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Dementia Journal
January 2015

This month:

- **Article from Teepa: "Exploitation & Dementia"**
- **A Focus on Lewy Body Dementia**
- **Where Did You Go? - I Am Still Here Film/Documentary ~ Kickstarter**
- **January Meditation: Ghandi's 10 Fundamentals for Change**
- **Living With with Dementia: "Norrm", Kate Swaffer, LBDA**
- **Updates from the Dementia Action Alliance**

Exploitation of those Living With Dementia

Exploitation of people living with dementia is a fast growing white-collar crime. While it is estimated 15-20% of all elders will experience some sort of neglect, abuse, or exploitation, [the number climbs to nearly 50% for those living with some form of dementia.](#)

Care providers who are overwhelmed, uninformed, or unsupported in their care giving efforts represent a large percent of those at-risk. More concerning, however, are opportunists and predators who are seeking out and 'cold-calling' on individuals living with dementia who are changing in ability, isolated, undiagnosed, and often obviously vulnerable.



Caution is advised as [perpetrators can take 'everything' from a person](#) and it commonly takes years to find or prosecute the criminals. Most cases go undetected until it is far too late for the person, their family, or even the courts to help. The symptoms of many types of dementia make it a 'feeding ground' for those who seek to cause harm. It can also be challenging territory for those who desire to protect and provide the often needed boundaries and warnings, support, or guidance for individuals truly at the mercy of their illness.

According to governmental agencies and national support organizations, the greatest weapons against these attacks and problems is AWARENESS, EDUCATION, and PREPARATION. I would encourage the addition and importance of learning specific dementia related interpersonal SKILLS to this list. There are valuable techniques and approaches available to help plan for and address these more difficult issues and relational dynamics.

The goal is to partner well with a client, friend or family member successfully protecting their assets, safety, and well-being WITHOUT ignoring their desires and need to remain independent and autonomous as long as possible. Dementia changes people, and will take [relational approach skills](#) that, in my 30 years of experience, well meaning professionals, friends and family may or may not instinctively have. When you are trying to help, meet resistance, and react negatively it increases the risk and vulnerability for others to step in and use their well developed victimization skill. You can help, [but may need new strategies to make a difference.](#)

~ Teepa Snow, MS, OTR/L, FAOTA

Resources to help understand the issues - Identify what can and should be done to reduce risk for families

- [Mistreatment and Abuse of People with Dementia: Alzheimer's Society](#)
- [Short-Changed: Protecting People with Dementia from Financial Abuse](#)
- [Elder Neglect and Abuse: Warning Signs, Risk factors, Prevention, Help](#)
- [Unconscionable: Financial Exploitation of Persons with Dementia: Marquette Elder's Advisor](#)
- [Protecting Mom and Dad's Money: Consumer Reports](#)
- [Schemers, Predators: Senate Hearing Report, 2002](#)

Donate Today And Help Teepa Raise Dementia Awareness

Enter Kerina Voltoph...

Fictional character in KICKSTARTER short film campaign
'Where Did You Go?'

Penelope Wildgoose, co-writer and lead actress in the film, shares with Positive Approach about the perpetrator in the film.

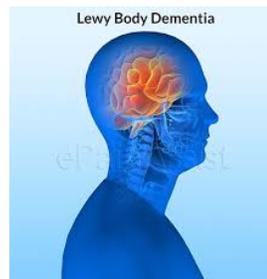
"It is hard to accept that there are those people in the world who are so severed from their own humanity that they cannot empathize. My character, Jean Rose meets just such a person in Kernina Voltoph. She is beautiful, charismatic, self-assured, and willing to use her perceptive intelligence to manipulate a vulnerable woman for personal gain. I would say Kerina is the classic narcissist. The kind of person who teaches the rest of us how not to trust. Kerina, a financial advisor by trade, is best described as a morph-ling with no shadow. She would sit beside you, smile sweetly and know exactly what to say, exactly how to 'care', exactly how to leave you with nothing. She is your friend with a face, and enemy without one.

In fact, Kerina is so good at what she does, that she knows you, better than you know yourself. Recently, I had an interaction with a family who knew this character all too well. This similar ruthless approach to Jean Rose's state of being and increasing disconnect with details of her 'reality', was a recipe for danger."



TODAY'S VOICE FOR DEMENTIA

Teepa is an advocate for those living with dementia and has made it her personal mission to help families and professionals better understand how it feels to be living with dementia related challenges and change. Her company, Positive Approach, LLC was founded in 2005 and offers education to family and professional care partners all over the world. Her goal? Making a difference...one mind at a time.



What is Lewy Body Dementia?

LBD is NOT a rare disease. It affects an estimated 1.3 million individuals and their families in the United States. Because symptoms can closely resemble other more commonly known diseases like Alzheimer's and Parkinson's, it is widely under-diagnosed. **Many doctors or other medical professionals still are not familiar with LBD.**

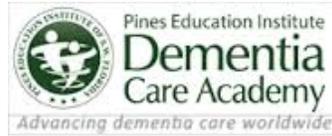
LBD is an umbrella term for two related diagnoses. It refers to both Parkinson's disease dementia and dementia with Lewy bodies. The earliest symptoms of these two diseases differ, but reflect the same underlying biological changes in the brain. Over time, people with both diagnoses will develop very similar cognitive, physical, sleep, and behavioral symptoms. While it may take more than a year or two for enough symptoms to develop for a doctor to diagnose LBD, it is critical to pursue a formal diagnosis. Early diagnosis allows for important early treatment that may extend quality of life and independence. **LBD is a multi-system disease and typically requires a comprehensive treatment approach. This approach involves a team of physicians from different specialties who collaborate to provide optimum treatment of each symptom without worsening other LBD symptoms.**

Many people with LBD enjoy significant improvement of their symptoms with a comprehensive approach to treatment, and some can have remarkably little change from year to year. It is also important to know **people with LBD are extremely sensitive or may react negatively to certain medications used to treat the symptoms of Alzheimer's or Parkinson's in addition to certain over-the-counter medications.**

Lewy Body Education From Teepa Snow



This 2 hour educational video is designed to help care providers recognize and appreciate the unique features of Lewy Body Dementia (LBD). LBD is estimated to be the third most common type of dementia. Although originally thought of as simply a combination of Alzheimer's and Parkinson's Disease, it is now viewed as a separate entity with a specific symptom profile, identifiable protein malformation, different progression pattern, and presenting special care and treatment challenges. The goal of this session is to help care partners better understand the condition so that care can be provided that is better matched to the person and their unique needs and challenges. For more information or to purchase *Lewy Body Dementia - What Everyone Needs to Know* please visit the [Pines Education Institute's Dementia Care Academy](https://www.pineseducationinstitute.com/dementia-care-academy).



Help fund us on **KICKSTARTER**

Please **PLEDGE!**
7 DAYS AND COUNTING

If everyone who visits this page would give as little as \$10 to the project
(that's a Starbucks coffee and a muffin right?)

THE PROJECT WOULD BE FUNDED!



[Short Film Teaser: Where Did You Go](#)
[Documentary Trailer: I Am Still Here](#)

January Meditation: Fundamentals for Change



Mahatma Gandhi's approach to humanity and ability to initiate needed change applies beautifully to the heart of soul of what individuals living with dementia need from everyone involved. Meditate on these 10 principles of his work and how they might improve your daily life and interaction with those you serve.

1. Change Yourself.

If you change yourself you will change your world. If you change how you think then you will change how you feel and what actions you take. And so the world around you will change.

"Nobody can hurt me without my permission"

2. You are in control.

Doing this makes life a whole lot easier and more pleasurable. What you feel and how you react to something is always up to you. You can choose your own thoughts, reactions and emotions to pretty much everything.

"The weak can never forgive. Forgiveness is the attribute of the strong."

3. Forgive and let it go.

When you can incorporate such a thought habit more and more into your life then you can react in a way that is more useful to you and others. Spending your time in some negative memory won't help you after you have learned the lessons you can learn from that experience. By forgiving you release yourself and then you can focus totally on, for instance, the next need.

"An ounce of practice is worth more than tons of preaching."

4. Without action you aren't going anywhere.

Without taking action very little will be done. Because action is hard, there can be much inner resistance and so you may resort to preaching, as Gandhi says, getting no practical results in the life you seek. To get where you want to go, and to really understand yourself and your current world, you need to practice. Reading words and new ideas may bring you knowledge, but you have to take action and translate that knowledge into results and understanding.

"I do not want to foresee the future. I am concerned with taking care of the present. God has given me no control over the the moment following."

5. Take care of this moment.

The best way that I have found to overcome the inner resistance is to stay in the present as much as possible and to be accepting of what is happening. Remember that connecting with and staying in the now is a mental habit, a sort of muscle, that you grow.

"It is unwise to be too sure of one's own wisdom. It is healthy to be reminded that the strongest might weaken and the wisest might err."

6. Everyone is human.

Keep in mind that everyone is just a human being and we are all prone to make mistakes. Holding people to unreasonable standards will only create negativity within you and more unnecessary conflicts in your world. Avoid falling into the pretty useless habit of beating yourself up over mistakes that you have made. Instead be able to see with clarity where you went wrong and what you can learn from your mistake, then try again.

"First they ignore you, then they laugh at you, then they fight you, then you win."

7. Persist.

Be persistent. In time the opposition around you will fade and fall away. And your inner resistance and self-sabotaging tendencies that want to hold you back and keep you like you have always been will grow weaker. Don't give up too soon and keep a good sense of humor. It's important to lighten things up at even the toughest times.

"Man becomes great exactly in the degree in which he works for the welfare of his fellow-men."

8. See the good in people and help them.

If you want improvement then focusing on the good in people is a useful choice. It also makes life easier for you as your world and relationships become more pleasant and positive. Being of service to others by giving them value not only makes their lives better, but over time, you get what you give.

"Happiness is when what you think, what you say, and what you do are in harmony."

9. Be congruent, be authentic, be your true self.

When words and thoughts are aligned communication is better and stronger. This is because voice tonality and body language are 90 percent of the message being shared.

"Constant development is the law of life, and a man who always tries to maintain his dogmas in order to appear consistent drives himself into a false position."

10. Continue to grow and evolve.

You always improve your skills, habits or re-evaluate your evaluations. You can gain deeper understanding of yourself and the world. If you don't, then as Ghandi says, you will drive yourself into a false position. It's not a fun place to be. Choose to grow and evolve is a happier and more useful path.

"The difference between what we do and what we are capable of doing would suffice to solve most of the world's problem."

Living Well...Dementia World News

GEMS™
 Dementia Aware
 Dementia Knowledgeable
 Dementia Skilled
 Dementia Competent

Aware:

Forget Me Not: Lewy Body Facebook Support Group

Posts from: Norrms

Common symptoms in Lewy Body Dementia include: wakefulness, visual hallucinations, and delusional thinking. These can become much worse at night, as described below by someone "living with" this experience.

Posted: Jan 22nd, 11:19 AM

For Peaceful Sleep

*As light fades, and darkness falls,
 In the distance, you hear Lewy's call,
 You know he's coming, to visit you,
 Once been heard, not much to do,
 Except sit and wait, with nerves in shreds,
 Lewy Body's dementia, has many heads,
 None are pretty, all are foul,
 As he arrives, you start to howl,
 This night of terror has just begun,
 And until the rising of the sun,
 He will stay with you, to plague your mind,
 Such utter torment, to one so kind,
 Then he's gone! So quick, so fast,
 Yet it feels a lifetime's last,
 Until again, he does return,
 For peaceful sleep we all will yearn*

Norrms was diagnosed with dementia 7 years ago and is still fighting it !!

Posted: Jan 23rd, 3:34 PM

Dementia

Leaving The Front Door Open

Last night I left the front door of my mind open, and Lewy Body's came walking straight in as if he owned the place. He is like a squatter who refuses to move out. Elaine says about an hour before I went to bed I had no understanding of what was going on or where I was. To be told this is soul sapping as I am completely helpless to stop my actions and to have no control over them is frightening beyond belief, but then things got much worse. I have often found myself stood in the front room, or bedroom, protecting my family from an unseen enemy to anybody else but they are very real and very present to me. Last night in the back of my mind I could hear my angel's voice shouting Norrms! Norrms! Its ok, it's ok! And a sentence that will haunt me forever as I heard her say..... "Please come back to me "

At the very moment I returned to "real Time " I was throwing the last punch into my pillow, hard and fast, and by the ache in my arm and the sweat on my brow it was quite obvious it had been happening for a couple of minute. I screamed one last time in frustration as I threw that last punch and fell into my loved ones arms, lost, confused and very frightened. It was only after a couple of minutes had passed did the awful truth dawn on me and I thought "WHAT IF..... ?"

OH MY GOD!!! Just the very thought made me shiver to the bone and I started to shake uncontrollably. For those of you who don't know me I abhor violence of any kind, to human or animals and if by chance I happen to see any kind of gratuitous violence on TV Etc. that is not a film but real life I have been known to be physically sick. So you can imagine what was, and still is going through my mind, I can't even say it!! The most frightening thing is, according to Elaine this is not uncommon and thankfully up to now the only harm has come to my poor pillow, but still ????????????????

*I despise this illness, HATE is a very strong word and I have always been brought up to forgive and forget, but if Ever? EVER? Even Just ONCE??
 It doesn't bear thinking about. I am sorry if this post upsets anybody, but this is what this disease is really like, laid bare for all to see." Unless we, with dementia teach you ? How can others learn??"*

A very tired and weary Norrms, Elaine & Family xxxxxxxxxxxxxxxxxxxx

Knowledgeable:



"Dementia care is caring for people who often do not know they need care, and don't want to be in care; no wonder we may become angry and upset."

Kate Swaffer: Creating Life with Words Inspiration, Love, and Truth

[Kate Swaffer](#) is a consultant for Alzheimer's Australia, working with them specifically on the dementia friendly initiatives around Australia. She has just completed a Masters of Science in Dementia Care at the University of Wollongong (2014), has a Bachelor of Psychology, a Bachelor of Arts in professional writing, a Chef's certificate, a Graduate Diploma in grief counseling, and was an RN, having worked in aged and dementia care, and operating theaters. Kate's professional and research interests now include the quality of the care provided for people diagnosed with dementia, the lived experience of dementia, and she has a specific focus on stigma, human rights, discrimination and language in the dementia sector.

She also lives well with younger onset dementia, having been diagnosed at the age of 49. She writes a daily blog which was archived in 2012 in the PANDORA collection of the South Australian and National Australian Library, where she is committed to meaningful dialogue with a wide range of stakeholders about the critical issues impacting a person living with a diagnosis of dementia and their loved ones. She is an international and national speaker having presented extensively on dementia including four Adelaide Fringe performances called 'My Unseen Disappearing World.' Kate is also a published author and poet, and volunteers as an advocate and activist for people with dementia and the homeless. Her new book ["What the Hell Happened to My Brain"](#) is set for release in August 2015.

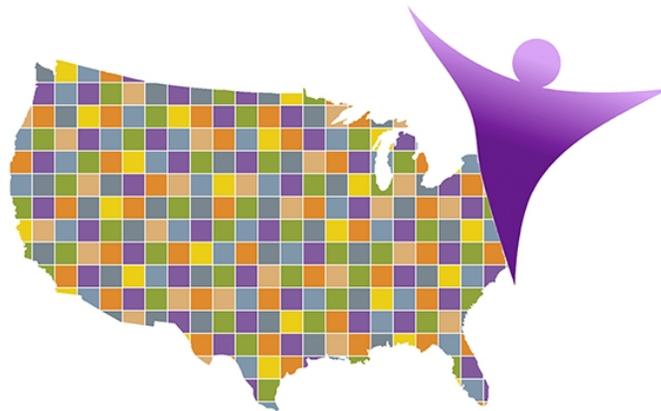
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[The Lewy Body Dementia Association \(LBDA\)](#) is a 501(c)(3) nonprofit organization dedicated to raising awareness of the Lewy body dementias (LBD), supporting people with LBD, their families and caregivers and promoting scientific advances. The Association's purposes are charitable, educational, and scientific. LBDA was formed by a group of caregivers who met in an online LBD caregiver support group. Discussions about the need of support for LBD caregivers and the lack of public awareness about LBD led to the organization's incorporation. The directors of the LBDA Board are located throughout the United States, and LBDA volunteers are from the United States, Canada, and the United Kingdom. The association consists of a dedicated group of people from all walks of life who understand the struggles of other caregivers due to their personal LBD experiences.

[The Lewy Body Society UK](#) is a registered charity whose purpose is to fund research into Dementia with Lewy Bodies (DLB). We also hope to provide a community focus for those who suffer from DLB along with their carers and families. The website provides information to help those who need to understand the disease and its impact. We also offer links to important groups working in all aspects of dementia care and research as well as other important information sources and books.

[A Nation Joined Together Will Make a Difference](#)



Dementia Action Alliance

[Learn More](#)

About the US Dementia Action Alliance and how you can get involved!

DEMENTIA ALLIANCE INTERNATIONAL

Kate Swaffer is the a co-founder of **Dementia Alliance International**, a non-profit advocacy and support group of, by and for people with dementia from the USA, Canada, Australia and other countries that seek to represent, support, and educate others living with the disease, and an organization that will provide a unified voice of strength, advocacy and support in the fight for individual autonomy and improved quality of life. Membership of Dementia Alliance International is open to anyone with a diagnosis of any type of dementia. [Click here to inquire about membership.](#) Anyone can subscribe to our [newsletter](#) or [weekly blog](#) series. Dementia Alliance International also runs monthly Webinars and an online support group called [Café Le Brain](#) in two time zones. Our Vision is...

A world where a person with dementia continues to be fully valued.

HELP OTHERS LIVE WELL

If you know someone working or living with dementia who might benefit from the teachings of Teepa Snow, please forward this to them now.

Be knowledgeable. Be prepared. Be positive.

If this journal was helpful to you, we would appreciate your feedback. Please share comments and further interest with us.
info@teepasnow.com

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www.teepasnow.com

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