

Psychological Support for Genetic Issues

**When dreams are shattered.... what to
do with the pieces**



Dr Sue Hawkins
Psychologist and Psychotherapist

Why do people come for support

- Testing for a Genetic Condition
- Family decision making
- Have a pregnancy at risk
- Have a child newly diagnosed
- Caring for child with a genetic condition



Its testing!



Testing: Possible Cons of testing



1. Syndromes sometimes have a wide range of functioning
2. Lack of information regarding the medical implications of unusual conditions
3. Unsure test results eg Mosaics in pregnancy.
4. Having to make a medical decision when not ready
5. Loss of hope (I have the condition) may lead to emotional implications such as depression and anxiety and social isolation
6. Discrimination by health, life, and disability insurers and employers

Testing: Possible Pros of Genetic Testing



- Provides a reason of why particular symptoms are present and the possible future trajectory of medical issues
- Provides more information about the disease that runs in families and getting possible treatments (if available or even access to clinical trials)
- Can help family planning and current and future health care decisions
- Provides Information for relatives
- Emotional benefits if they do not have the gene for the disease: For example it removes the “living as if I have the disease” Fear and uncertainty
- Contribution to research

Emotional Responses to a Genetic Diagnosis as an Adult

- Some closure in knowing
- Deeper connection with family members
- Loss of “I can hope I do not have it”
- Difficulties coping with the knowledge of a physical or mental decline. Difficulties coping with the **uncertainty**
- Possible PTSD, and hypervigilance.
- Grief and loss identity and life expectations.
- Family issues members: dealing with their survivor guilt, unfairness, jealousy and disclosure.
- Issues with intimate relationships: Disclosure issues, guilt of passing the gene on and being a burden and future family planning.

Emotional Responses to a genetic diagnosis during pregnancy

- Ability to make a more informed decision regarding possible outcomes
- Relief at being able to choose a different future
- Different responses on what to do from each parent causing issues between couple
- Different responses on what to do from extended family causing issues between couple
- Difficulties coping with the **uncertainty** of a “syndrome”. “How bad will it be” “where is the road map”
- Time pressures working through options: termination, adoption or continuing the pregnancy
- Possible PTSD, Shame and guilt if terminating

Emotional Responses to a genetic diagnosis after a pregnancy

- Different responses from each parent causing couple issues
- Different responses from extended family causing issues between couple
- Possible maternal PTSD from birth trauma and diagnosis
- Parental shock and feeling numb
- Denial of severity following diagnosis
- Hypervigilance towards symptoms ..looking for the next medical emergency or the what could be's
- Overwhelm coping with child's medical needs. e.g medical appointments, treatments and physical safety.
- Negative impact on work, relationships and other children in the family
- Some consolation and validation on knowing what is wrong

How a genetic condition influences family creation



Future pregnancies are generally more anxiety provoking
If genetic testing is needed then IVF may be needed and takes away the normal way to make a baby.

The partner who carries the genetic condition can feel guilty about making their partner go through a medical procedure to have a child.

The partner with the genetic condition may find it difficult to parent as the disease progressed putting a strain on the couple relationship

The IVF Emotional Rollercoaster



The real IVF



Day 1



Day 2



Day 3
8 cell



Day 4
Morula



Day 5
Blastocyst



**IVF success rates over 40
are less than 20% .**

Difficult Parts Of IVF for Patients

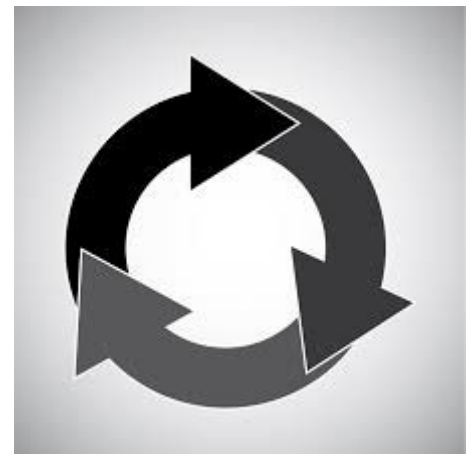
- Unsuccessful cycles – grief and loss
- Waiting - 2 weeks till pg test, eggs and embryos. Longer waits for genetic testing.
- Impact on the couple relationship + sex
- Family, friends, other pregnant people
- Fitting in with work
- Stress and anxiety - fears loom large
- Terminating treatment –fears all come surging back
- Being around others - esp. the fertile world

Possible Issues doing PGD/PG cycle

- Anxiety is high usually result of previous termination or miscarriage
- Distress can be experienced if all embryos come back with an issue or no eggs are collected
- Shame associated with infertility and a genetic problems can be bigger
- A failed cycle after a tested embryo transfer is confusing and anxiety provoking for patients

Ongoing Grief issues often associated with Genetic Conditions

- Ongoing trauma and uncertainty
- Identity loss
- Guilt
- Disenfranchised grief, loss of hopes and dreams
- Death loss of function of family members
- Difficulties in creating a family
- Couple and/or family issues
- Existential crisis



Reactions to grief influenced by



Gender

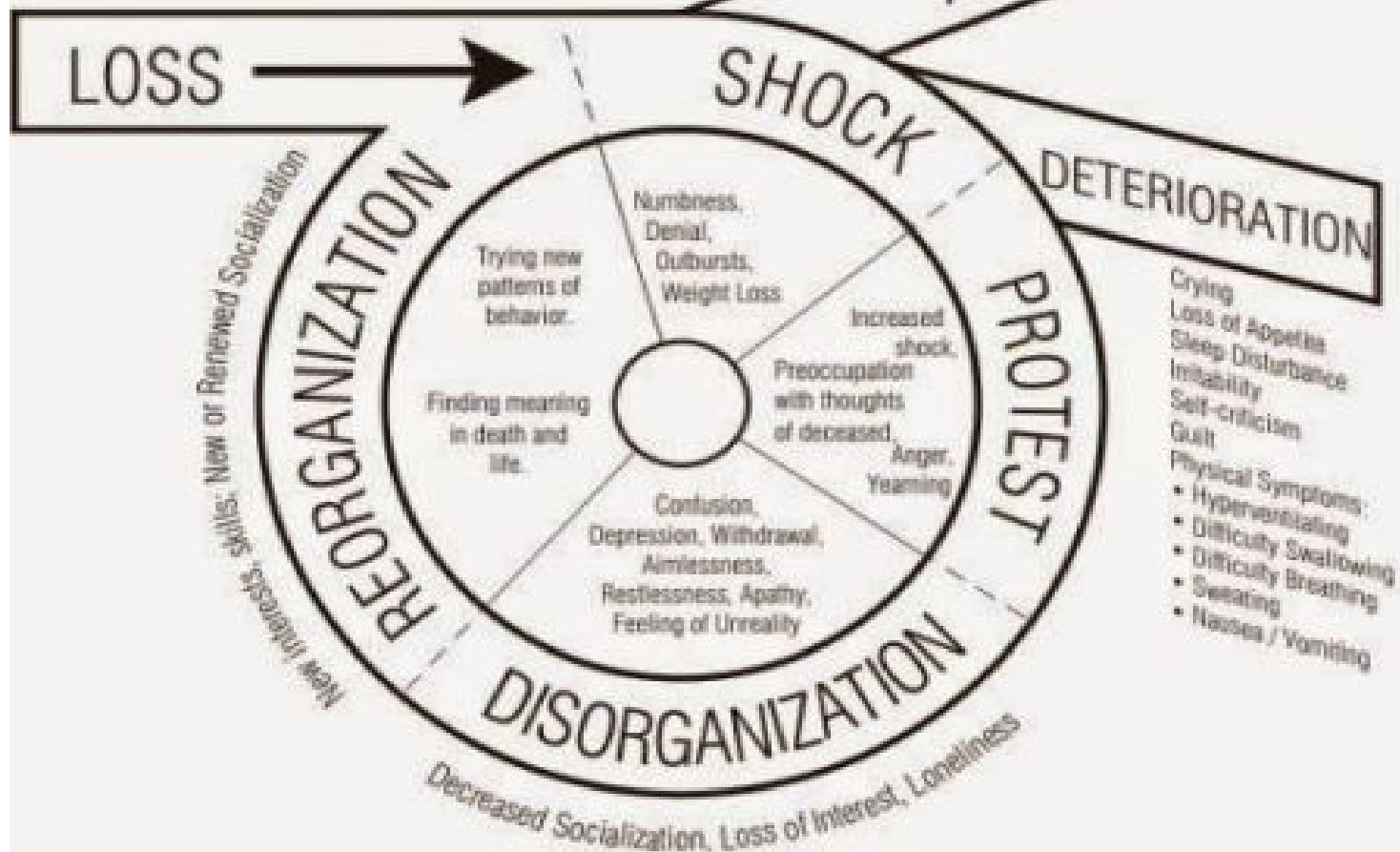
Culture

Support

Family of origin dynamics

Mental health history

GRIEF WHEEL



the tasks of grief

T = To accept the reality of
the loss

E = Experience the pain of the loss

A = Adjust to the new environment
without the lost person

R = Reinvest in the new
reality

Traumatic Grief=Grief plus PTSD



- Feelings of person can feel prolonged numbness, disbelief, a loss of trust in people and hopelessness about the future.
- Can last for many years can have negative effects on the lives of sufferers and their relationships.
- PTSD Symptoms: hypervigilance; depressed mood; problems controlling emotions; distressing flashbacks; and difficulties in interpersonal relationships.

Traumatic grief- Common Issues



Why me? I'm alone, injustice, out of step

Failure : partner; family; self esteem; body broken / defective

Feeling punished, superstitious,

Crisis of meaning, purpose, beyond comprehension

Guilt; self blame; partner blame; God blame

Dealing with others: Envy, jealousy, bitterness, frustration, anger

Hypervigilance: What can go wrong next

Loss of control: limbo land, anxiety, helplessness

Decision making, foggy brain, no good options

Grief and loss - all aspects - whole family system - lifespan

Managing difficult emotions: stressors, anxiety, longing, anger

Flashbacks: Re-experiencing emotions and body states around the diagnosis, or events attached to the condition.

What is

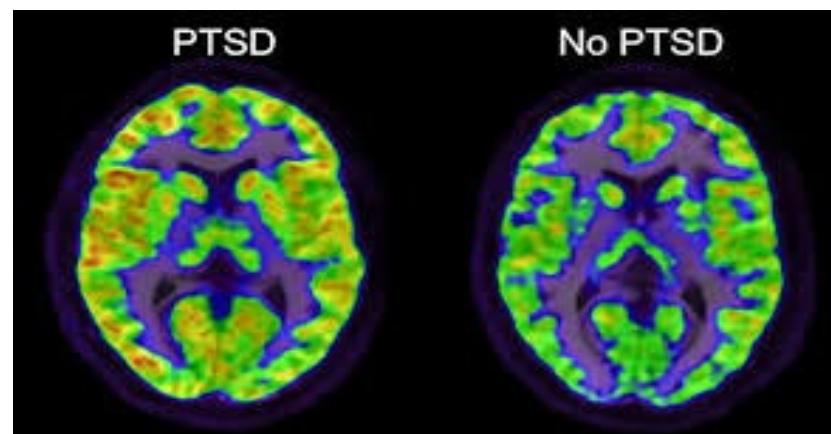


“Psychological trauma is the unique individual experience of an event, a series of events, or a set of enduring conditions, in which the individual’s ability to integrate his or her emotional experience is overwhelmed

Their ability to stay present, understand the experience, integrate the feelings is lost.”

The Four Groups of PTSD Symptoms

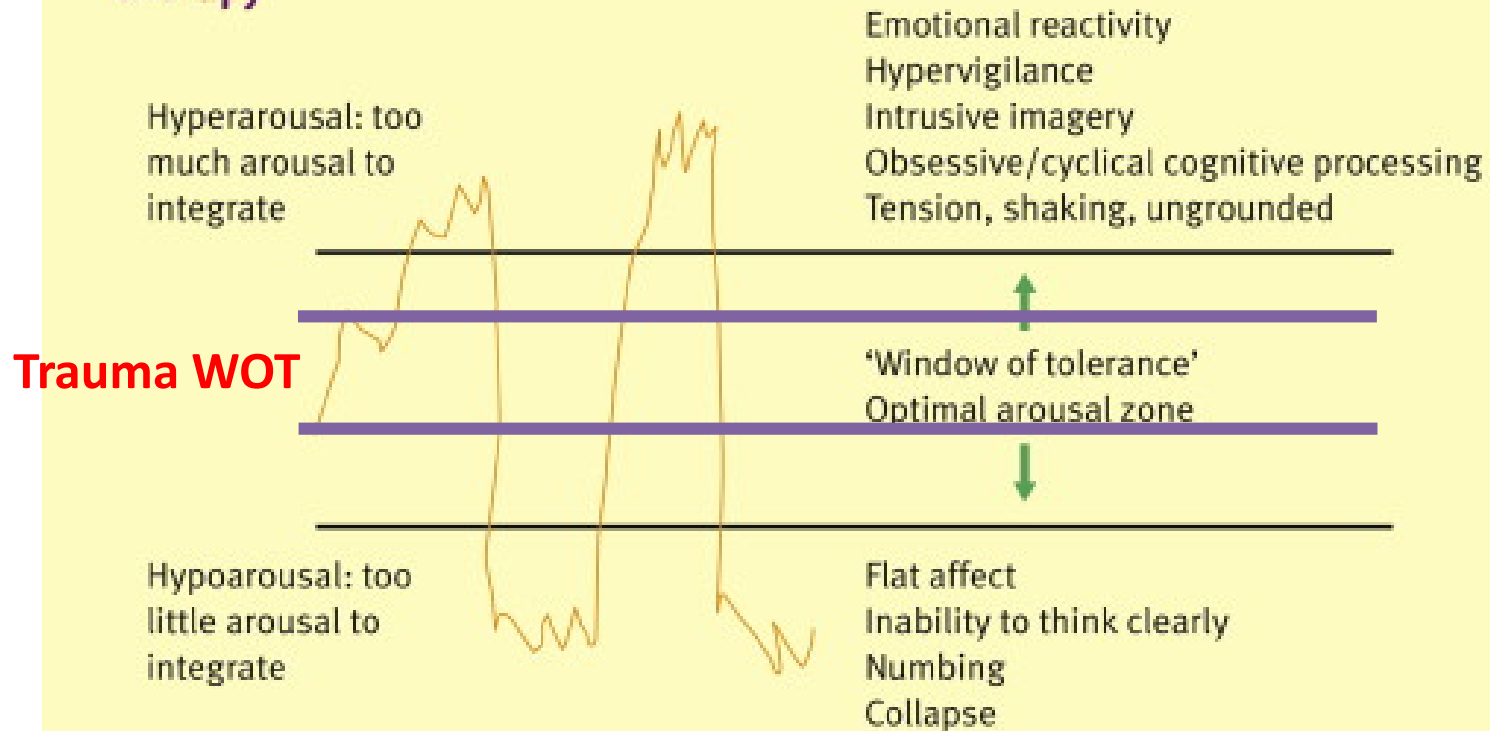
- 1. Re-experiencing the trauma
- 2. Avoiding reminders of the event
- 3. Negative changes in thoughts and mood after the trauma
- 4. Feeling 'on edge' and overly aroused



PSYCOEDUCATION

The Window of Tolerance

The 'window of tolerance': maintaining optimal arousal for trauma-focused therapy



(Adapted from Ogden and Minton 2000)¹⁰

What will help- Living with a genetic condition

Remember: It is a Marathon not a Race



What will help-being diagnosed with a genetic condition

- Take into account you will be in shock for a while.
- Self care and be gentle on yourself
- When going to medical appointments write down questions before hand and then write down information or take someone with you
- Reach out for support and put your needs out
- Seek counselling support
- Take you time in working out what is next.
- Find the right people to support you medically and psychologically
- Make sure information about you is shared with all your health providers
- Join a support group or an online group
- Accept respite and take holidays
- Take medication



How Does Psychological Support Help?

- Can reduce effects of PTSD and increase window of tolerance
- Non judgemental space to discuss difficult topics
- Its all about you and is a safe place to be listen to
- Validate and normalise experience
- Grief and loss counselling-helps disenfranchised grief
- Help find ways of managing mood and anxiety
- Couples counselling
- Support in working with other family members

Where can I find Support?



The Australian Psychological Website: Find a psychologist

Genetic counsellors

The Gidget Foundation: <https://gidgetfoundation.org.au/>

IVF Clinic Counsellors

Your GP

University Counselling Services

Relationships Australia

Facebook support groups

Genetic support groups

