

Not being Believed = Abuse

Now I'm 64 its ELDER ABUSE

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‘Finding Lewy’ – i.e. Lewy Body’s

‘When you don’t fit the box.’

In memory of Robin Williams.

Not being Believed = Abuse

- **My lot** – last eighteen months – a nightmare
- **I'm taking on the medical establishment** – The MR's – the medical specialists with lots of block letters after their name – 'If you don't fit my box; I don't believe you' – feels like abuse!
- 'normal age related changes' – could be disease in its early stages but not called it
- ***--- If you are satisfied with 'normal' –you don't look for disease- If you don't know?***

Not being Believed = Abuse

- **Vulnerable** person seeking help needs to feel supported and believed.
- **Strikes at self worth** – having life stuff needing appointments with the specialist- the **MR's**, the last thing they need is to NOT be believed – **I've not been believed by several MR's and I feel traumatised, belittled – I feel ABUSED...**
- **Becomes 'abuse'** when person in power says or implies 'I don't believe you!' disregards- countermands – dis-empowers the client – *may even miss a diagnosis..*
- **Health professionals with power have a MORAL and ethical right to not cause harm by NOT believing**

Not being Believed = Abuse

- **I don't fit the box-**
- I had **unprecedented response** to a common Alzheimer's drug called **Aricept** [Donepezil Hydrochloride]-**unbelievable 'they say'**
- I have **FOUR indicators** to find the **third** most common dementia ***really early*** – **Dementia with Lewy Body- DLB.**
- I'm still not formally diagnosed – **I say I have Lewy Bodies as well as other wide spread damage** frontal temporal parietal
- I'm a community educator – fearless – well educated, body aware and **passionate advocate** for millions of us -- ***the Robin William's-un-diagnosed / mis-diagnosed DLB's***

Not being Believed = Abuse

- **I'm a pioneering farmer** – not a 'city slicker'
- Married 45 years, Mum of 3- Grandma to 8
- **Health professional for 32 yrs – Acupuncturist Physiotherapist** with *peer respect* - 'Val the Physio- my Physio' to thousands.
- **Consultant physio in nursing homes for 10 yrs** implementing better pain relief in **dementia care**. *I'm very knowledgeable about all aspects of dementia – never thought I'd get it tho'.*
- **Complex pain was my speciality-**
- I always **believed** my clients/got good outcomes
- I'm no longer registered – I can now speak freely!
- I'm a well travelled '**grey nomad**' – but the wheels have wobbled- I'm on a different journey to what I had thought would be my lot.

Not being Believed = Abuse

- With every major life issue – our response is only **Bitter or Better– I’m choosing Better** – I’m choosing to **live life** to the max. I lead from the front foot
- I’m different now – *I’m a ‘pit bull terrier with lip stick’* if fronted by a bully. **I’m not intimidated** by any MR who doesn’t believe me.
- I’m made an **exciting discovery** and I’m sprouting it on this platform and on social media – *Face Book is my work now* – I blog **‘Val’s Journey – Dementia is a Word not a Sentence’**
- *I’m gifted at disseminating information- I know my stuff...*

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- **last year** July 2015 I was a **crippled old woman** with orthotic granny shoes– *couldn't walk bare foot or more than 200 metres*. TRUE – sleeping twelve hours and **lethargic with brain fog which fluctuates** – I could function when fog cleared..
- **In hindsight** a *insidious brain rigidity* developing over **twenty years** progressively *inflamed /tightened* the **deep fascia** – back of skull, thoraco-lumbar and psoas fascia forcing a **dowager hump, stooped posture, restless legs, frequent falls..**
- **Increasing spinal and pelvic stiffness, deep pain and increasing disability-** *no belly dancing- couldn't progress line dancing 15yrs ago, L hand not able to play the piano scales- singing less. No lasting relief from any physical treatments ..*

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- *Early 2015* I'm exhausted with **severe night pain** with cramps, spasms and a **rapidly disintegrating brain-**
- but because I have **fat cheeks** and a **big grin** and I'm a woman –I'm **not being believed** – *a lot of things were self reported on by me as we travelled out bush extensively.*
- **all the extensive medical reports 'normal age related changes'** 'worried well' too high expectations. I could feel/ see damage tho'. – not even believed by my family—they excused my behaviour- only my husband believed me - my 'bestie'.. **I had Doppler scan, CT s MRI and SPECT scans**
- I've also had a **psychiatric assessment** and I'm not bi-polar
- *We kept looking for ANSWERS* - and **found them**

Not being Believed = Abuse

- **I HAVE MY LIFE BACK – with hypo-mania-** all 15 boxes – but it IS a life..
- How ? – one **Aricept 10mg** tablet a **Day before 7.30 am - That's it –**
- *4hrs late* –I get lost in the car park – *24hrs late –I'm a 'locked in zombie'* – fully aware but unable to initiate and the rigidity cramps spasms and pain return – **the disease is only controlled**. The medication takes longer to kick in after each break ..I refuse to stop taking it..
- ***'Un-believable' ... I know-***
- I say I'm only found super early, a **fore-runner not a 'freak'**.
- If you are suffering from Lewy Bodies...***Others DLB people report the same thing- 'I got my life back- the brain fog went !***

Not being Believed = Abuse

- **I went searching world wide** –for what had happened to me - love **'Dr Google'** I have a burning NEED TO KNOW – an encyclopaedic knowledge and I always think outside the square.
- I'm very **body aware** so I'm internally checking and with the **brain fog and sludge gone** out of my brain **my mental acuity is back** and I can remember very clearly now.
- ***Come and join me in my search for Lewy Body.***

Finding Lewy Body

- **In memory of Robin Williams the famous actor** -His brain was being attacked by Lewy Bodies -found at autopsy –affected his voice, moods and movement– Poor bloke took his life— Dementia with Lewy Body DLB --**they thought he had early Parkinson’s symptoms and was depressed.** He was given psychiatric medication. Poor sod wasn’t even given a trial of Aricept!
- **‘the sea monster with fifty tentacles’ ‘Whack the mole’ – quotes from his wife describing DLB**
- Other people describe it as having a **‘tornado in your brain’** with a ***multitude of attacks*** in various ***deep areas*** of the brain. I talk of **‘gnawing in the brain’..!**-affected my singing voice too

Finding Lewy Body

- reference re – ‘Robin Williams’ Wife Breaks Silence on ‘Monster’ Disease He Was Battling’
- [Daily Records](#) USA Daily Records
- [admin April 11, 2016 Robin Williams’ Wife Breaks Silence on ‘Monster’ Disease He Was Battling](#)2016-04-11T17:06:32+00:00[Dementia](#)
- **Robin Williams'** wife Susan Schneider has revealed her husband **killed himself** Aug 2014 because he was suffering from **debilitating brain disorder Lewy body dementia-** depression, just a **symptom of the disease.**

Finding Lewy Body

- Cont – ‘She hopes her family’s struggles and findings can help others with DLB.
- **“This was a *very unique case* and I pray to God that it will shed some light on Lewy bodies for the millions of people and their loved ones who are suffering with it,” she told People. “Because we didn’t know. He didn’t know.”**
- I’m hoping to make it less unknown...

WHAT is Lewy Bodies – DLB ?

- Dementia with Lewy Bodies DLB is only conclusively **diagnosed** at **post mortem/ autopsy**- Ref- The Alzheimer's Association.
- **Third most common form of dementia after Alzheimer's and vascular dementia**, - may cause *HALLUCINATIONS, impairment of MOTOR function and Parkinson's type symptoms*
- **Lewy bodies are found throughout the brain** and in other brain disorders, including **Alzheimer's disease AD** and **Parkinson's disease dementia PDD**.

What is Lewy Bodies – DLB ?

- **Named** after **Frederick H. Lewy, M.D.**, the neurologist who discovered them while working in **Dr. Alois Alzheimer's** laboratory during the early **1900s**.
- **Alpha-synuclein protein**, is the chief component of Lewy bodies- ***found widely in the brain- normal function unknown.***
- UK Dementia with Lewy Bodies founded in **1995**. - recent!
- [I didn't know about DLB when I retired 2005
- - in hindsight many of my clients were afflicted]

Finding Lewy Body

- Why it matters.
- **Dementia with Lewy Body DLB responds to 'Aricept'**
[Donepezil Hydrochloride tablet – daily 5mg 10mg] – **clears the 'brain fog' 'I've got my life back'**.
- **Acts like a *Battey reconditioner*** - reduces rigidity spasm and gives a window of improvement.- how long ---?
- **Education needed!** Aricept generally prescribed only for Alzheimer's Dementia AD - not for DLB-
- **Rarely found early enough** – *mimics depression* and Parkinson's for 3-4 yrs and then told nothing can be done -

Finding Lewy Body – Why it matters...

- **Facing a dementia epidemic..world-wide** eg -Lewy body dementias (LBD) -1.4 million individuals and their families in the United States. **Ref- Lewy Body Dementia Association, [LBDA]** - much more in reality –
- **LBDA – ‘*few individuals and medical professionals are aware of the symptoms, diagnostic criteria, or even that LBD exists.*’**
- **Matters for you, a loved one, or a patient you are treating to know about Lewy Bodies..**

Important FACTS about DLB

- 1- DLB patients come out of **anaesthetics** more slowly
- 2- **Anti-psychotics contraindicated** for individuals living with LBD: DLB affects an individual's brain differently than other dementias. ***Many traditional antipsychotic medications*** to control behavioural symptoms e.g., haloperidol, thioridazine cause a ***severe worsening*** of movement and neuroleptic malignant syndrome (NMS) causing severe fever, muscle rigidity and breakdown that can lead to kidney failure- ***potentially fatal***
- 3- **Not steady/ slow progress**- more acute episodes /differing symptoms / more rapid / difficult to manage 'end stage' than other dementia's

Important FACTS about DLB cont

- 4 - affects an individual's **cognitive abilities, motor functions**, and/or *ability to complete activities of daily living ADL's* -**early recognition of DLB helps in knowing WHAT is going on --important to be believed...**
- 5 - **Treatment should always be monitored by a physician** and may include: prescriptive and other therapies, exercise, diet, sleep habits, changes in behaviour and daily routines
- 6- **Get a DIAGNOSIS – MRI and SPECT scan neuropsychological assessment and a trial of Aricept – 2 months --- see if it clears the brain fog ...‘I’ve got my life back’ too**

Finding Lewy Body

- **Cause .. None known** – not genetic or family history
- ‘Researchers have not yet identified any specific causes of dementia with Lewy bodies.
- Most people diagnosed with DLB have **no family history** of the disorder, and **no genes** linked to DLB have been conclusively identified’ **..ref LBDA..**

Finding Lewy Body -- by me

- **FOUR** tests
- **Fast Feet'**
- **IQ drop > 20 points**
- **3-4 Cerebral Funnies**
- **Lewy Body Composite Risk Score [LBCRS] -**
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Finding Lewy Body.. No 1

- **1 -FAST FEET**– have a go – can do it in sitting ..
- **Fast feet – ‘soft shoe shuffle’ – 20 patters in 3 secs** – Cant = rigidity = Why ?
- **tests neurological ability**- not just a physical drill
- Background – I could do it at 38yr old netballer– could no longer do it at 45 yrs old- I can do it again now after treatment– **peer approval...**

Finding Lewy Body.. No 2

- **2- IQ drop > 20 points**
- Background-
- **Last two years I felt stupid, did stupid –was stupid – Aug 2015 self tested IQ 90 ... Ave is IQ 97 *still easily passed all mini-mentals pre Aricept.*** [My IQ was MENSA when I was a uni student – still IQ 131 at 50- national testing 2002]
- **Neuropsychology assessment Jan 2016-Six months on Aricept 10mg –[Donepezil Hydrochloride]-*extensive testing*** found I have many *wide ranging deficits relative to cognitive reserves affecting frontal /temporal / parietal lobes*
- Superior Intelligence IQ 121- *my ‘smarts’ are back -- sharp mental acuity.. Brain fog gone ..*

Finding Lewy Body.. No 3

- **3 - Cerebral Funnies - 3 – 4** I have a page full of these
- **2004 I lost the ability to map read-** couldn't drop on my knees on a trampoline – **Fright reflex +++**
- **2008** ON my daughter said I was changing-/**depressed?**- I had many ongoing life-grievous events – life's stuff.
- **four years ago-** my husband started to tell me '**you are losing the plot**' – '**Valerisms**' become '**Val-zheimer's**' – he stopped when it got too painful
- **Feb 2014- Aug 20125 -L foot sprain became an RSD +** changed reflexes/weakness L side
- **Oct 2014** I had an out of character **outburst/lability++** not coping with stress or toxic people – **imploding**
- **Nov 2014** my **tongue deviated to the right** blurred vision turned out to be cataracts with now two new lens – '
- **April 2015 I'm getting lost/confused/mistakes +++**
- **May 2016 I had a TGA Transient Global Amnesia lasting over 8 hours.** [*no acute lesions –bleeds /tumours found – 'normal age related changes ' minor atrophy –worried well' 'too high expectations'*]
- **I could see the changes** on the SPECT scans and read **diverse minor changes on the MRI – –** - not the MR's opinion until he saw the **SPECT scan and read the results – He organised a trial of Aricept 10mg Aug 6th 2016 – within a day I had my life back with hypo-mania– but at least its a life.. Didn't believe me again Jan 2016 when he saw me after 5mths ...**

Finding Lewy Body.. No 4

- ***a REAL BREAKTHROUGH*** plus with other **3 tests**
- **accurate and sensitive in finding Lewy Body** apart from other dementia's and *cognitive impairments*
- **Lewy Body Composite Risk Score [LBCRS] - Copyright 2015 James E. Galvin** questionnaire
- - Ten questions - takes three minutes > **3/10** is **positive DLB**
- *More info go to 'Dr Google'*

Finding Lewy Body.. No 4

- **LEWY BODY COMPOSITE RISK SCORE [LBCRS]**
- Please **rate** the following **physical findings** being **present or absent** for the **past 6 months** and **symptoms** as being **present or absent** for at **least 3 times over the past 6 months**.
Does the patient...
- **Yes / No** marks

Finding Lewy Body No 4

- **No 1-** Have **slowness** in initiating and maintaining movement or have **frequent hesitations** or pauses during movement? **Yes-** I had **slowness in initiating** movement - often pushed past and told to **hurry up- dowager hump stooped posture- always stretching /writhing** to overcome stiffness and **severe restless legs at night.** – *went*
- **No 2 - Have rigidity** (with or without cogwheeling) on passive range of motion in any of the 4 extremities?
Yes- Rigidity -- started over 15 yrs ago

The Lewy Body Composite Risk Score cont ..

- **No 3 - Have a loss of postural stability** (balance) with or without **frequent falls?**- **Yes - 5 falls / 6mths** -... *[I now can freely rock hop and dance-sure footed and be the adventure grandma...]*
- **No 4-Have a tremor at rest in any of the 4 extremities or head?** Sort of - Wii Fit showed **whole body fine tremor- fine tremor in my hands** when 'stretched' emotionally. Feet often went into **clonus**..[- gone]

The Lewy Body Composite Risk Score cont ..

- **No 5- Have excessive daytime sleepiness and/or seem drowsy and lethargic when awake? - Yes.. zombie in front of TV or on the bed -Apathy /Lethargy +++ Aricept -full of adrenalin -Hypo-mania -insomniac - jobs done !**

The Lewy Body Composite Risk Score cont ..

- **No 6-** Have episodes of **illogical thinking** or **incoherent, random thoughts?** **Yes-** ‘Valerisms’ to Val-zheimer’s strange word computations-using wrong word- **when heavy brain fog present –gabbling/ making no sense at all..**
- **No 7-** Have frequent **staring spells** or periods of **blank looks?** **Yes-** ‘stunned mullet’- **fully aware but unable to participate** now ALL gone..

The Lewy Body Composite Risk Score cont ..

- **No 8- Have visual hallucinations** (see things not really there)? **Yes-** not full blown but frequent **allusions** - seeing animals in objects . **Had one 'real' vision about my father**—could smell his acrid tobacco sweat for days in my nose – *all gone with Aricept ..*
- **No 9- Appear to act out his/her dreams** (kick, punch, thrash, shout or scream)? – **No** - certainly weird ***pointless dreams*** – never could remember my dreams before.

The Lewy Body Composite Risk Score cont ..

- **No 10-** Have **orthostatic hypotension** or other signs of **autonomic insufficiency**? **Yes** - return of **hot flushes** and **full body sweats** , **sphincters weakening** - messy mouth- often unaware until told to '**Wipe your Moosh**', **hiccups +++ oesophageal hiatus sliding hernia** becomes ulcerated -**frequent UTI's urinary dribbling** without weakened pelvic floor an **explosive bowel**. **Blood pressure difficult to stabilise- Yes Not well sorted even now!**
- **TOTAL SCORE** My score **8.5 / 10 = DLB**
- **Knowledge is power** -realistic expectations now..
- - **A mixed bunch with the frontal / temporal /parietal damage as well - It is what it is!**
- **I found this LBCRS – James Galvin 2015 form a breakthrough** – added to the other **three tests-** wild thoughts become coherent through these questions..

Finding Lewy Body.... **WHY ?**

- **DLB responds to Aricept** – sometimes quite dramatically if found early enough
- **Different rate of decline and set of issues** for client, family, carer and institutionalised care
- **Not to be given anti-psychotic drugs**
- **Come out of anaesthetics slower**
- Usually **memory aware** for longer – knowing..
- **Very common---** third – *most under diagnosed*
- **Scans** – CT MRI SPECT PET - to be **accurately read**
–*when is ‘normal age related’ significant disease?*

Finding Lewy Body -- new findings

- The Queensland Brain Institute **QBI** is starting **human trials** in **2017** using **ultra sound** to break up **neurofibrillary tangles** and **tau plaques** in **Alzheimer patients** – mice trials show **75% improvement** in maze running with **NO** damaging side effects..
- **brain inflammation – microglia – role ??**
- My **hair analysis says** high levels of **Rubidium**. I also I'm a fast metabolism No 1-- **Rubidium** found in **high concentrations** in **pre-clinical dementia** but gone at autopsy with severe dementia – **significance? – an indicator only or a treatment.**
- **Curcumin [Turmeric-'Indian Aspirin'], Vit. D3 and Coconut Oil** all show **significant promise** in improving dementia symptoms .
- **High protein low complex carb diet -no sugar also clears brain fog.**

Finding Lewy Body- **IT MATTERS !**

- **The face of dementia is rapidly changing** –major research breakthroughs **last five years** – The MR's – the establishment needs to come along and be proactive too – **being diagnosed super early with dementia matters** – esp. DLB *It may not be terminal tub chair with the associated **STIGMA***
- It could be managed like **diabetes**-regular /daily medication **controlling** the disease
- like **PSA and DRE testing[finger up the butt] for Prostate cancer** – my husband is a survivor.

Finding Lewy Body-Mimics depression

My health professional family and friends thought

I was depressed – since 2008- I wasn't

I ticked most of those boxes with lethargy +++ and apathy most prominent – always tired – in bed 12+ hrs- apathetic/ zombie with weakening sphincters – mouth, gullet and bowel/bladder.

No interest /cant initiate --even work my camera-**imploded**. Getting stressed/labile /lost- gabbling.. What's wrong with me ?? Told only 'worried well', 'normal ageing' get over yourself!-not believed...



FOUND -- Lewy Body..

- I'm not depressed I have Lewy bodies- cant 'fast feet', IQ drop > 20 points, > 4 Cerebral Funnies , LBCRS Score 8.5/10 = DLB...**
- My SPECT scan shows only < 2/5th of my brain needs blood at rest- Hypo-perfusion found in bilateral mild to moderate frontal-temporal parietal lobes – Mixed dementia?- still to have a PET scan and a formal diagnosis....**
- I have got my life back with daily Aricept 10mg.**

FOUND Lewy Body..Conclusions

- **I know how to walk in divine health** being a Holy Spirit Filled Christian since 1978. I know where I'm going to end up! When God says to jump I just ask 'how high?' I love God and love my fellow man.
- **I also practice Dr Caroline Leaf's 'Neuroplasticity of the Brain'** – overcoming **toxic thinking**- what we think determines our brain health- we are not wired to worry – wrecks our immune system.
- **End stage DLB is nasty– a terminal disease..**
- **Google it yourself please-**

FOUND Lewy Body.. **Conclusions**

- I am as **proactive** as possible in my personal affairs- while I can. Life's a roller coaster – very full on...
- **Legal requirements-** Dementia is **notifiable** to the authorities ***Aricept is NOT*** – **I have my drivers licence returned - annual medical review** - can have a two month trial of Aricept without risking your drivers licence..
- **My will is upgraded.** My attorneys / guardians are appointed.
- My **LIVING WILL** made in 2008 **updated** now states **'when I can't put a cup to my lips myself, palliation is to start'** – no tub chair gaga existence for me.

FOUND Lewy Body...and **action taken.**

- I wear a **Medic alert bracelet** in public- DNR Active Directives in place – Inside- **Dementia Do NOT resuscitate.** – I considered a chest tattoo ‘You Resuscitate I Sue’. **My guardians, family GP and the nursing home are all in agreement.** - *not assisted suicide/ euthanasia..*
- **My name is now down at a nursing home** – the same one I was a consultant physio in for ten years. The administrator said I may need them as early as *three months for respite* or in **three years. I want to go into care – sooner rather than later, when I lack insight or become a ‘sundowner’.** I know dementia- from ALL sides- the effects on the family - It is what it is.

FOUND Lewy Body...**future action**

- At times my brain goes **berserk** with what my dementia future looks like –. My **bestie comforts me** by saying ‘Its not today– You know me today, you know who you are today- Live in the present – it’s a gift - Live it to the max. God knows..
- I have regular psychologist appointments to vent safely with wise people

FOUND Lewy Body - Summary

- **Be kind – believe a person – don't cause abuse..**
- **Finding Dementia with Lewy Body early matters eg - Check someone who is depressed for DLB-**
- **Can they – fast feet? IQ drop > 20? 3-4 cerebral funnies? LBCRS >3 /10 have a 2 month trial of Aricept [Donepezil hydrochloride] and clear the Brian Fog- may get their life back too...**
- **I am in a unique position and being enabled to live a very full life- I'm able to take on the *medical establishment* to give the other *millions of blokes* like Robin Williams a chance at early treatment – while I can....**

Found Lewy Body

- **From the lady who pats TIGERS**
...Dreamworld The Gold Coast
- - **who drives the Brock V8 virtual super car very fast ! Bathurst trip 3. 47mins only 60secs slower than legend Larry Perkins.. – adventure Grandma !!**
- – **I choose life -to live to the MAX-**
- I'm safely tied on the bosses utility/truck-like the beloved dog -
Father God is the driver- He knows the way
- I hang on and enjoy the ride.
Have a good day mate..

