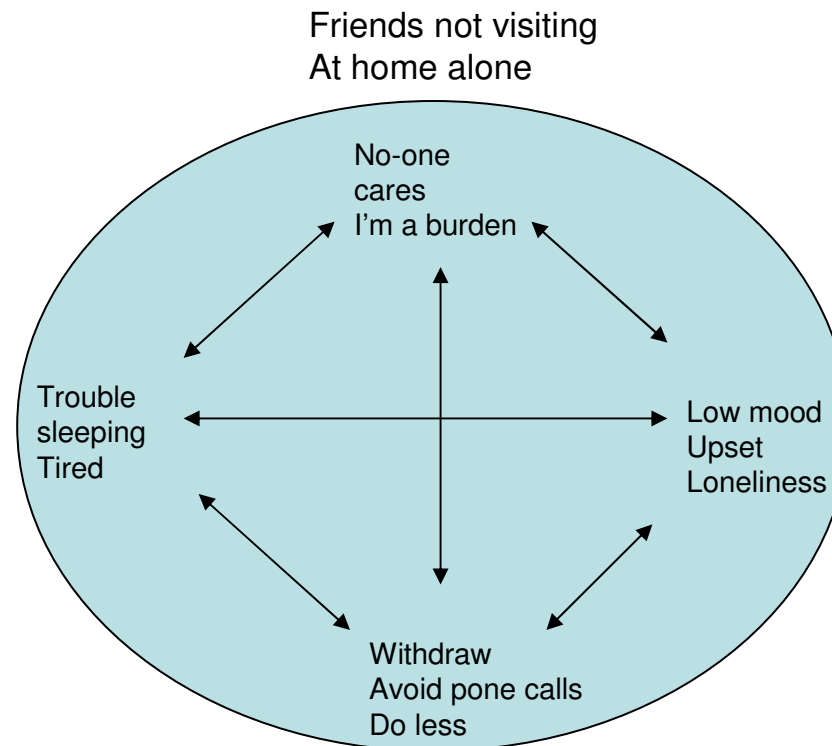
Helpful strategies

- Complimentary therapies
- Relaxation / visualisation / meditation
- Specific phobias
 - Needle phobia
 - Phobia relating to radiotherapy masks (see handout)
- Strategies for managing uncertainty (see handout)
- Psychological support
 - eg. CBT

Cognitive behaviour therapy



'Socialisation to the model'



Thoughts	Emotions	Behaviour	Physical sensations	Environment
<p>I'm going to make a complete mess of this</p> <p>This presentation might not be what they wanted</p>	<p>Anxious</p> <p>Embarrassed</p>	<p>'Nervy'</p> <p>Seek reassurance</p>	<p>Sweaty palms</p> <p>Dry mouth</p> <p>Butterflies</p> <p>Red face</p>	<p>Hostile audience</p> <p>Clearly bored and tired</p>

Most common impediments:

Motor difficulties

Cognitive deficits

Behavioural problems

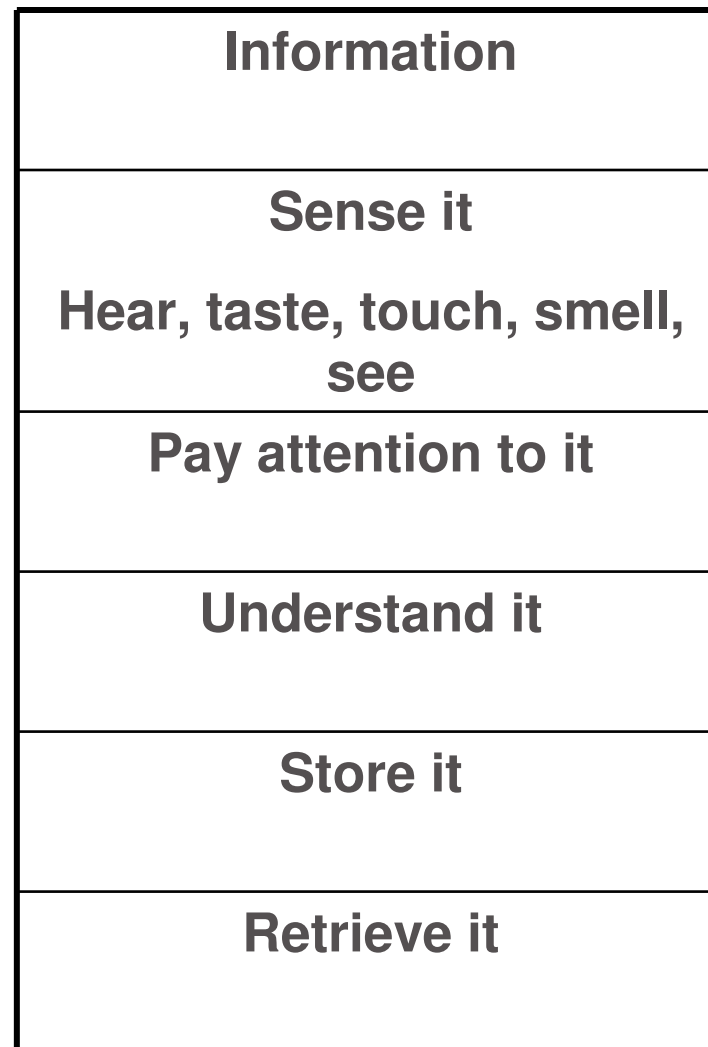
Emotional problems

- Motor difficulties
 - Physiotherapists
- Cognitive deficits
 - **Memory**, language and perceptual impairments
 - Speech therapy
- Behavioural problems
 - Shouting, swearing, disinhibition
- Emotional problems
 - Anxiety, depression, fear

Memory difficulties

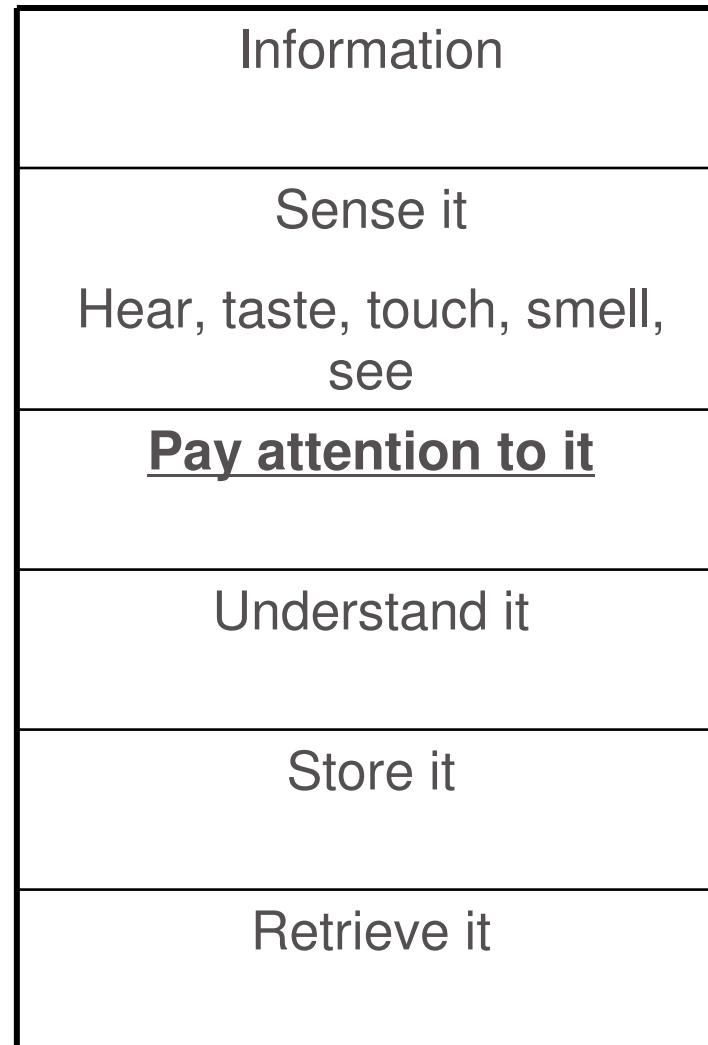
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- Impact can be from the tumour itself or from treatment



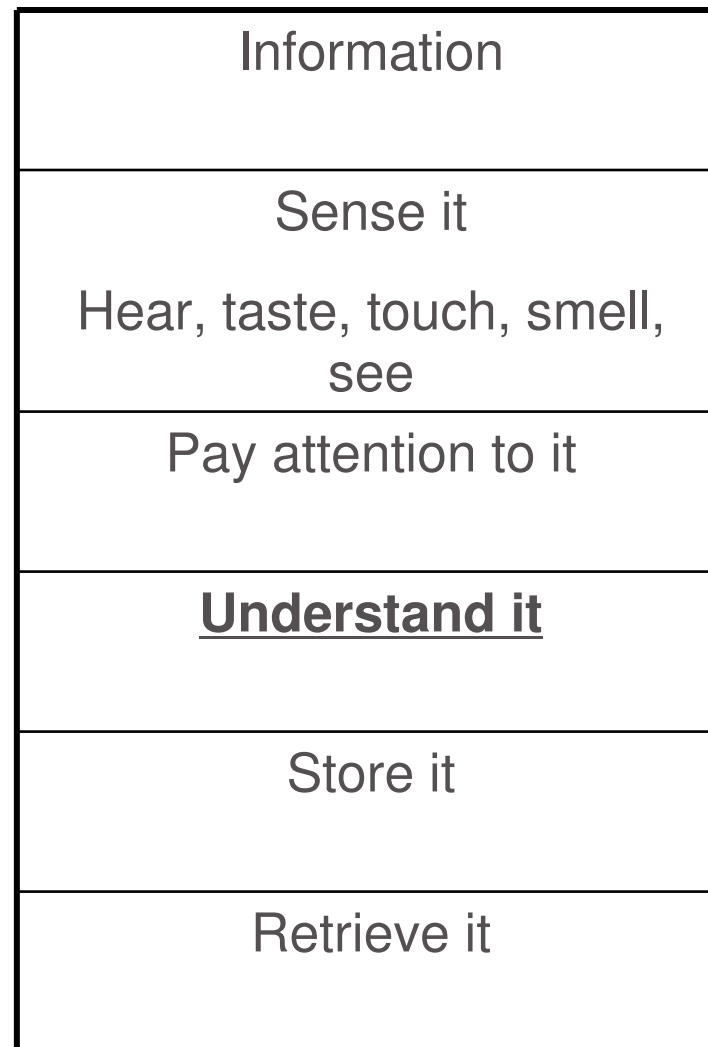
Improving attention

- Get enough sleep
- Plan ahead
- Take breaks
- Regularly change tasks to maintain interest
- Do the least interesting things first when most alert
- Minimize distractions
- Gentle background music
- Focus on one thing at a time



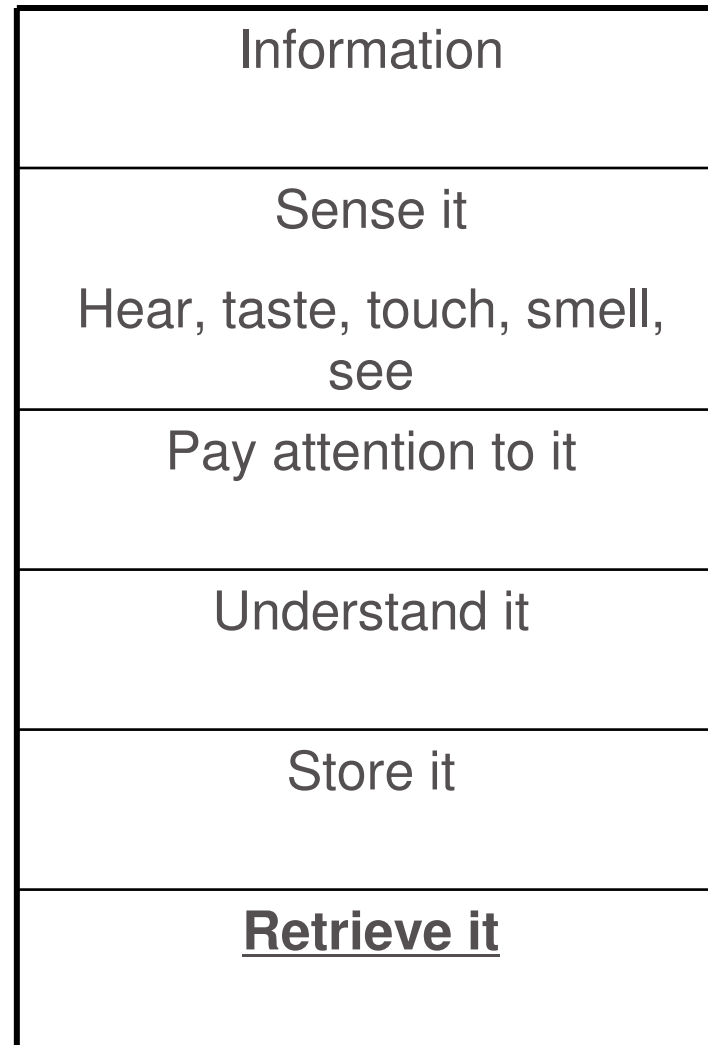
Improving understanding

- Ask questions
- Actively listen
- Ask people to repeat information or to go through it more slowly
- Paraphrase and repeat



Improving retrieval

- Use cues and reminders
 - Diary
 - Photos / pictures
 - Lists
 - Calendar
 - Electronic diaries
 - Other people should refer to these systems
 - Alarms can be useful but can just be a reminder that *something* needs to be remembered



General tips for improving memory

- Crosswords
- Puzzles
- Reading
- Writing

- Further points to note:
- Memory therapy – Brain injury units, neuropsychology, occupational therapy
- Don't be too hard on yourself

Personality changes

Behavioural & emotional
problems

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Personality changes

- Personality = underlying characteristics including temperament, behaviour, emotional and cognitive factors
- Changes could be due to the tumour itself or treatment
 - Steroids – people can appear wired or edgy, manic and restless, anxious and depressed
- Changes can be linked to changes in self esteem and body image
- Can be very difficult and upsetting
- Useful to have a 'base line'
- Useful to observe and record changes, and any triggers
- For family members it is very important to remind yourselves that it's not necessarily done on purpose

- Depression
- Anxiety
- Apathy
- Irritability
- Anger
- Confusion
- Paranoia
- Agitation
- Insomnia
- Mood swings
- Aggression and violence
- Impulsivity
- Lack of inhibition
- Acting out
- Noncompliance
- Being socially inappropriate
- Emotional outbursts
- Childish behaviour
- Impaired self control
- Impaired self awareness

- Inability to take responsibility or to accept criticism
- Inappropriate sexual activity
- Alcohol or drug abuse

Depression, anxiety	Psychotherapy, CBT, medication
Apathy	Make a plan, give choices – on condition that a choice has to be made
Anger	A.N.G.E.R A nticipate triggers N otice signs of rising anger G o through temper regime E xtricate self R ecord how you coped
Acting out Being socially inappropriate	Reinforcement and reward

- Minor illness, drug or alcohol use and fatigue can all make personality changes seem worse
- Brain is plastic
- Changes may not be permanent
- For family members to assist insight can be useful
- Talking about it can help

Mood swings

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- Can be triggered by many things
 - Daily events
 - Frustration
 - Feeling unwell
 - Feeling fatigued
 - Worry and anxiety
 - Lowered self esteem and self confidence
 - Loss of independence
 - Shame and guilt

Helpful strategies

- Talking
- Listening
- Being kind to yourself
- Taking time out
- Setting achievable goals
- Recognising achievements
- Having a routine and structure to days (see handout)
- Being involved and engaged in activities
- Being aware of unhelpful thinking patterns (see handout)

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Anyone affected by cancer, from anywhere, at any stage

Drop-in

- Monday – Friday
- 9am – 5pm

- Cancer support specialists
 - Information
 - Support
 - Guidance on accessing the Maggie's programme

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