Supporting families with post-TBI neuro-behavioural changes

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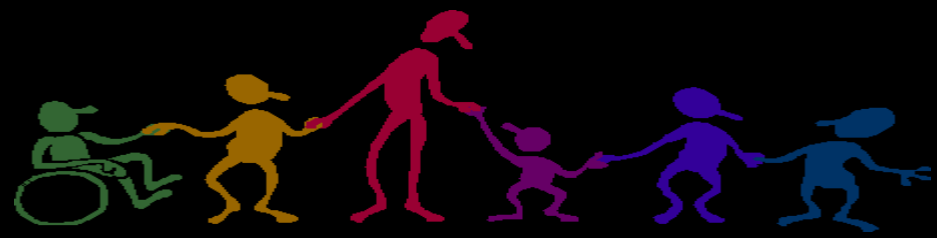


Thank you for inviting me

- Consultant Clinical Neuropsychologist
  - Private practice – Oxford Neuropsychology Practitioners (ONP)
  - NHS - Oxford Centre for Enablement (OCE Level 1 NHSE neuro-rehabilitation unit) - Lead for OCE Clinical Neuropsychology and Family Support Service
- Specialise in working with people who have acquired brain injury and progressive neurological conditions, their families and carers
- Expertise in working with children affected by neurological illness / injury in a close family member (first UK NHS service for child relatives)

Post-TBI neuro-behavioural changes & families :

- What changes after TBI and why? – a brief overview
- Why is it important to focus on this?
- Impact on the family - including children
- Resilience (NOT deficit) focused approaches to supporting families to cope with the changed relative after TBI
- Tom and his family – what can be done? What would I do?

What changes after TBI and why?

- Neuro-behavioural changes - i.e. alterations in behaviour arising from impairments in cognition and emotional regulation - very common after TBI – "personality" changes
- They are on a continuum - subtle to challenging
- Some behavioural problems will resolve quickly, others will take longer, many are life long - some people may need specialist support / residential care to maintain their safety e.g. Kemsley Unit St Andrews
- *Dynamic process – behavioural problems affect and are affected by the environment and those in it*

What changes?

- Social awareness / social cognition – e.g. Egocentricity, loss of empathy, difficulty recognising / responding to social cues, may seem tactless, rude, sexually inappropriate behaviour, not see the joke, disclose personal information too freely, behave in a ways that may seem childish or selfish, seem unappreciative of family / staff, appear self-absorbed

- insight into problems related to their brain injury (e.g. may deny problems or argue the point), see themselves same as before, not understand why they can't do certain things (e.g. drive) & get angry with others, have unrealistic goals and expectations

- Memory – confusion, disorientation, confabulation

What changes?

- Ability to self-monitor - e.g. not aware they are talking too much, changes in self-care (poor hygiene etc)
- Thinking / reasoning – typically becomes rigid / concrete, impaired problem solving, can be very literal, not see the joke , perseveration or repetitive behaviours have difficulty turning thoughts from one topic to another, getting stuck on one response
- Tolerance – may appear non-compliant, uncooperative, especially with rehabilitation activities (compounded by reduced insight)

What changes?

- Attention & concentration – e.g. easily distracted, problems dividing attention; can become quickly 'mentally' overloaded - fatigue and irritability can result

- Ability to control impulses – ideas / behaviours occur without evaluation, –e.g. can't put the brakes on, risky / unsafe behaviours, self-injury, make rash decisions, appear impatient

- Activity levels –
  - Reduced – apathy, inertia, appear to have no motivation or initiation, may seem lazy/ disinterested , become withdrawn, lost their spark,
  - Increased – restless, agitated, feeling as if they have more energy, complain of boredom

What changes?

- Emotions / mood - TBI greatly increases the risk of the survivor developing psychiatric/ psychological problems such as:
  - Anger – ranging from increased irritability to verbal and physical aggression , short fuse,
  - Increased sensitivity to criticism,
  - rapid shifts between mood states
  - PTSD
  - depression,
  - Anxiety disorders (including OCD)
  - Psychosis
  - control of emotions, e.g. Lability of mood, increased swearing

Why do changes occur?

- Multi-factorial – dynamic interaction of any number of factors at a given time (hence the variability).

- Requires detailed neuropsychological and functional assessment and formulation. Must consider –

  - Organic factors: brain based changes arising out of damage to key areas such as the frontal lobes and
  - injury factors: site/extent of lesions, length of coma etc These interact with
  - Pre-injury factors: history of risk taking, pre-existing LDs, education, employment, family background, previous personality and

Why do changes occur?

- post injury factors – such as symptoms / functional limitations / losses: e.g. pain, fatigue, sensory sensitivity, impaired cognition, reduced physical mobility, lack of independence, communication impairments, seizures, loss of relationships, work, ability to drive

- Survivor's psychological adjustment / coping with the injury and its consequences – and how they understand their problems; depression, grief, low self-esteem, loss of self confidence – play role in development of behavioural problems,

- **Behaviour / responses of others – often overlooked! Family and staff response to behaviour / hospital environment**

Why focus on behavioural change?

- Neuro-behavioural problems are reported as most debilitating by survivors
- Research repeatedly shows that they are the key factor in determining a person's long term social, vocational and functional recovery ; Interfering with an injured person's ability to: live independently in the community / return home, be with their family safely, to work, study or to have good relationships with others
- From a family perspective – these changes typically disrupt all aspects of normal family life; when these behavioural changes are extensive **the whole family is likely to suffer emotionally**

Why focus on behavioural change?

- Decades of research has repeatedly shown that - neurobehavioral disturbance in a TBI survivor is the strongest predictor of family distress and poorer family functioning
  - i.e. level of family distress is related to neurobehavioral changes **more than any other post-TBI symptom**

- However – this is not a one way process because: Family emotional status strongly influences patient outcome

- If left unaddressed these issues WILL reverberate around the family AND professional system leading to:
  - increased tension, distress and poorer outcomes for ALL.

Why do neuro-behavioural changes present such an adjustment challenge for families?

- Neuro-behavioural problems typically result in profound loss and change for survivor & family – "strike at the core"
  - Losses go well beyond the physical & practical: affecting identity, roles, relationships, belief systems, communication patterns, meaning, purpose, life plans...
  - Leaves families searching for answers to very difficult questions "will he ever be himself again?"
- Lack of clarity re prognosis:
  - Recovery markers often inaccurate & misleading ("all recovery happens in the first year")
  - or no guidance given re timelines leaving families adrift and unsure – they don't know what's normal for TBI or what to expect

Why do neuro-behavioural changes present such an adjustment challenge for families?

- Fluctuating capabilities / unpredictable nature of neuro-behavioural problems: “play tricks with your mind”
  - Attempts to adapt to “new” normal disrupted by “behaviours” that can seem to come and go
  - Creates more uncertainty – families ask whether these behaviours are “really from the brain injury” ; he can keep his temper when he wants to!”
  - Adjustment to the “new” changed person disrupted by momentary glimpses of the “old” familiar person

For families this means:

- Having to hold competing viewpoints about the survivor / situation (e.g. “he is gone, yet remains; I’m glad she survived – I resent the burden”)
- Wishing to mourn but there is no death ; they are grieving while the “lost” person is still present
- They struggle with very dark emotions (“I wish he’d died”) – especially in the long term (not good news when we know that family response is related to survivor outcome & rehab effectiveness)
- At the same time we expect them to carry on, work alongside us, make decisions, plan ahead, work with legal teams....amidst considerable uncertainty and distress

Families tell us

- “it’s like living with a stranger”
- “he’s more like my child now than my husband”
- “I miss us - how we used to be with each other”
- “Here’s a picture of my real mummy”
- “she’s an embarrassment in public”
- “There’s not a name to describe his role in our family now”

- They may talk about the relative in the past tense (do we promote that in how we ask questions?)

- Survivors lack of psychological presence in the family combined with distressing post-injury behaviours can lead to significant family stress

Issues for couples

- Particularly vulnerable to the unique loss of
  - "us" – life partner, sexual partner, co-parent, friend
  - Security
  - Connection / attachment
  - Future life plans

- Core of the relationship can start to erode masked by the remaining fragile exterior shell (Godwin et al 2014)

Reading that I recommend to families

- "...she almost died. If she had, my life would have been easier. I would have grieved the loss and then gone back to whatever I was doing. In time I would have found another love. But she didn't die...though the person who survived is someone else; someone other who carries with her echoes of the lost one who was my wife" by Tom Gallant: A Hard Chance (2005)

- "how can I explain the personality oddities of brain injury to people who think Alan is the same as he was before? I ask for Bill's advice. "Just tell them to imagine the things they hate about their spouses most and then multiply that trait by a hundred times "he advises. How true" By Cathy Crimmins: Where is the Mango Princess (2000)

Issues for child relatives when a parent has neuro-behavioural problems

- Neglected group – but at risk for adjustment problems like adults
- They experience loss of parental role model
- 'Loss' of the non-injured parent
- Increased exposure to distressing behaviours of the injured parent; emotional distress of other relatives
- May be at increased risk of harm (reduced parenting abilities in parent with ABI; effects of post-injury behaviour

Issues for child relatives

- Vulnerable to misunderstandings about neuro-behavioural problems
  - "he can't remember 'cos he hurt his brain..but he shouts and swears as he just wants to be horrible to us"
  - "maybe she got sick because I was naughty"
- Loss of natural place within family e.g. Children as carers; "daddy acts silly all the time – like a baby"
- Little or no life experience to draw upon and few specialist NHS services to support them (see Daisley & Webster 2008)

The impact of these challenges on family members

- Vast literature spanning decades points to the typically devastating impact on **adult relatives (less research on children):**
  - Depression,
  - Anxiety
  - Anger
  - reduced functioning
  - Inability to make decisions
  - Sleep disorders
  - problems coping,
  - exhaustion,
  - feeling tortured / tormented, trapped
  - Loss of control
  - Hopelessness

Family emotional reactions (Mauss-Clum & Ryan 1981)

	Mothers	wives	survivors
depression	45%	79%	57%
irritability	55%	74%	53%
Anger outbursts	45%	63%	50%

Impact of these challenges on family members

- Literature on adults – consistently shows worsening of emotional problems over time in the context of neuro-behavioural problems
- Daisley (2002): found that child adjustment problems correlated with injured parents pre- and post injury behavioural problems
- Uysal et al (1998) and Pessar et al (1993) found that depression in BIP and NBIP – related to child problems –
- Adjustment problems in child relatives found to be a significant source of stress for non-injured parent (Harris et al, 2001)

The impact of these challenges on relationships

- Couples / family conflict
- Reduced / no intimacy
- Feelings of dislike of the injured person
- Spouses/ partners feel trapped
- Relationship strain and break down
- Divorce
- Can’t divorce – fear being judged
- Cessation of family rituals / celebrations
- Mistrust and anger towards health professionals due to dissatisfaction with effectiveness of rehabilitation

So how do we support families with neurobehavioral changes in their relative?

- Obvious! - Reduce the neuro-behavioural problems?
  - Most common approach – employing behavioural and cognitive principles to help modify / reduce behaviours that challenge; these are the best evidence based methods for changing behaviour.
  - Behavioural and cognitive rehabilitation interventions typically form the foundation of most in-patient neuro-rehab programmes (e.g. OCE, BIRT, Kemsley unit) – combined with pharmacological and psychotherapeutic approaches and environmental modification - with good outcomes – but not for all!
  - Not going to focus on these direct approaches today but rather on family approaches (which are sometimes lacking in services)

Traditional approaches with families

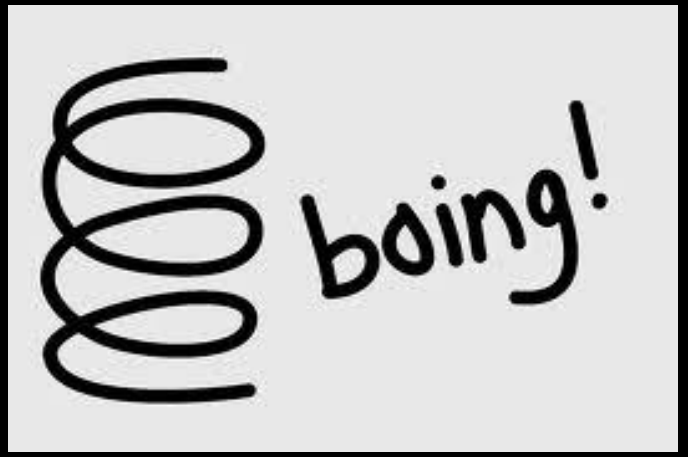
- Traditional rehab approaches tend to be problem focused - This has shaped services that tend to:
  - Focus more on deficits and problems to be "fixed" by professionals - strengths can be often overlooked
  - Ask families to provide accounts of "what's gone wrong" e.g. focus on when problem behaviours occurred, recording them, training families in behavioural methods – focus is typically on failure and not on success
  - Some survivors & families referred time after time fostering hopelessness
  - We decided to work in a slightly different way with families

Working towards living well with the changed relative

- **Resilience & strengths** focused approaches to supporting families to manage neuro-behavioural changes (alongside traditional methods)
- What is resilience?

Resilience

- Typical dictionary definition:
  - "the capacity to recover quickly from difficulties...toughness" (Oxford English Dictionary)
  - "bouncing back....."



Resilience

- But is it more than just bouncing back from adversity?.....

- Walsh (2006):
  - " struggling well, effectively working through and learning from adversity...and integrating the experience into the fabric of individual and shared lives"

  - Being able to withstand & rebound from life challenges, BUT CRUCIALLY.. ***emerging strengthened & more resourceful***....

Resilience

- Not just hardiness or bouncing back from a crisis but...BOUNCING FORWARDS!

Resilience focused approaches to helping families cope with neuro-behavioural changes

- Place families central to the recovery process – stresses that individual resilience and family resilience mutually influence each other & are inter-dependent
- Place emphasis on collaboration, openness and shared goals
- The focus is on family strengths, solutions & possibilities and **HOPE** - not problems (more acceptable and less painful for families)
- Target key relational processes important in resilience e.g. how families communicate with each other, their belief systems, how they approach & make sense of the challenge of the behavioural problems, how they problem solve....

Getting started: assumptions (based on Kreutzer)

- Most people want their old lives back – there WILL be anger that we can't do that
- All family members are affected by the changes in the injured person - but usually in different ways (this may not be explicit); some relatives will be easier to work with than others
- Well informed people do better – but typically people have received little or misleading information so may hold many misconceptions or have little faith in us
- There will be disappointment in amount of rehab provided and its effectiveness

Assumptions

- Families are doing the best they can with what they have but...
- Most feel as if they should be doing better, especially those living with LT effects (because the problems are still there)
- The family is the key rehabilitation / support provider long after we have gone - we must acknowledge this
- Family members typically exhausted and must take care of themselves to effectively support others (but can be difficult to convince them of this)
- These are shared with families as a starting point

What does this look like in practice?: Tom and his family

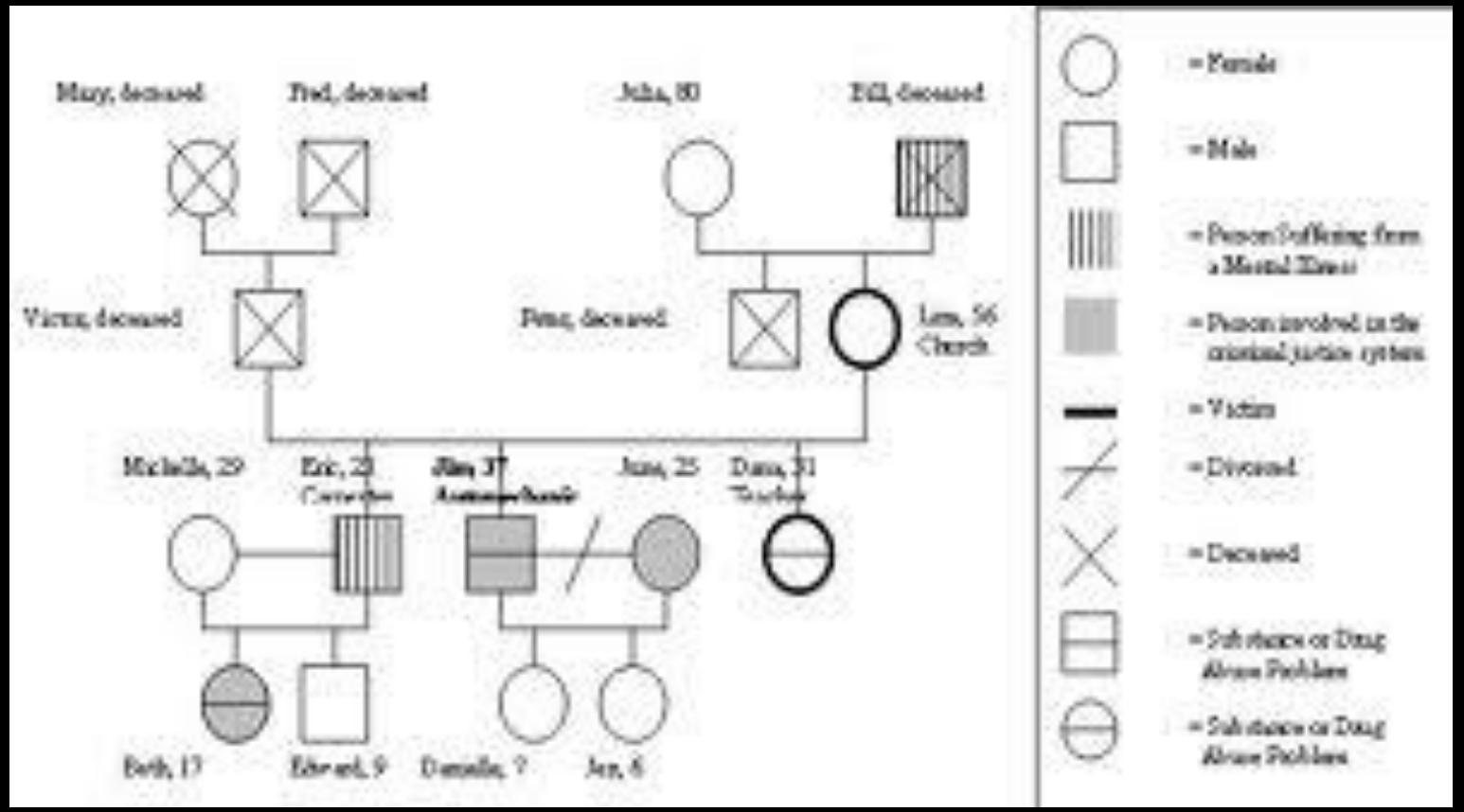
- Assessment:trad neuropsych and systemic
  - Who do we include? What methods do we use to understand neuro-behavioural changes and their impact
  - direct assessment of Tom – includes detailed neuropsychological assessment with Tom
  - Functional assessments from MDT and behavioural observations (with his knowledge and permission)
  - Then - therapeutic feedback to Tom and family – using motivational interviewing techniques (essential for engagement)

Widening the assessment – looking for family resources / stories of strength

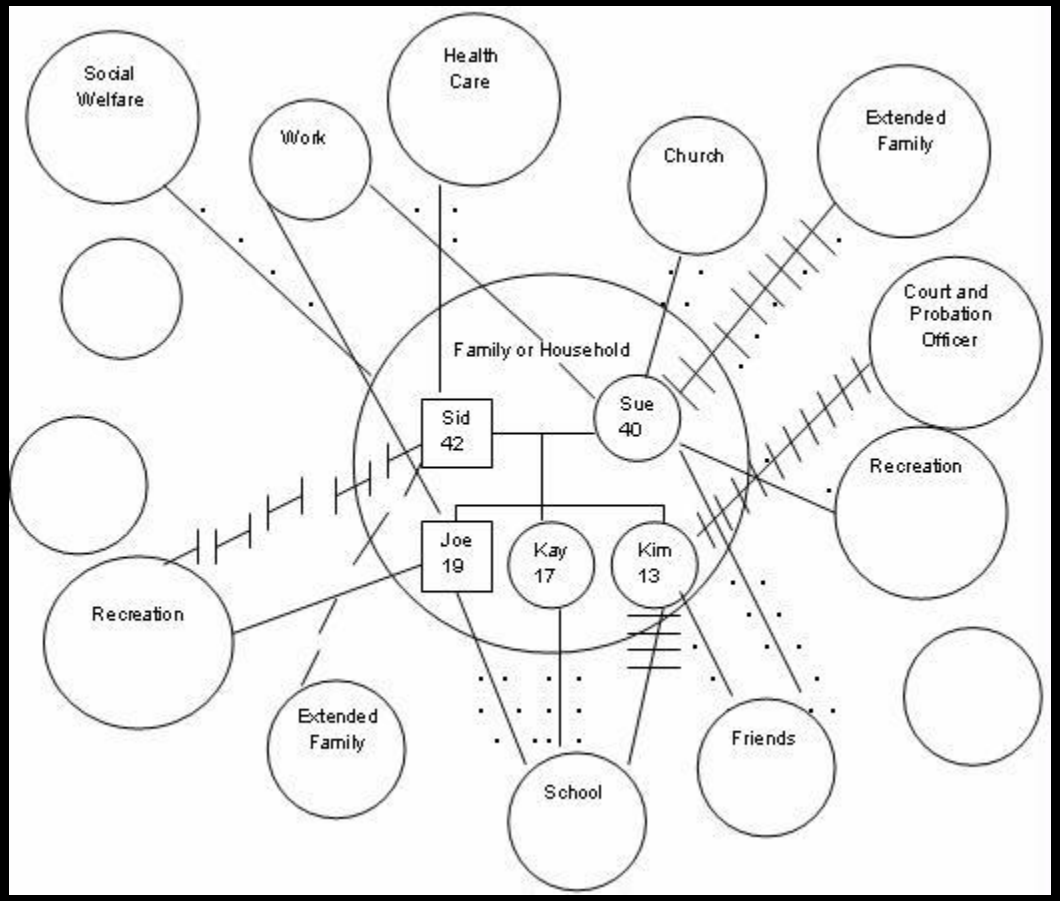
- Genograms:
  - Pictorial display of family relationships
  - Identify resources and support
  - Useful for prompting discussions of resilience and strength already within the system

- Eco-mapping:
  - “ariel-view” of the family
  - visual mapping of relationships beyond the family, including relationships to different agencies /services
  - Stimulates reflexive questions about who else is involved with the family / gaps

Genograms / family trees



Eco-maps


Social Welfare
Health Care
Work
Church
Extended Family
Court and Probation Officer
Family or Household
Sue 40
Sid 42
Recreation
Joe 19
Kay 17
Kim 13
Recreation
Extended Family
Friends
School

Family focused questions about neuro-behavioural changes (these form assessment and intervention)

- **Exception questions:** Based on the idea that no problem occurs all the time (although to families it might feel that way!)
  - E.g. "Tom let's talk about a time when the brain injury didn't get in the way of you and Kate being able to enjoy yourselves as a couple".
  - Tom, tell me about a time when you were able to keep the lid on your anger with your daughters? What did Kate do to help? What did you notice that was different about that time; how did that feel"
  - **Subsequent session- Tom – tell me what's been going well since I last saw you?**

Family focused questions about neuro-behavioural changes

- Externalising questions: Encourage communication that separates the person from the problem behaviours (the TBI becomes the problem)
  - "Tom let's talk about times when the brain injury comes between you and your children...
  - let's discuss times when the brain injury prevents you from being the kind of friend you would like to be;
  - does the brain injury ever have you saying things you wouldn't normally say to your wife .."
  - This externalising approach shifts blame (decreases self blame)– the TBI is the problem not Tom

Family focused questions about neuro-behavioural changes

- Future questions:
  - Tom and Kate, imagine a time in the future when this problem (e.g. the lack of motivation) is solved. What would be different then, what would have changed?
- Resiliency questions:
  - Tell me about a time when you as a family had a problem that caused you a lot of upset like this that you were able to deal with? Focus on other past successes of managing difficulties
- Relational slant to general questions:
  - Tom who notices when you are having a bad day?
  - What would your mother say about this problem?

Family focused questions about neuro-behavioural changes

- Promote conversations that encourage positive accounts
  - Focus on family strengths & skill when problems are raised
    - e.g.: Tom you've noticed that the brain injury tends to result in you rushing into things without thinking first - tell me about a time in the last week when you felt you managed that problem really well; what did you do then; how did that feel; how can we help you do more of that?
    - Kate how does it feel to see Tom making so much effort to think things through?

Family focused questions about neuro-behavioural changes

- Ask about the injury story:
  - people must feel heard / tell their story
  - Listen out for attributions for causes of the changes in the person (especially from children)
  - What sustains them? / where do they get strength from?
- The pre-injury story:
  - the family's context (this will be their comparison point)
  - previous stories of adversity and how it was managed
- Discrepancy between the two accounts
  - What has changed and what does this mean for them?
  - e.g. Differences in the survivors psychological presence in the family

Consider Tom's family life cycle stage

- Family life cycle stage:
  - Married
  - Parent to two young children (are they planning more?) – expect impact on his parenting skills
  - High levels of dependency in the children still
  - Peak of career - disrupted life plans will be of concern (may fear loss of worker role)
  - Likely to have considerable financial commitments at this life stage
  - Impact on wife, couples relationship, her future plans (will she still resume work as planned)
  - Commitment to aging parents – additional care taking duties

Intervention: Resilience focused therapy goals for Tom and his family

- Help Tom and his family (including his two daughters) to explore & understand the nature of the behaviour and personality changes (losses) associated with his TBI (e.g. they need to know that this is not the same as a bereavement)
- Help Tom and his family face difficult facts about their situation and find new meanings and ways forward
- For Tom and his family to be supported to learn ways to manage the emotional tidal wave that this situation brings - emphasis on “good enough” coping

Intervention: Resilience focused therapy goals for Tom and his family

- For Tom and his family to feel more hopeful about their situation - Help them replace responses that fuel hopelessness with more empowering ones
- Help Tom and his family develop ways to accept and live with uncertainty associated with his TBI
- To help the family rethink their ideas of who does what within the family at the present time - (reconstruct ideas of who they are and rethink their attachments & connections)
- For Tom to continue being a good dad to his daughters - (resuming his parental role as as fully and safely as possible)

Helping Tom and his family understand his TBI and nature of loss

- We would work with Tom and his family on the notion that loss associated with TBI is NOT the same as a bereavement

- I always use the **Ambiguous Loss Model** (Boss 1990) (linear models are misleading)– key messages:
  - You've had a sudden and traumatic loss resulting in
  - Tom being very changed – you've told me Tom that you look like yourself but don't feel like yourself; Kate you have told Tom you sometimes don't recognise how he acts "(Psychological absence of survivor with physical presence (complex type of loss)
  - The difficult thing is that many of these problems cant be "cured" - Loss without closure "and this is so distressing for you all"

Helping Tom and his family understand his TBI and nature of loss

- "no wonder you are feeling so exhausted and hopeless right now" – "it's credit to you that you are here trying to work this out" - ongoing family sadness / distress is understandable (not pathological)

- "These changes in Tom have come between you all recently and this has caused a lot of upset. We have to help you find some ways back to each other again" (Relational problem = relational solutions – help Search for new meanings and ways of connecting with 'lost' changed person)

- NB doing this work alongside ..psycho-education (with relational slant), behavioural approaches, Cog rehab etc

Helping Tom and his wife understand TBI and nature of neuro-behavioural changes

- Essential starting point - What's normal for brain injury:
  Provide Tom and his family fundamental info about common neuro-behavioural changes after TBI

  - Normal recovery times for neuro-behavioural problems– using handouts (based on Kreutzer)
  - Variability & longevity of neuro-behavioural problems families have high expectations of recovery - usually based on the experience of more rapid early physical recovery e.g. emotional and physical recovery are not the same
  - Challenge of predicting outcomes (so it's ok to feel unsure)

Helping Tom and his family understand TBI and nature of the neuro-behavioural changes

- Strategies to promote recovery – playing to strengths, ways to avoid delaying recovery through realistic goal setting
- Using stories of previous patients to manage expectations / insight issues. "many patients I have worked with have felt just like you do. They are certain they will get back to work very quickly Some do but many don't and it would be good at this stage if you were able to prepare yourself for that possibility"
- Normalise differences in perceptions & opinions about changes in Tom's behaviour but listen out for & emphasise points of agreement

Helping Toms daughters understand his TBI and the resulting changes

- Meet with children early on and then regularly update them - Open up discussions even if children don't seem curious (they usually are!); parental anxiety can be tricky here "we don't want you to upset them"

- Crucial to address their ideas about self blame "did he have his accident because I was naughty?" and other misconceptions (e.g. Emotional and behavioural problems poorly understood)

- We use a number of ways to convey information to children to help them develop an understanding of the changes in the parent including scrapbooks, special stories, arts & crafts, toys & games, learning by doing.... More published materials on ABI for children now available (contact me for details)

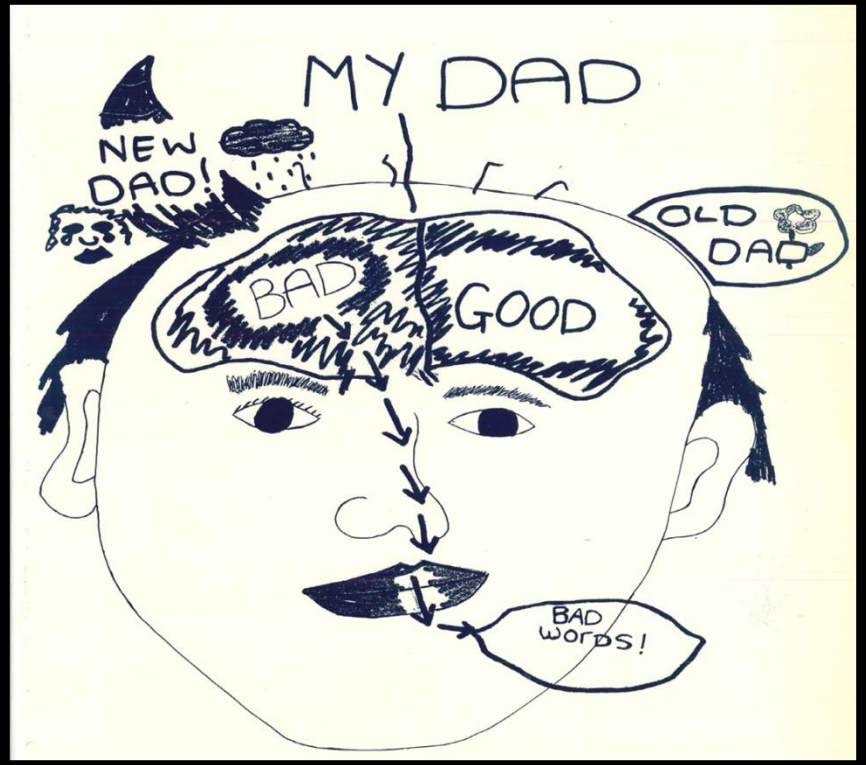
Narrative Therapy based scrapbooking with children (see Daisley, Prangnell & Seed, 2014)

- Aim to help children create a coherent & personalised narrative about the changes in family member
- Informed by the Y shaped model (Gracey, Evans & Malley 2009) focuses on helping children understand the parent as they are (after the TBI) versus the parent they "ought" to be (the "before" parent) (and reduce distress caused by discrepancy)

- **Step 1: Building the family story**
- **Step 2: building the injury story**
  - e.g. events around the injury, causality, understanding the parent's symptoms: how impairments are seen in every day life, taking part in rehab to see what the parent can still do
- **Step 3: creating the scrap book** – provides a less discrepant, up to date, realistic and safer narrative about the parent and situation

Helping children understand TBI

- *"he swears a lot now because the stroke made a hole in his brain, just at the bit where the swear words are made…so bad words just sort of leak out of the hole…he can't help it" (age 10)*



Helping Tom and his family talk about & better understand how each of them and the family unit has been affected the changes in him

- Focus on normalising ambivalence and negative feelings about the behavioural changes:
  - Normalising guilt and negative feelings
  - Emotional roller coaster as part of the journey
  - Ambivalent feelings into the open
  - View conflict as positive for change
  - Encourage use of cognitive coping strategies
  - Teach that the usual ways of coping don’t work
  - Foster self-care

Self care:

- Family members typically find this very difficult

Supporting Tom and his family to think about the TBI and its challenges in different ways

- Finding mew meanings:
  - Dialectical thinking – places emphasis on fluidity, change, movement in life; “nothing is what we think it is, nothing taken for granted; the world isn't always fair or just”
  - letting go of the old – focus on spontaneity, turning quantity into quality
  - Help families to discuss meaning of shared sadness, losses, anxieties - what does the injury means to them as a family; what can they learn together about this experience
  - To develop coping strategies that facilitate emotional recovery

Helping Tom and his family explore new meanings

- Reframing the TBI as a shared family challenge which has meaning (?spiritual) or purpose e.g. can contribute to their growth, strength & closeness

Helping Tom and his family to families tolerate the uncertainty surrounding the prognosis / future

- Acknowledging / exploring the contradictions
  - I am sad but can still be happy
  - I feel both alone and yet still connected to her
  - I feel stuck / frozen yet I'm also transforming & changing
  - I am both burdened by and grateful for his survival
  - I'm glad he's here yet sometimes I wish he had died

This can be very painful for families – requires trusted relationship with the therapist

Helping them rethink future roles and relationships

- Resilient families tend to develop a new flexible definition of success (in their relationships & activities). Foster this through:
  - Reframing & relabeling relationship & roles changes – emphasis on skills and strengths that are still present in Tom; what makes Tom and Kate's relationship still worthwhile
  - Encouraging Tom and Kate to ask for help, talk openly to Tom's friends and colleagues Most people don't have much experience of asking others for help – so addressing help seeking as a goal can be useful
  - Find meaningful & valued (new / different) ways to connect (re-connect with each other / society)

Helping Tom and his family set reasonable goals for themselves

- Discourage pre-injury comparison by using “how Tom was one week post-injury” as marker for progress – not his pre-injury self
- Both survivor’s progress AND family progress should be discussed (e.g. Family drawing up new schedule of routines that’s working well – we are in this together)
- Address openly any ‘tug of war’ over goals between family and survivor (are Tom and Kate aiming for the same things?)
- Goals around shared commitment to work together and to mobilise support

Helping Tom's wife reflect on her relationship with Tom now

- Kreutzer (2010): "learning to love a stranger" family work; key topics for discussion
  - Not everything about the survivor or family will have changed (but it feels that way!)
  - Post injury change is a continuing process
  - Recognise the survivor and family's ability to change for the better – often overlooked
  - Get to know the new person – they will become more familiar over time
  - Use patient / family accounts of positive changes

Helping Tom's wife reflect on her relationship with Tom now

- Larry and Beth Jameson "The Brain Injury Survivors Guide" 2007
- "I mentioned earlier about being married to Beth number 1 (before the TBI) and Beth number 2 (after the TBI). I have been fortunate to be married to two wonderful ladies. The second one has a more independent spirit and is far more willing to explore new ideas.
- Of course she tried for some time to become the way she had once been.....she wanted to be Beth number 1 – but she finally decided to improve Beth number 2. That decision is probably the most important one she made that has led to us having a successful life (after the TBI)"

Helping Tom and his family find hope after his TBI

- Resilient families tend to have an optimistic bias – awareness of the "grim reality" but have confidence that they can overcome problems & things will improve

- Start with encouraging the idea that hope might be possible
- Setting reasonable goals that won't overwhelm
- Finding spirituality (for some)
- Use of humour
- No problem lasts all the time – things can change

Brain Injury Family Intervention (BIFI) (Kreutzer et al 2010)

- Much of my work is based on the BIFI - Whole family intervention focusing on enhancing relational resiliency, effective coping & instilling hope after ABI
- Provides information on:
  - ABI impact & challenges (systemic focus)
  - Coping with loss and change
  - Effective problem solving
  - Realistic goal setting
  - Focusing on gains and accomplishments
  - Coping strategy enhancement
  - Communicating effectively
- BIFI-A is the adolescent TBI version

Emotionally Focused Couples Therapy (EFT)

- Pioneered by Johnson (1980s) - applied to ABI by Giles Yeates (Yeates et al 2013) – who I am in private practice with
- Structured approach to working with couples in distress arising as result of emotional / behavioural changes in injured person. Focuses on:
  - Helping couples re-organise key emotional responses
  - Shift their interactional positions
  - Initiate new cycles of interaction and ways of communicating
  - Emphasis is on feelings (not thoughts) – helpful for people with ABI who can struggle with this
- (AD and GN offer this to couples and whole families)

Supporting Tom as a parent

- TBI can impact significantly on parenting ability and confidence to parent – many of my clients feel they have to prove themselves and can't just be good enough
- Parenting post TBI typically approached (often unnecessarily) from a safe guarding perspective – results in patients being fearful of social services involvement
- At OCE we undertake sensitive, real world assessment of parenting (not always addressed by services)
- Helps to construe parenting as a skill, like others such as driving, that can be impaired by TBI and must be re-learned. Reduces shame and guilt

Conclusions

- Tom and his family's life will never be the same again.
- Neuro-behavioural changes have been repeatedly shown to be the most challenging to manage and result in huge long term personal, relational and economic costs
- Tom and his family require specialist family focused psychological support (to complement other rehab approaches)
  - to help them build capacity to sustain themselves in the longer term (family distress typically worsens with time in the context of neuro-behavioural changes)
  - and to live as well as possible with the changes they have experienced

Conclusions

- Essential that funding is sought for ongoing family focused work for clients like Tom and his family – one of the best investments you can make for your client!
- Through resilience focused work many families have been able to see the crisis of TBI as a potential springboard for increased competence and for gaining a different perspective on life – despite still living with significant residual difficulties
- “we may not wish for adversity...but our worst times can also become our best”

Want to know more?

- Daisley, A, Tams, R & Kischka, U (2009) Head Injury: the facts; Oxford University Press
- Walsh, F (2006) Strengthening Family Resilience. (2nd edition) New York: The Guildford Press
- Kreutzer, J et al (2010) Practical approaches to effective family intervention. Journal of Head Trauma Rehab 25, 113-20
- Bowen, C et al (2010) A Relational Approach to Rehabilitation: thinking about relationships after brain injury Karnac :London

Questions / comments?

Thank you for listening

Any questions?

To discuss family referrals, clinical or research supervision, consultation, staff training, conference presentations please contact me:

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