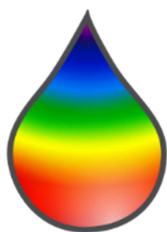




The Guide for anybody touched by Parkinson's

Living with Parkinson's

A life changing insight into the reality of Parkinson's



Alexander Reed

Founder and President of the **European Parkinson Therapy Centre**, Italy.

We all have a degenerative condition called ageing, yet most people of 70 years do not blame their age for their lesser ability to do things. When we have Parkinson's this acceptance and adapting to the reality is harder as we are less prepared, Parkinson's was never part of our future plans and it's arrival puts everything on hold which often makes us feel depressed and unsure, but never the less we must adapt and like old age, accept that change. That does not mean we will lose our quality of life, but it does mean that we must re-evaluate and restructure our life and plans.

Our health systems are also not always in our favor. We get the Diagnosis, a packet of pills and an appointment somewhere down the line. It's a shock to the system and it is little understood that it is a shock to the family too. What are we meant to do? What is going to happen? No wonder that anxiety and fear raise their ugly heads. We are afraid of what we do not know or understand.

Parkinson's effects the whole family and the whole family needs support and reassurance. It is wrong to call such people as caregivers as this word suggests we need care, a nurse. Not the case, we need a wife, daughter, son or more specifically we need Support not care. The correct word for a caregiver would be "People who Care" (PWcare)

It's not surprising to know that over 50% of People with Parkinson's (PWP) are clinically depressed and that the vast majority do not seek help but head for the nearest desk and hide under it, figuratively speaking! The sad truth about Parkinson's is that the truth is never made clear.

I wish that when first diagnosed I was told that; “You can reduce symptoms by up to 40%, you can help slow progression, and that your life will become more precious not less if you do and make the right choices”. We are not victims... by the very definition of the word. A victim of war or with certain diseases may lose their right to choose. Parkinson’s does not destroy, it may limit, but we still have the ability to choose, even if we have less to choose from.

Some of us are reluctant to admit that we have Parkinson’s, almost as if we are afraid to be looked upon as different or weaker yet even the person who comes last in an event in the Paralympics is applauded because he or she chooses to fight and indeed anybody who faces adversity with determination is stronger for it. The truth is that many do not want to face the reality. This is unfortunate because the truth is we can live with Parkinson’s but we have to adapt to the reality.

Words like “Parkinson’s made me a better man” or “Parkinson’s was an opportunity” make little sense at that moment of diagnosis. In one famous study the number one thing that destroyed a person with Parkinson’s quality of life was Apathy and depression and not all the usual suspects which are related to motor functions. This point is essential in learning to live with Parkinson’s. Indeed one leading Neurologist stated “it’s not Parkinson’s that destroys quality of life but Apathy.” We can deal with Parkinson’s if we can be bothered to or at least know that you can.

Time and time again, I meet families devastated by Parkinson’s and week in and week out we explain that Parkinson’s will change their lives BUT we get to choose what changes to make. Some people choose to close themselves into themselves. It is not a conscious choice but it is a choice never the less..

It is fundamental to understand that our quality of life is based on the concept that there are 4 key elements (what we call Pillars). Medicines are of course at the core but like a house with one wall, it will not keep the roof up. Medicines to a depressed person will not change his or her life. You need all four Pillars delivered in one place intensively.

If you want to learn a foreign language, one hour per week will not work. 2 weeks of full immersion will have a much higher impact. Same for Parkinson’s, an appointment here and a dance class there will not be enough to change our quality of life.

Doctors refer us to therapy programs, this is a misunderstanding of what therapy is and how to apply it. Give a man a fish he will eat for a day, teach a man to fish he can eat for the rest of his life. PWP should be given the knowledge as to how to integrate therapy into their daily lives such that it is no longer called therapy. Therapy is something we have to submit to. Integrating therapy into our daily life is called living with Parkinson’s.

Parkinson’s does not change who you are but may often change your perception of who you are. In truth this perception can be distorted as others still see the same person. We may lose confidence and focus and start to feel different.

Those 3 words “you’ve got Parkinson’s” followed by “take these pills and come back and see me in 12 month” destroy the world as we know it, and effects those around us profoundly. There has to be a better way.

What are The 4 Pillars of Parkinson's?



- 1) Medicine. It's what keeps us moving and eases some aspects of Parkinson's. One well known British Neurologist told me recently. "We know a lot about Parkinson's but we don't and can't know Parkinson's" (because they have never lived with it). A remarkable truth and probably why this Neurologist is so exceptional.

Medicines may of course have side effects. The rule of thumb...keep your meds as low as necessary so as to control the main symptoms and don't expect your Neurologist to prescribe happiness. Happiness comes from within. Try looking there. Our Neurologists do not intervene on medicines unless a problem is evident. We believe the relationship between a Neurologist and their "patient" is a fundamental link.



2. Physical movement is now understood better and like medicine, it is now understood it must "taken" daily. Regularity and not quantity is as important.. But what must we do? Walking is a basic and fundamental aspect of daily life with Parkinson's. It produces a Neuro protective effect, in short it helps slow down Neuro degeneration and is good for everybody but is especially important for us. Tango therapy, gym and physiotherapy are often mentioned but in reality if not done regularly, they have limited effect. So hiding under the figurative table will actually speed up the condition when infact living is a highly effective way of fighting Parkinson's

Studies show physiotherapy needs to be combined with conscious thought, "think before you move", this point is often missed and is based on the concept of Neuroplasticity. If we break a leg, we may do Physiotherapy (Physical Therapy) but for us the problem is inside our head so "physiotherapy" must be combined with conscious thought. If we think and correct our posture, length of stride and arm movement and then actually consciously do it, we find that over a short period of time the brain adapts and this correction becomes automatic (Neurotherapy). Rather like if you sleep on your side and one day have a broken

rib and we find we have to sleep on our back. For the first few nights this means little sleep but then our brain accepts the new reality and even after the rib is healed, we continue to sleep happily on our back.

Group therapy is popular too but everybody is different in their Parkinson's. Take 4 chefs and give them the same ten ingredients and you'll end up with 4 different meals. If you really want to reduce your symptoms you need to work individually with a specialist to identify, correct and learn to maintain this correction yourself

3. Life style is perhaps the least understood and hence the less treated. Apart from obvious points about what and when we eat and the avoidance of stress, what is essential to understand is that we have a choice. We can choose to be apathetic and negative or we can choose to take control. We can choose to delegate our quality of life to a Neurologist or to our spouses or we can choose to focus our lives on doing what we can enjoy. Choosing to continue at full speed is not a choice, it's denial. Full speed is like driving a car fast with an engine that is slowly losing power, at some stage it will breakdown. Life will change but who says we cannot decide how it should change. If we choose to do less but do more of what we enjoy, then quality of life is maintained.

It is ironic that the highest rate of suicide (% of population) is amongst teenagers who have all the quantity (ability) yet fail to understand the concept of Quality.

This failure is as much a failure to understand what makes them happy as often we build our lives on what others expect of us. STOP. Get off the merry-go-round and ask yourself. What do I like or love doing (given the restraints of age and Parkinson's) and how can I do more of this



4. Psychological. We use the ACMA approach. We must first ACCEPT we have Parkinson's, that means accepting something we don't want but just like ageing, it is a fact. How can we fight something if we do not accept it exists? Like going into a boxing ring with a blindfold, we are going to get hit hard. Take the blindfold off, we can hit back!. COMPREHENSION of the reality of Parkinson makes us stronger as we realize we can influence progression and symptoms. It's much harder to fight in a war we do not believe in or one in which we do not understand the strategy.

Only if we accept and comprehend can we be MOTIVATED and this will only be effective if we combine what we need to do with what we enjoy. We cannot stay

motivated if we are always doing things we have to do with no reward. Just like Dopamine is released when we do something enjoyable so we become more inclined to take a long walk if it brings a reward like a stop at an ice cream shop or your local pub. These 3 stages bring about real ACTION which we can sustain and believe in. Too many people talk about what we must do (Action) without understanding that we have not yet accepted, understood and decided to do it.

If one of the above Pillars goes down, it may pull down others to. That's why Apathy and depression are so destructive. If we stop caring, we stop exercising and we stop living. We are then left with just the Medicines. Back to square one and worse we enter what one leading Neurologist called "The Vortex of Apathy". The vortex pulls us down, eliminates Neuro protection and Neuroplasticity and destroys people with Parkinson and the lives of those around them

Looking back at what we were able to do before Parkinson's instead of all the things we can still do is at the root of many people's depression. Looking forward we may experience fear and anxiety. "Where will I be in 10 years, what does the future hold". This put together can create the Apathy so associated with Parkinson's. The truth is that neither looking backwards or forwards is relevant. Today is very relevant and we should focus on managing and maximizing our lives every day. See the funny side, learn the truth and live a full life with Parkinson's. In our bestselling book "Shaken But not Stirred" (available from Amazon worldwide compiled by Alexander Reed), Richard Curtis (comedy writer and director whose credits include Love Actually, Notting Hill, Four Weddings and a Funeral, and Mr Bean) wrote "Parkinson's is of course seen as a "serious illness", and the trouble with serious illnesses is that when people get a serious illness we all tend to become very serious about it. Too frequently we give them seriously sympathetic looks and we say "How are you?" in our most serious voice".

People with Parkinson's have a simple request; We need support not as patients but as people and families. That is the reason the European Parkinson Therapy Centre has been so successful and has consulted for Parkinson UK, Cure Parkinson Trust and work with many Universities (Like Oxford Brookes) and Hospitals. The Centre was created with the help of many leading names in the Parkinson's world but it's director, critically, has Parkinson's. The combination is a program that reflects the latest research in all areas and the needs of People with Parkinson's.

Learn More at www.ParkinsonTherapy.com

