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CREATE CHANGE

Is this mental illness?

Dr Cathy Franklin
Psychiatrist
Director, Mater Intellectual Disability and Autism Service (MIDAS)
Director, Qld Centre of Intellectual and Developmental Disability (QCIDD)
Brisbane, Queensland, Australia

INTRODUCTIONS

About me

- Australian Psychiatrist specialising in intellectual disability and autism since 2004
- Lead a clinical service and a research team in Brisbane, Australia
- Special interest in DS and Regression since seeing my first patient with it over 10 years ago and finding very little in the literature.
- Other interest: building capacity of medical profession to work with people with intellectual or developmental disability
- Vice President of the Australian Association of Developmental Disability Medicine (AADDM)

Caveats for today's presentation:

- I work with adolescents and adults, not with children
- I do supervise some clinical trial work in Rett syndrome and autism

Presentation outline

- Introductions
- Concepts & Context
- Common themes and styles in Down Syndrome & relationship to mental illness
- Other Disorders
- Summary
- Resources

CONCEPTS & CONTEXT

What is mental health?

World Health Organization

A state of **well-being** in which every individual:

- realizes his or her own potential
- can cope with the normal stresses of life
- can work productively and fruitfully
- is able to make a contribution to her or his community

(NB: Health - a state of complete physical, mental and social well-being - not merely the absence of disease or infirmity)

What do we know about mental illness and neurodevelopmental disorders in Down syndrome?

- CAVEAT = NEEDS MORE RESEARCH!

MORE COMMON

- ? depression, anxiety
- OCD, obsessional slowness, hoarding
- Psychosis, catatonia, regression
- ADHD
- Autism

- Earlier onset of Alzheimer's dementia

Physical Health affects Mental Health

Congenital heart disease (almost 50%) – may be undiagnosed

Eyes: Cataracts, strabismus, keratoconus

Hearing loss (almost 75%), recurrent otitis media

Infections, impaired immune function: 12X more likely to die from untreated or unmonitored infection

Leukemia, polycythemia, anemia

Autoimmune – Hypothyroidism, Celiac

Hypotonia

Atlanto-axial instability (10%?)

Sleep apnea

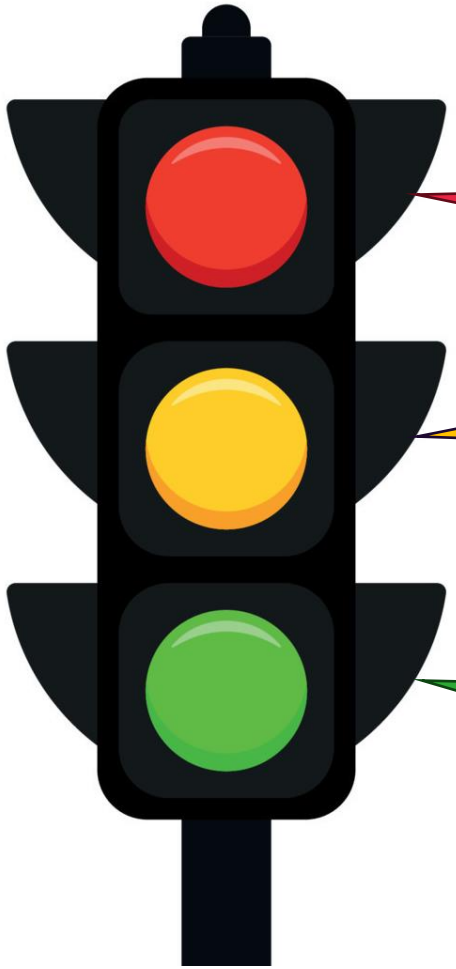
Gum disease and dental problems

Epilepsy – onset age 0-2 or over 40 (assoc with dementia) – almost 50% of > 50's

High cholesterol, obesity, diabetes

Behaviour is Communication – There is always a reason!

Traffic Lights in Today's Presentation



MENTAL ILLNESS
Definitely abnormal
Definitely requires assessment by health professional

MONITOR
Some warning signs and red flags = keep an eye on things
May benefit from consulting with health professional re: early intervention

NORMAL
In this presentation "normal" = no signs of mental illness
Note: Normal does not = no problems!
"Normal" behaviours can still cause issues and require attention

COMMON THEMES AND STYLES

in people with Down syndrome

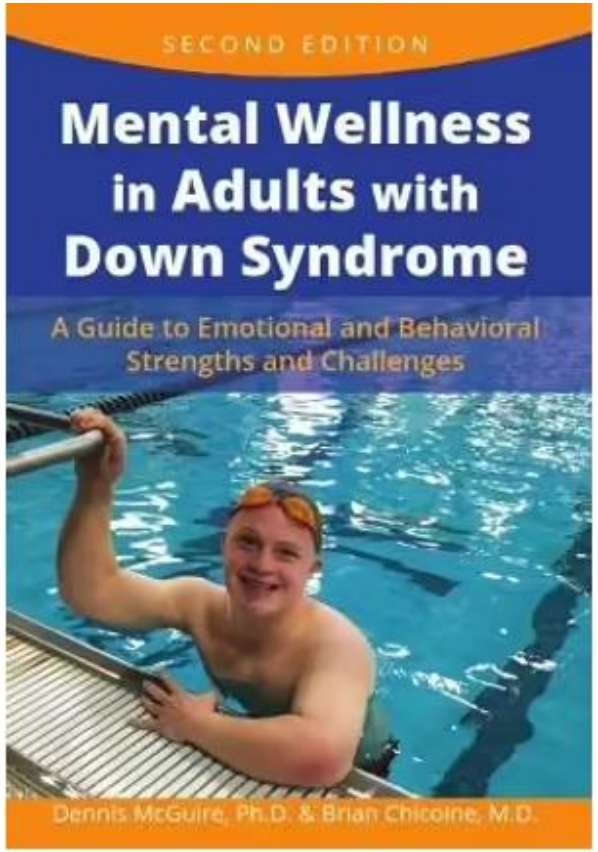
A word about stereotypes….

All Australians?

All people with Down syndrome??

Common themes and styles

- Concrete thinking
- Language strengths and weaknesses
- Memory
- Vivid Fantasy Life
- Self-talk
- Getting stuck
- Taking time
- Worrying
- Emotional awareness



CONCRETE THINKING

Adaptive

- Assists in being practical, grounded
- Able to live in the “here and now” (and embrace it)
- No worry about the broader implications / big picture

Maladaptive

- Can create challenges in communication
- Can make it harder to generalize skills to new settings
- Can limit flexibility & adaptiveness to change

LANGUAGE

Strength = Receptive Language = Understanding what is said

- Person can be very perceptive, emotionally intuitive
- Heightened emotional sensitivity for others can cause problems (other's emotions can affect them greatly)

Weakness = Expressive Language = Saying what you are thinking

- Makes it difficult to identify and solve problems
- Increased risk for isolation, people not understanding, depression

EXCELLENT VISUAL/ VISUO-SPATIAL MEMORY

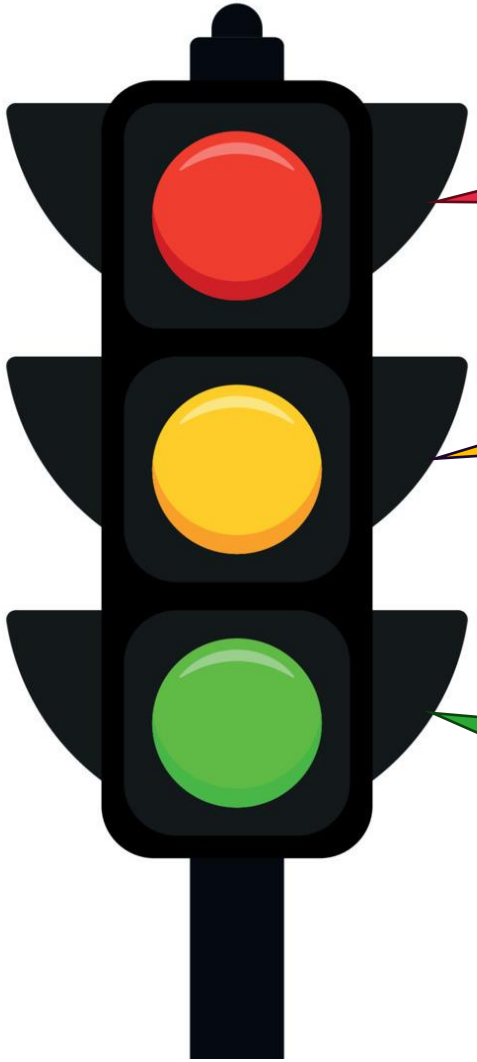
Adaptive

- Able to remember past people, places and events in great detail
- Good memory for directions
- Excellent recall of movies, TV scenes

Maladaptive

- Keep replaying past events in their mind – as if it were happening now – good or bad depending on the memory
- Can develop phobias relating to something that happened once a long time ago
- Can prolong grief and loss reactions

GRIEF vs DEPRESSION



DEPRESSION
Poor sleep and appetite
Withdrawn and won't engage in usual activities
Lost interest in usual tasks and activities
Preoccupied with death and dying

MONITOR
Nightmares, bad dreams, change in sleep
Difficulty engaging in routine tasks and activities
Withdrawn and less communicative

NORMAL GRIEVING
Keeps talking & crying about lost one as if it just happened
Keeps going over events, fact checking
Sad, crying
Takes longer than everyone else
Seems not to be moving on, same things over and over, stuck on things
May pretend it hasn't happened

VIVID FANTASY LIFE

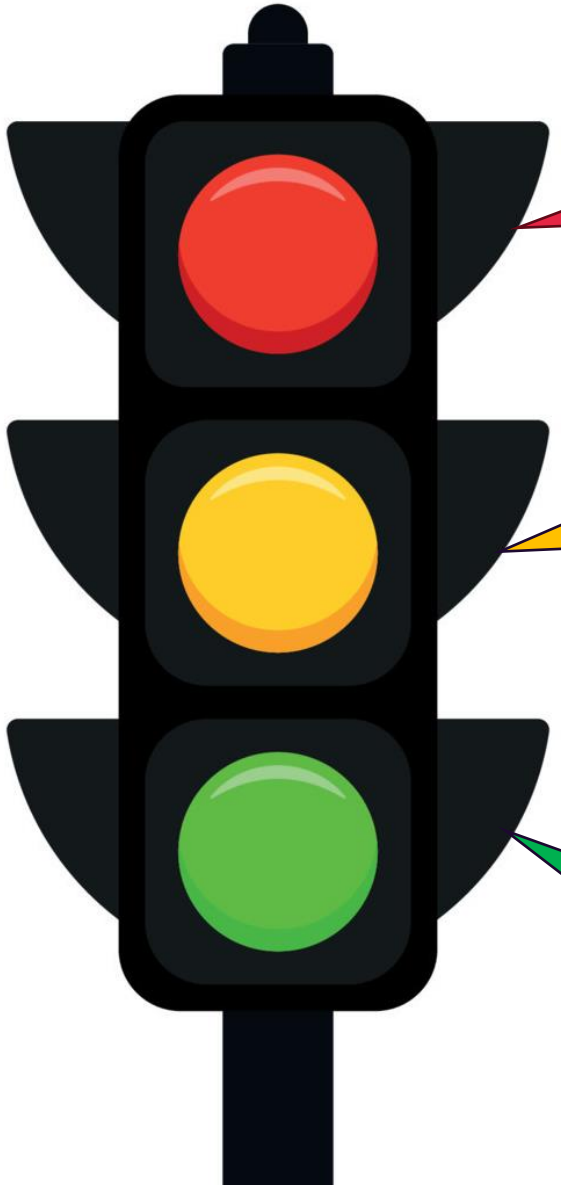
- Possibly related to strong visual memory
- May function to fill in the developmental gaps e.g. Marrying Harry Styles, having his children
- May be associated with boredom / lack of stimulating activities (think about a neurotypical teenager's life)
- May be more rewarding than real life
- Beware inadvertent reinforcement – difficult to change once reinforced

Is it a delusion?

Delusion

- Fixed abnormal belief that is not amenable to change in spite of conflicting evidence.
- Varying themes include: persecutory, somatic, religious, grandiose
- Not in keeping with cultural or religious norms
- e.g. believing your family is fake and not really your family, believing someone is going to harm you (when there is no objective evidence to support this)

FANTASY vs DELUSIONS



DELUSIONS
Associated with poor sleep, unusual behaviours, unable to concentrate on tasks and activities

MONITOR
Becoming increasingly preoccupied with talking to themselves at the expense of ‘real’ relationships
No longer able to stop talking about it when asked in company of others
Too distracted to engage in usual tasks and activities

NORMAL
Obsessed with recognisable names and personalities (e.g. from movies, social circle)
Occurs when alone / possibly bored / lack of activities
Normal function / able to engage in activities and tasks

SELF-TALK

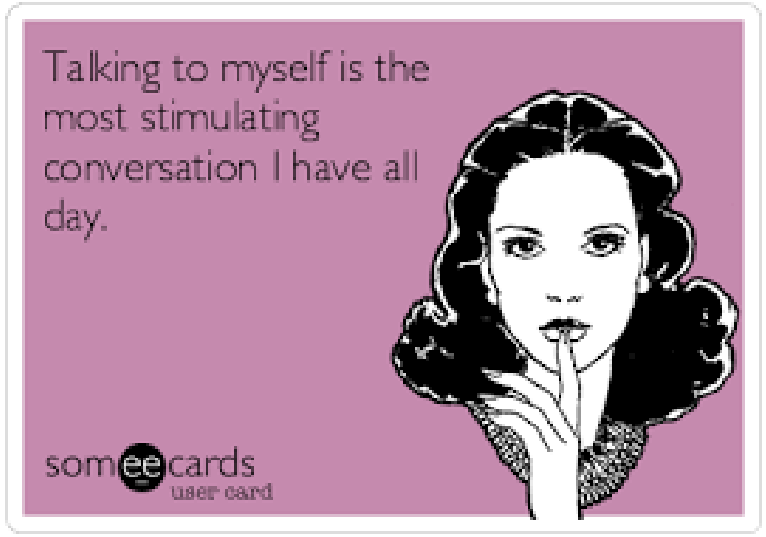
The inner speech that includes the questions and comments you make to yourself.

Used to:

- Think things through
- Interpret events
- Interpret messages of others
- Respond to your own experiences
- Respond to your interactions with others

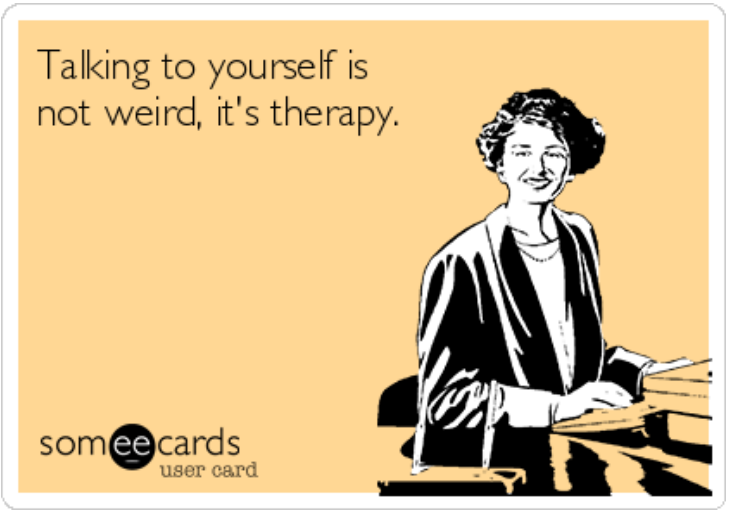
Most people learn to think this speech silently. Self talk occurs when it is audible.

Why do people use self-talk?



Boredom / lack of stimulation

Fun / entertainment



Processing events

Self Talk

Adaptive

- Can help process information
- Improves memory (due to verbal repetition)
- Can provide social benefit (rehearsing, planning)

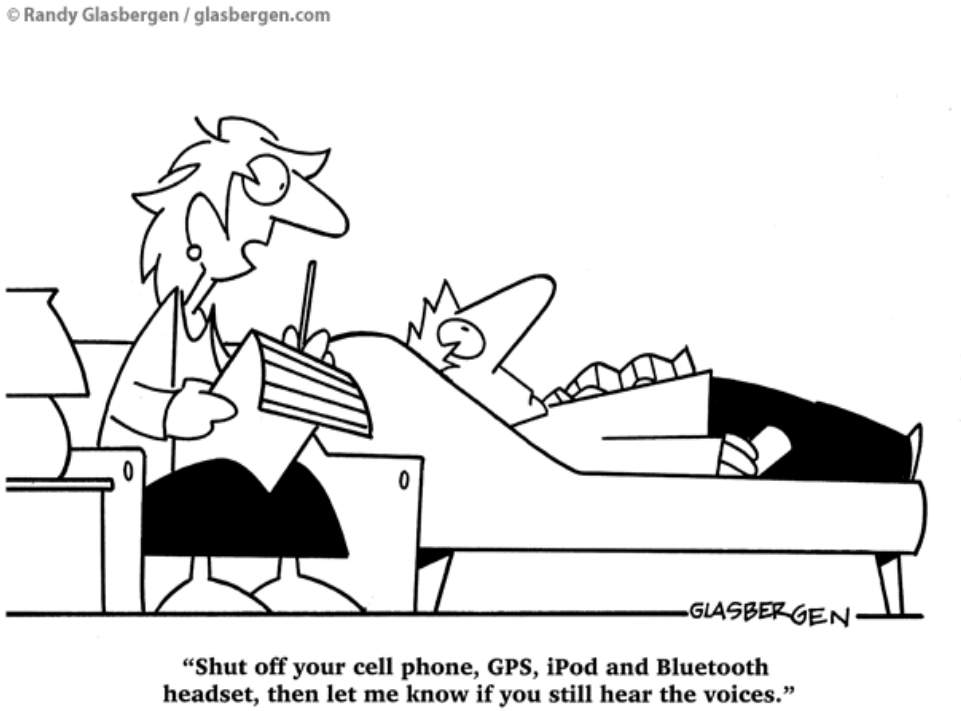
Maladaptive

- Can cause issues in public
- Can be mistaken for mental illness
- Can be difficult to distinguish fantasy from reality (as it can be very vivid and real-sounding)
- Can grow into mental illness under stress (uncommonly)

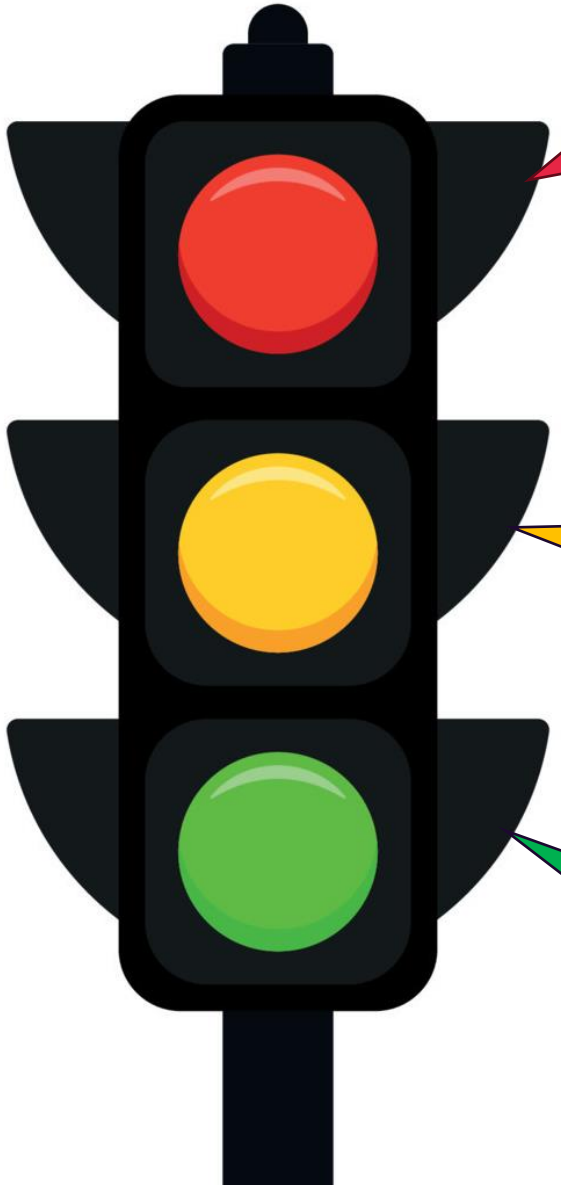
Is it hallucinations?

Hallucination

- Abnormal perception that occurs in the absence of a true stimulus
- Clear and vivid, with the full force of normal perceptions
- Not under voluntary control
- Occur in any sensory modality (sight, sound, taste, smell, touch)
- Causes include physical cause (delirium – seeing visions and strange things and sound), metal illness (schizophrenia – hearing voices is most common)
- Can occur normally as you fall asleep and wake up
- NB “Do you hear voices?” – NOT a good question for a concrete thinker! Better to ask – “Can you hear people talking when no one else can see or hear them?”



SELF-TALK vs HALLUCINATIONS



HALLUCINATIONS

Feels like the person is seeing or hearing things others can't see
Shouting, cowering, hiding
Angry, Scared
Conversation doesn't resemble any familiar themes
Talking to self is a new phenomenon
Associated with poor sleep, unusual behaviours, unable to concentrate on tasks and activities

MONITOR

Becoming increasingly preoccupied with talking to themselves at the expense of 'real' relationships
No longer able to stop when in company of others
Too distracted to engage in usual tasks and activities

NORMAL

Person has always talked to themselves
Recognisable names and personalities (e.g. from movies, social circle)
May be very animated, may be loud
Occurs when alone / possibly bored / lack of activities
Normal function / able to engage in activities and tasks

GETTING “STUCK”

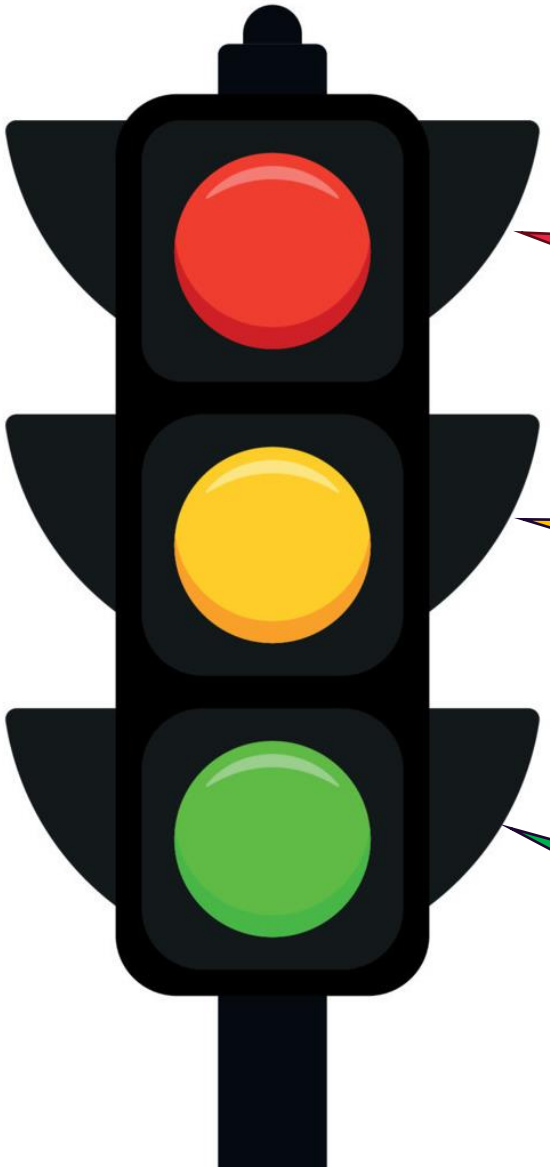
Maladaptive

- Can slow everything down
- Can make change more difficult and stressful
- Can lead to hoarding / excessive collecting
- Can cause interpersonal problems (can drive others crazy!!!)
- Can grow into mental illness under stress

Adaptive

- Can give order and structure to life
- Can increase independence due to constant practicing of skills
- Can help people be more careful with grooming, how to speak to others
- Good for hobbies

HOARDING DISORDER

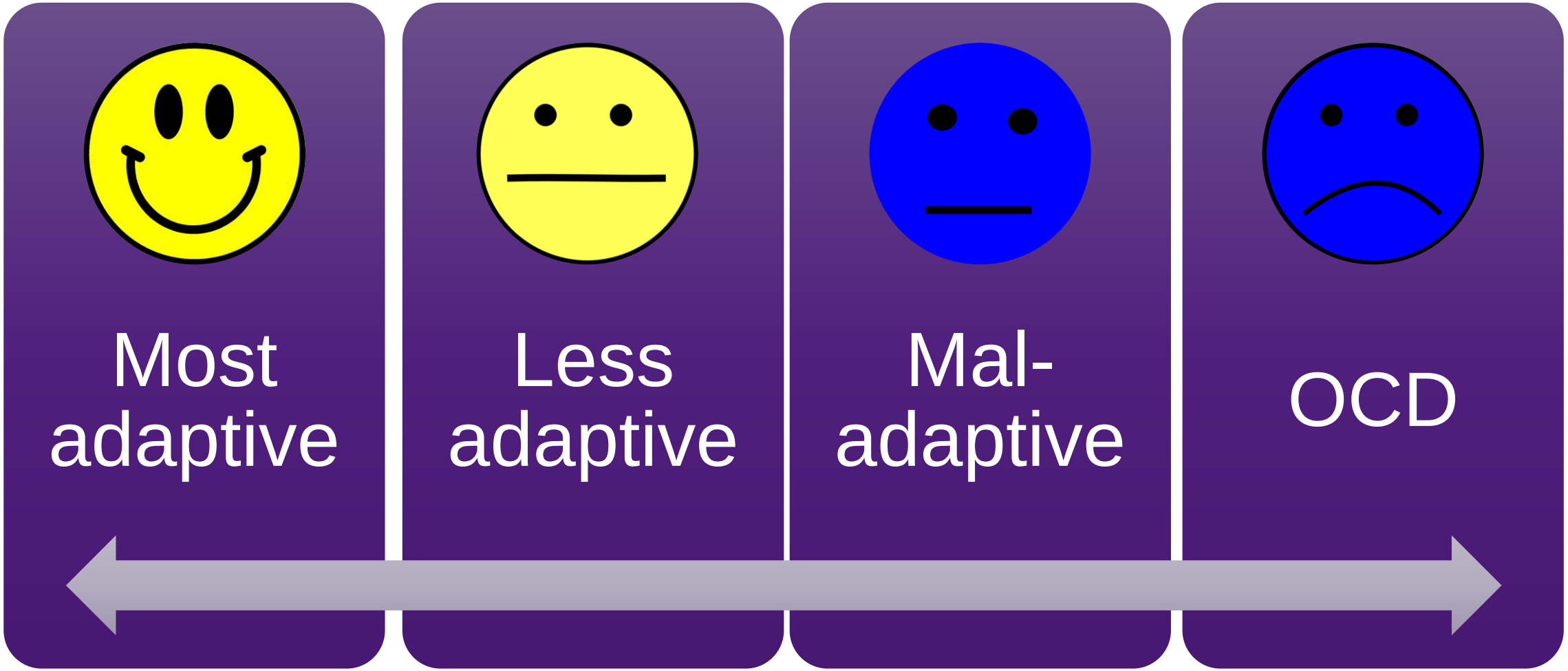


OBSESSIVE-COMPULSIVE DISORDER
Must check light switches, take set number of steps
Skin is raw from handwashing
Too busy doing rituals to concentrate on routine tasks and activities

MONITOR
Must take multiple bags with them
Running out of space in bedroom
Starts taking over other areas of home

NORMAL
Collects seemingly worthless objects and will not throw them out
Usually has a common theme (but always need ‘just one more’!)
Arranges objects in certain way

The Groove Continuum



(Adapted from “Mental Wellness in Adults with Down Syndrome” by McGuire & Chicoine, 2006)

Obsessive Compulsive Disorder

Obsessions

recurrent and persistent thoughts, urges or images that are experienced as intrusive and unwanted

ANXIETY

Compulsions

repetitive behaviours or mental acts that an individual feels driven to perform in response to an obsession or according to rules that must be applied rigidly.

The behaviours / mental acts are aimed at reducing anxiety or distress, or preventing some dreaded situation, however are not connected in a realistic way with what they are trying to neutralize.

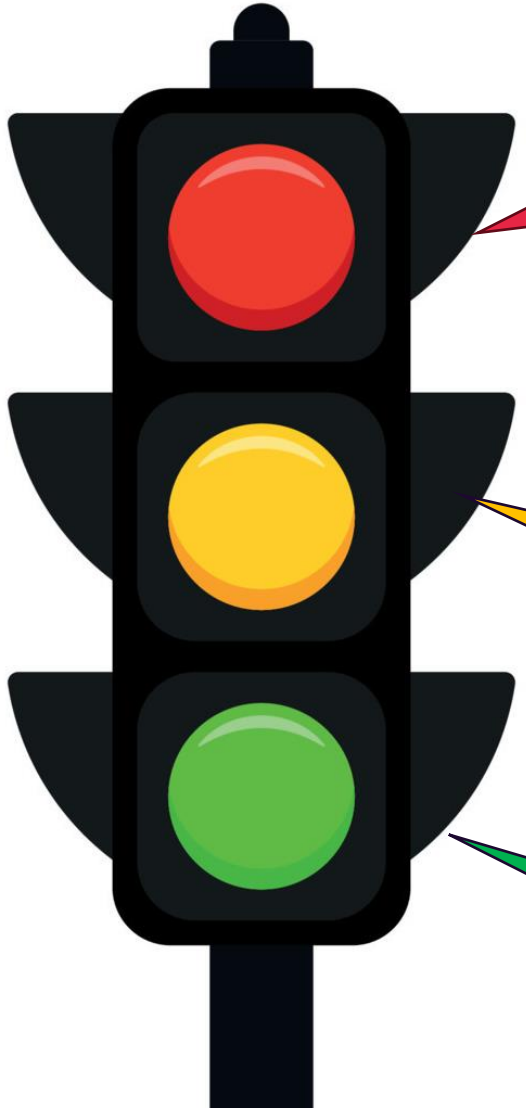
REDUCES ANXIETY

Obsessive Compulsive Disorder

- Diagnosed when the obsessional thoughts become excessively intrusive and the obsessions and compulsions become time-consuming (over 1 hour / day) and interfere with daily functioning.
- Occurs in about 1.5% of the general population, average of onset is 15 years. ?About 6% in DS.

Obsessive-Compulsive Disorder To Do List

OBSESSIVE-COMPULSIVE DISORDER



OBSESSIVE-COMPULSIVE DISORDER

Must check light switches, take set number of steps

Skin is raw from handwashing

Too busy doing rituals to concentrate on routine tasks and activities

Socially withdrawn, not leaving house

Becomes very agitated / aggressive when interrupted

MONITOR

Rituals taking up increasing amounts of time at the cost of usual activities and tasks

Long time handwashing and can't be re-directed

NORMAL

Likes everything in its 'right place' (and will move it back if not)

Likes things to be done a certain way (e.g. driving route, order of household tasks)

TAKING TIME- SLOW AND SLOWER

Adaptive

Enables greater enjoyment and happiness in life – taking time to smell the roses, to notice the detail (mindfulness - that lots of us need to work at!)

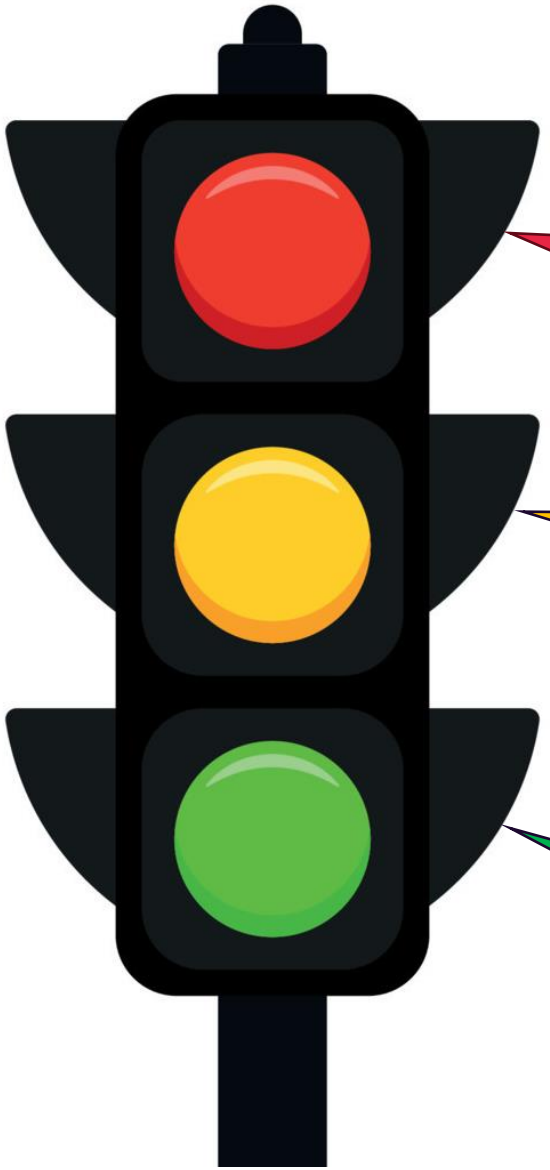
Maladaptive

- Everything takes longer
- Can drive others crazy and increase household stress levels

Catatonia is a disorder of movement and control.
It can make it hard for your brain to tell your body what to do.

- It can make your body very slow, or even completely stuck and unable to move at all. (***stupor***)
- Your body might get stuck in unusual positions *(**posturing** – self; **catalepsy** – by examiner)*
- Your body might move differently, or feel stiff *(**rigidity**, **waxy flexibility, gegenhalten**)*
- You might have trouble speaking or stop speaking altogether. *(**mutism**)*
- Your thoughts, speech and body might get stuck on the same thing. *(Thoughts and speech: **verbigeration** – stuck record**, perseveration** – returning to same topic) (Body: **ambitendency**)*
- Your body might make unusual movements that you can't control. *(**Mannerisms, stereotypies, tics**)*
- You might smile (***grimacing***), laugh or cry for no reason.
- It might be hard to chew or swallow.
- It might be hard to do your usual activities, so you might need more help with things like showering, dressing, toileting and moving.

CATATONIA



CATATONIA

New onset severe slowness with daily tasks (a few hours for breakfast)
May get ‘stuck’ in certain positions
May develop different ways of moving (e.g. walks backwards)
Runs out of time to complete all usual tasks or activities
May have associated features of depression, autism or DS regression disorder

MONITOR

Increased slowness with normal activities
Repeats some tasks beyond ‘normal for the person’ range

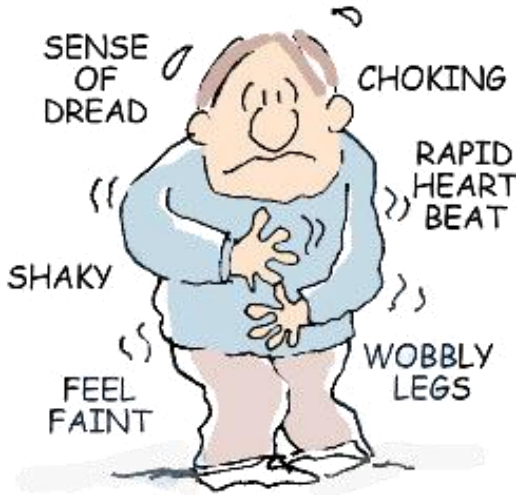
NORMAL

Need to allow extra time for everything
Can’t be rushed (may get slower if rushed!)
Gets worse under stress

ANXIETY & WORRYING

Adaptive

- Feelings of anxiety are common and can be normal, even helpful.
- They help us check through what's happening, run through things in our head and prepare ourselves to perform
- They can help us to be careful
- Whilst such feelings can be unpleasant, they rarely last long and most people can cope and function.



Maladaptive

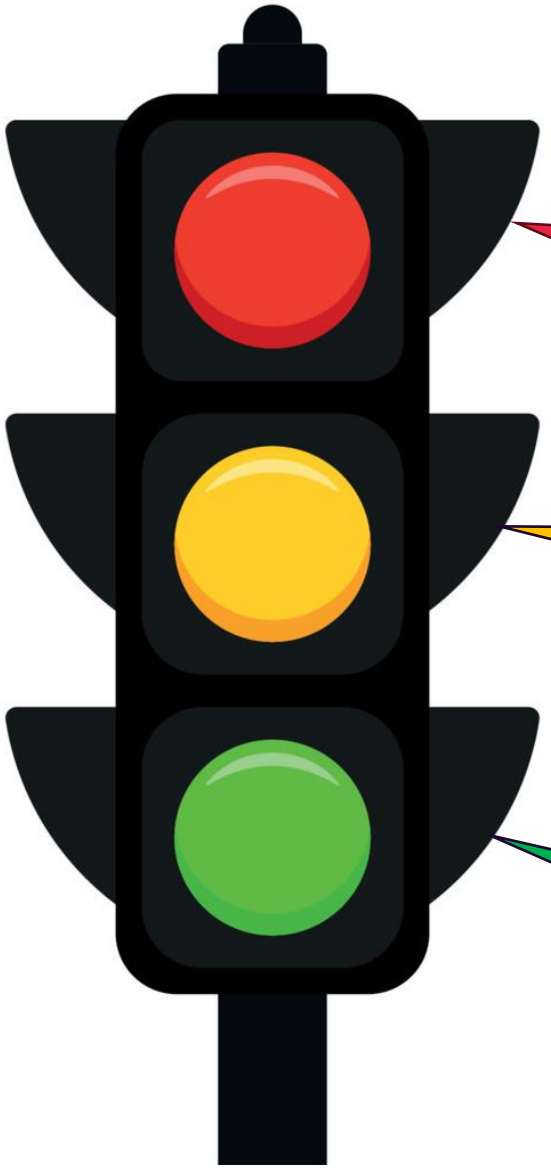
- For some people the feelings do not go away and interfere with their daily routine and functioning.
- They may feel anxious all the time and this anxiety controls their life.
- There may be physical symptoms, such as palpitations, rapid breathing, sweating and dry mouth. Sleep may also be disturbed.
- Often start in childhood
- Can be associated with depression

BUT REMEMBER!

Sometimes there are very good reasons someone may be anxious (bullying, abuse, pain, interpersonal problems).

Generalized Anxiety Disorder

ANXIETY vs ANXIETY DISORDER



ANXIETY DISORDER

Won't separate from family when previously could do so for routine activities (e.g. school, enjoyable activities)

Teary, loses temper, withdrawn, irritable, aggression

Unusual or bizarre behaviours when overwhelmed (e.g. sudden drop to floor)

Stops person doing normal activities & affects function

MONITOR

"High maintenance", in people's face, won't stop going on and on

Aggressive outbursts out of character

NORMAL

Asks same question several times (fact checking)

Seeks reassurance frequently

May become very anxious in new situations

Emotions & Response to Other's Emotions

- People with Down syndrome often show greater response to and concern for others who are in distress
- 6th sense for emotional state of those around them
- Don't necessarily feel more
- Do show greater responses to others and may worry more about them
- ?more sensitive to social rejection and loss

Depression

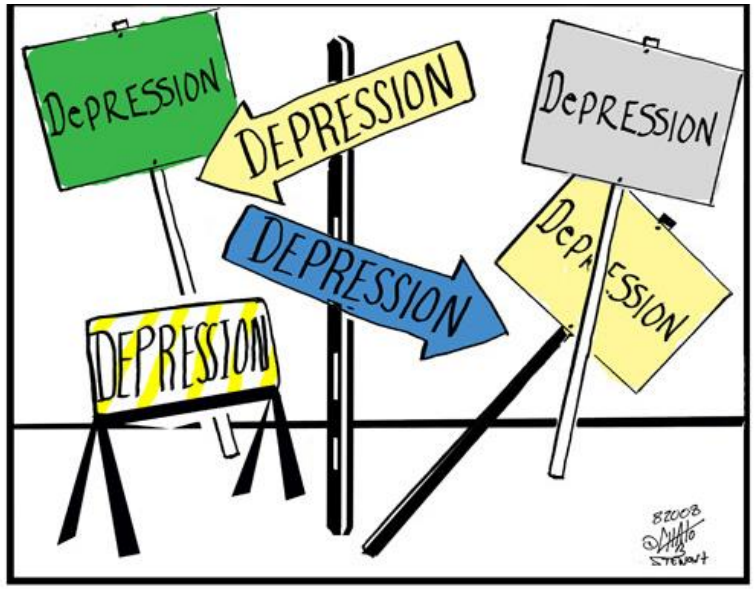
- > 2 weeks of sad, empty or irritable mood

and / or

- Loss of interest in activities, family and friends

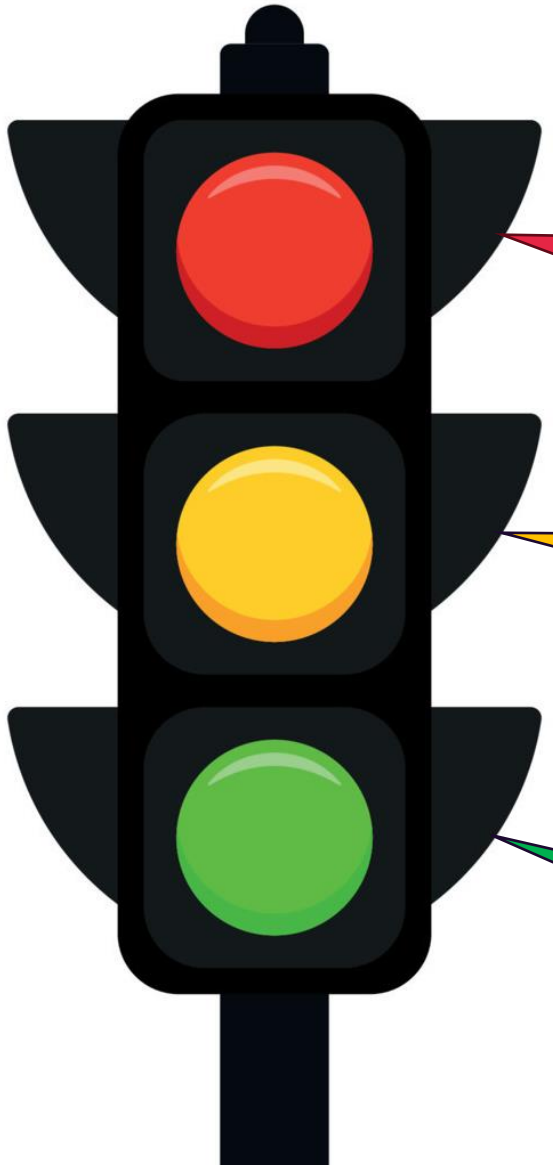
And some of:

- Changes in sleep, appetite, energy levels
- Self-absorbed, inattentive, unresponsive to people / things
- Inappropriate fears or avoidance of people or things
- Anxiety
- Hallucinations



Signs of Depression

EMOTIONS vs DEPRESSION



DEPRESSION

Teary, loses temper, withdrawn, irritable, aggression
May wake early (2am) and not go back to sleep
No interest in hobbies or favourite things
May talk of death or dying
May worry something will happen to close family / friends
No appetite / may lose weight

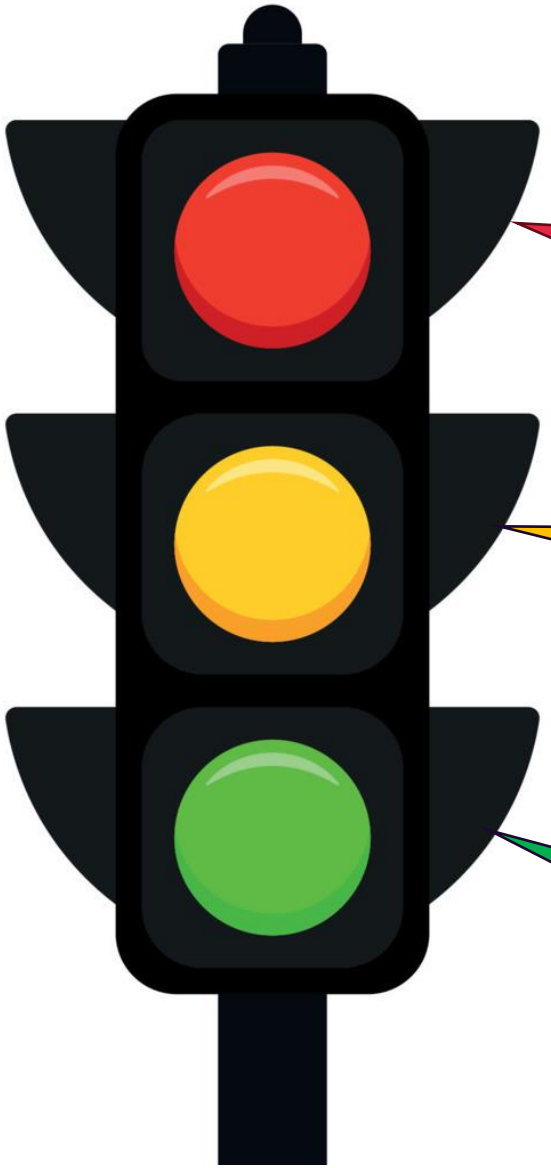
MONITOR

Not their usual self
Disinterested in usual activities
Fixated on some events

NORMAL

Greater extremes of emotion
Crying when others are upset
Poor tolerance of other's emotional extremes

STRESS vs BIPOLAR DISORDER



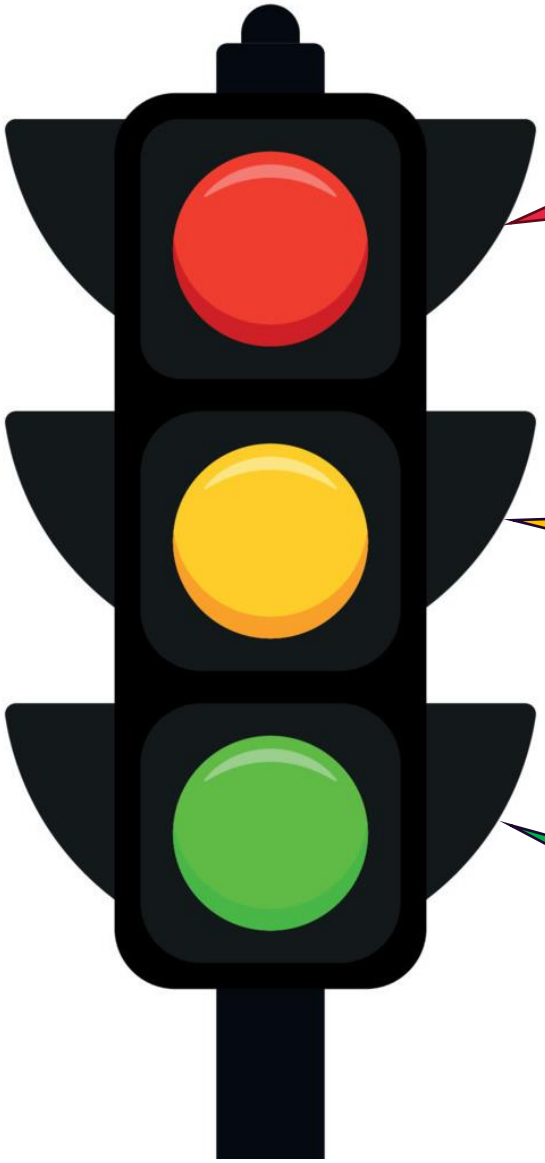
BIPOLAR DISORDER
Severe sleep disturbance (no sleep at all for days)
Uncharacteristic irritability, aggression
Increased activity
Periods of illness interspersed with clear periods of return to wellness / baseline functioning

MONITOR
Aggressive outbursts out of character
Energetic and doesn't seem to need as much sleep as usually does
Cyclic pattern

NORMAL
May be more unpredictable under stress
May need extra reassurance under stress
Some restless sleeping
Mood changes but settle

OTHER DISORDERS

DOWN SYNDROME REGRESSION DISORDER



DSRD
Severe reduction in communication
Severe reduction in ability to function / activities of daily living
Associated features of catatonia, psychosis or depression

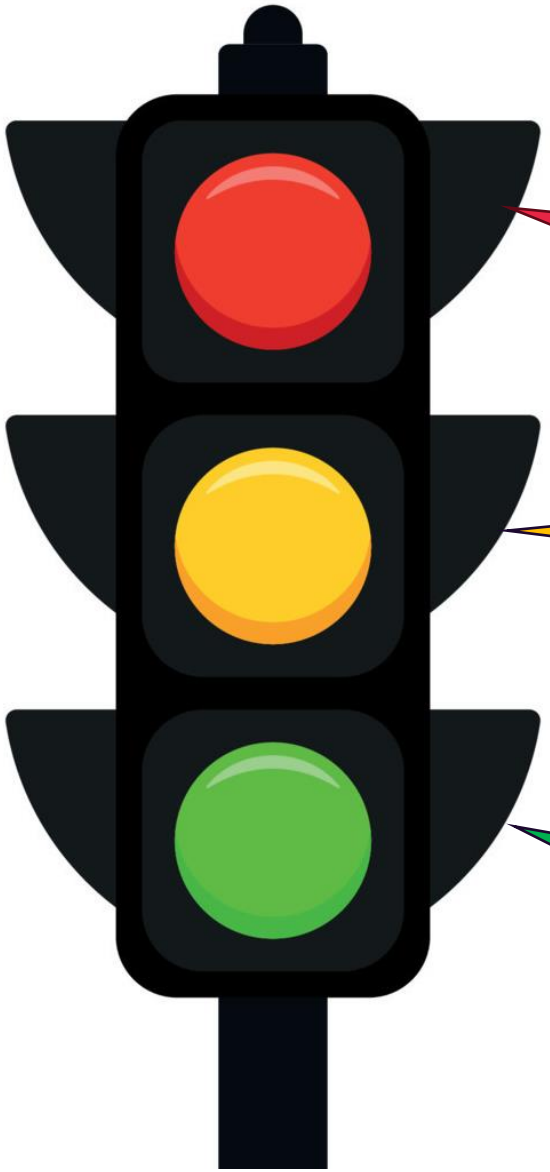
MONITOR
Increased slowness with normal activities
Some reduction in communication but still communicating
Needing additional prompting / support but still able to complete tasks

NORMAL
Need to allow extra time for everything
Withdrawn / quiet / anxious under stress
Takes longer than expected to process losses or traumatic events

Attention Deficit Hyperactivity Disorder

- Unknown incidence in DS “more common than general population”
- Up to 25% of children with ASD also have ADHD
- Must compare with peers of similar developmental age / stage
- Hints: Requires a lot of prompting to stay on task, very talkative, can’t stay on task
- In adulthood, hyperactivity is less prominent, poor attention and impulsivity (doing silly things) can continue
- Clinical experience: this diagnosis may be missed in people with DS and symptoms written off as - “Its just their Down syndrome”

ATTENTION DEFICIT HYPERACTIVITY DISORDER



ADHD

Inability to sit still or stick with an appropriate activity
Frequent impulsive acts in spite of knowing risks
Unable to concentrate for long, always on move, doesn't finish things

MONITOR

Needing additional prompting / support but still able to complete tasks

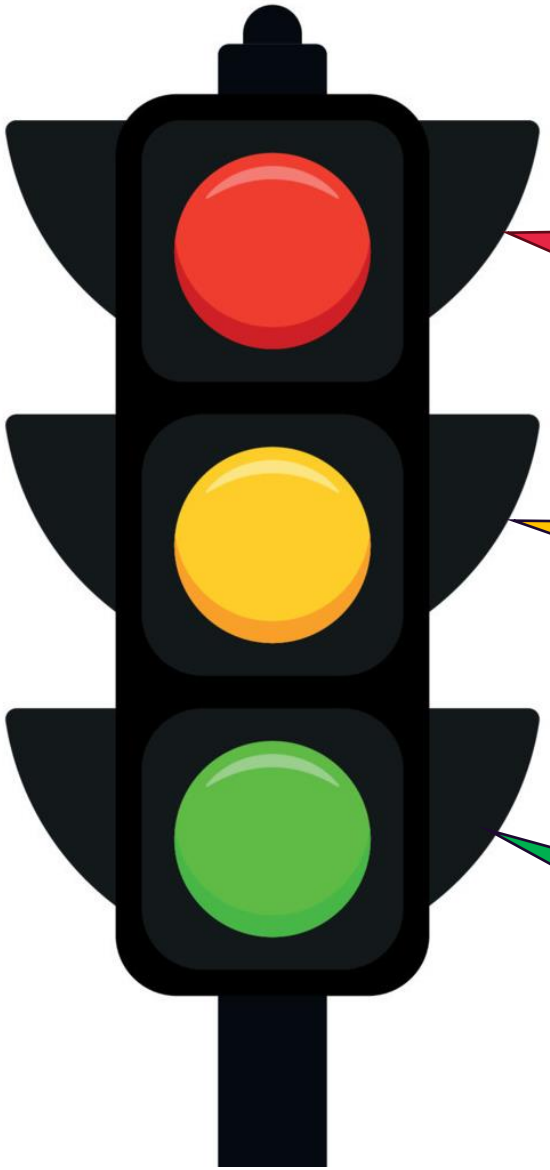
NORMAL

Won't concentrate or sit still if not interested / not engaged
Acts without thinking but can be redirected
Always on the move, especially if excited, lots going on

Autism Spectrum Disorder

- ASD is not a mental illness as such but does contribute to mental health
- Until 1990's, it was thought not to coexist with DS – so there's a lot of catching up to do in the academic literature!
- Parents may not notice differences in someone with DS until age 5-8 (ASD alone: age 2-3)
- Impaired Communication & Social skills – less marked than in ASD alone (may delay diagnosis), do still have issues with interpreting social cues, may have difficulty with eye contact, may have limited ability to respond to family affectionately, interacting with peers
- Restricted & Repetitive Interests / Behaviours – repetitive motor behaviours (hand flapping etc), unusual vocalisations, preoccupied with inanimate objects – can still occur in DS without ASD
- Sensory issues
- Behavioural issues – self-injury, sleep probs, ADHD

AUTISM SPECTRUM DISORDER



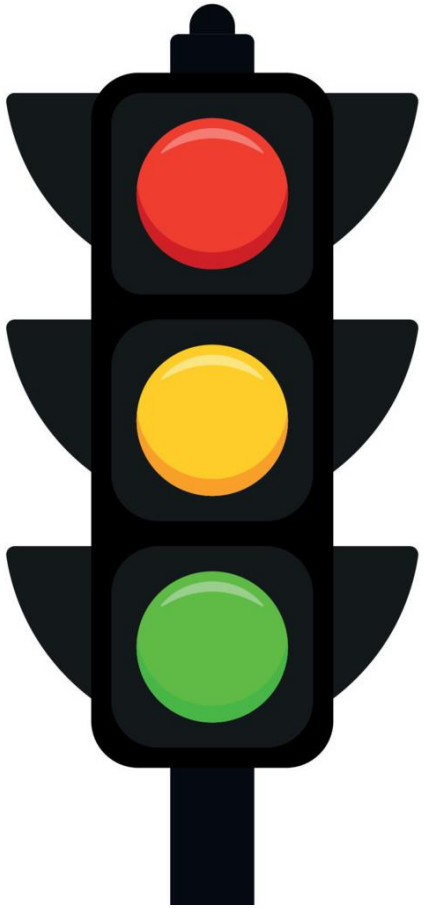
AUTISM
Onset in early developmental period of:
Disinterest in social interactions & relationships
Restricted interests to exclusion of all else
Repetitive behaviours
Greater difficulties with language
Marked sensory sensitivities
Extreme difficulty with change

MONITOR
Prefers to be on their own, lack of eye contact
Everyone knows about their hobby & they spend a lot of their time on it
Sensory sensitivities cause some issues
Dislikes change and needs warning but can cope

NORMAL
Better at talking to others than listening to them
Hobbies that they are very focussed on (esp collecting things)
Some sensory preferences (e.g. food)
Dislike of change but can cope

SUMMARY

Overview of Warning signs



Mental illness?

Change…

- Behaviour: new or different behaviours
- Sleep
- Nature of self-talk
- Function is affected

Neurodevelopmental problems?

Long-standing problems with

- Paying attention, sitting still, reckless behaviour (ADHD)
- Caught up in own world, lots of repetitive movements, very rigid, intolerant of small changes, very sensory-driven (?ASD)

- If you think something is wrong, get it checked out!
- Keep up with annual health and dental checks, vision and hearing
- Maximize strengths
- Be mindful of grief and loss, especially around time when school is finishing, siblings are moving out of home, transition to adult services
- If looking for help, look for someone who listens and is genuinely interested

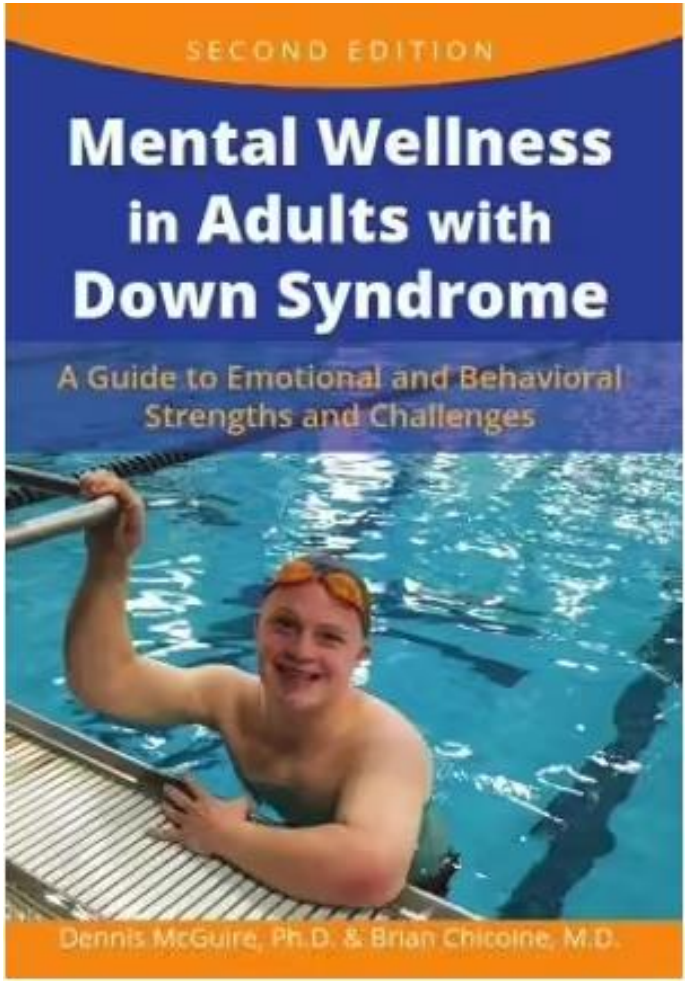
RESOURCES

Understanding Mental Wellness in DS

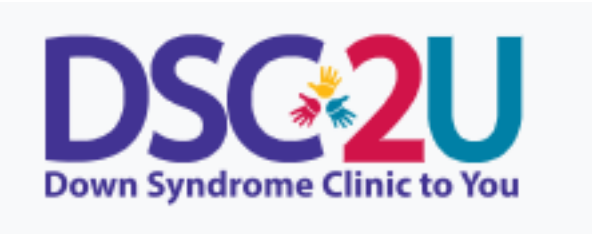
Dennis McGuire and Brian Chicoine's book "Mental Wellness in Adults with Down Syndrome", 2021

Available for download at:

https://adscresources.advocatehealth.com/mental-wellness-in-adults-with-down-syndrome-2nd-edition/



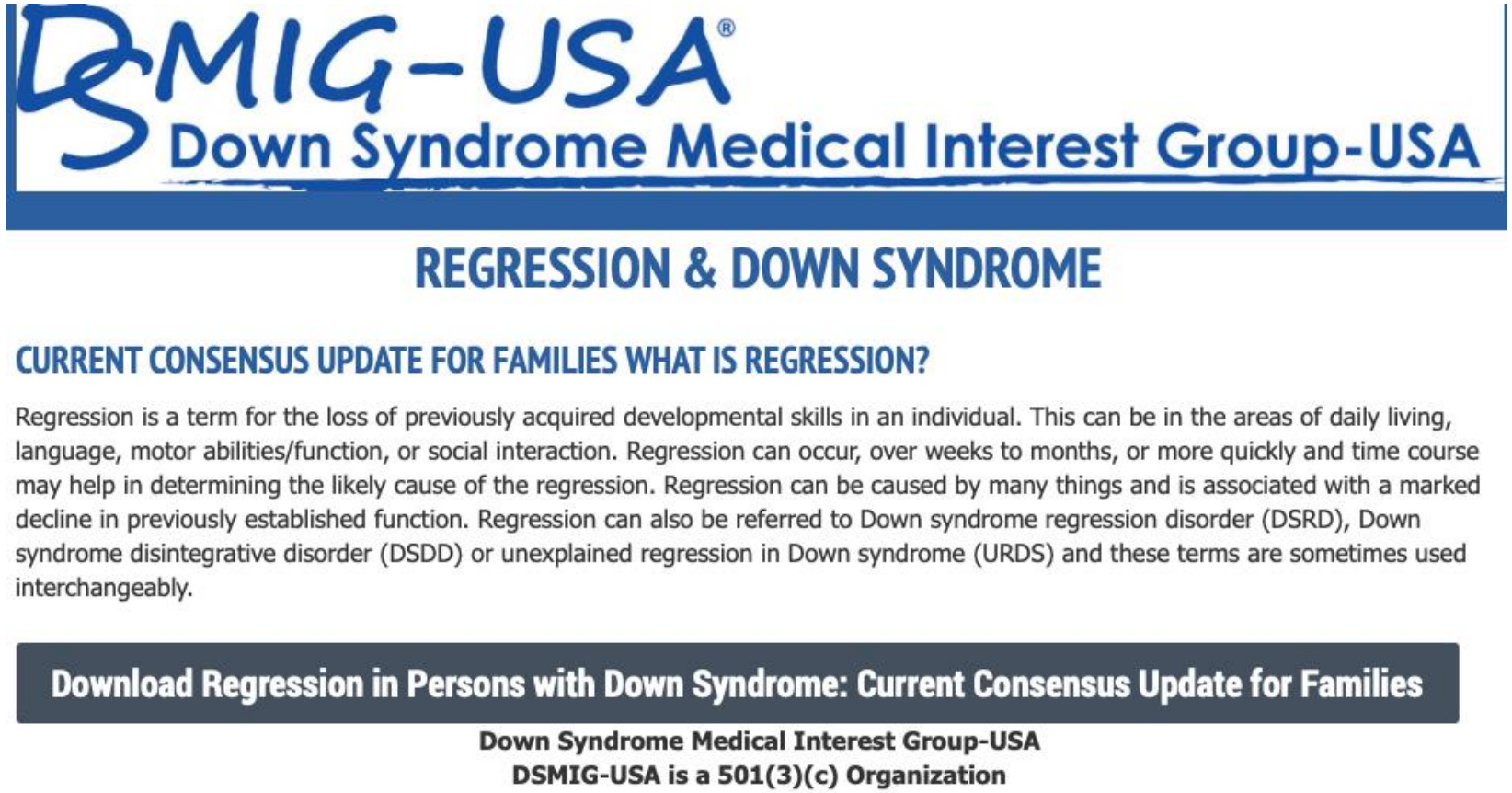
Health Check Tool



DSC2U

- Developed by Prof Brian Skotko and team
- Online, DS-specific health assessment tool that screens for symptoms
- Fee-based (may be covered by insurance)
- https://www.dsc2u.org

DSRD Information for Families



https://www.dsmig-usa.org/Regression

Webinar for Medical & Health Professionals

https://www.dsmig-usa.org/Speaker-Series

SESSION V & VI: REGRESSION & DOWN SYNDROME

Date: March 14, 2023 – Part 1 & May 9, 2023 – Part 2
Time: 7:00 – 8:00 PM EST

Individuals with Down syndrome may experience regression in previously acquired skills. This two-part webinar will present panel discussions on regression, with a key focus on Down Syndrome Regression Disorder (DSRD). This condition occurs most commonly between the ages of 10 and 30 years and is associated with loss of skills in language, cognition, behavior, motor and adaptive skills. Discussion will include what we currently know about DSRD diagnosis and management.

Part 1 Speakers	Part 2 Speakers
Eileen A. Quinn, MD UT College of Medicine and Life Sciences **Lina Patel, PsyD** University of Colorado School of Medicine **Robyn Filipink, MD** UPMC's Children's Hospital of Pittsburgh **Dr Cathy Franklin** QCIDD Queensland Centre for Intellectual and Developmental Disability Mater Research Institute - University of Queensland	**Eileen A. Quinn, MD** UT College of Medicine and Life Sciences **Lina Patel, PsyD** University of Colorado School of Medicine **Jonathan Santoro, MD** Assistant Professor of Neurology at CHLA and the Keck School of Medicine at USC **Cassie Karlsson, MD** Director - Child and Adolescent Psychiatry Fellowship Program & Clinical Associate Professor Department of Psychiatry and Behavioral Sciences at UK School of Medicine – Wichita

WATCH PART 1 RECORDING HERE

WATCH PART 2 RECORDING HERE

THE UNIVERSITY OF QUEENSLAND
AUSTRALIA
CREATE CHANGE

Thank you

DrCathyFranklin
Dr Cathy Franklin
DrCathyFranklin
Cathy Franklin

Email: c.franklin1@uq.edu.au
midas@mater.org.au