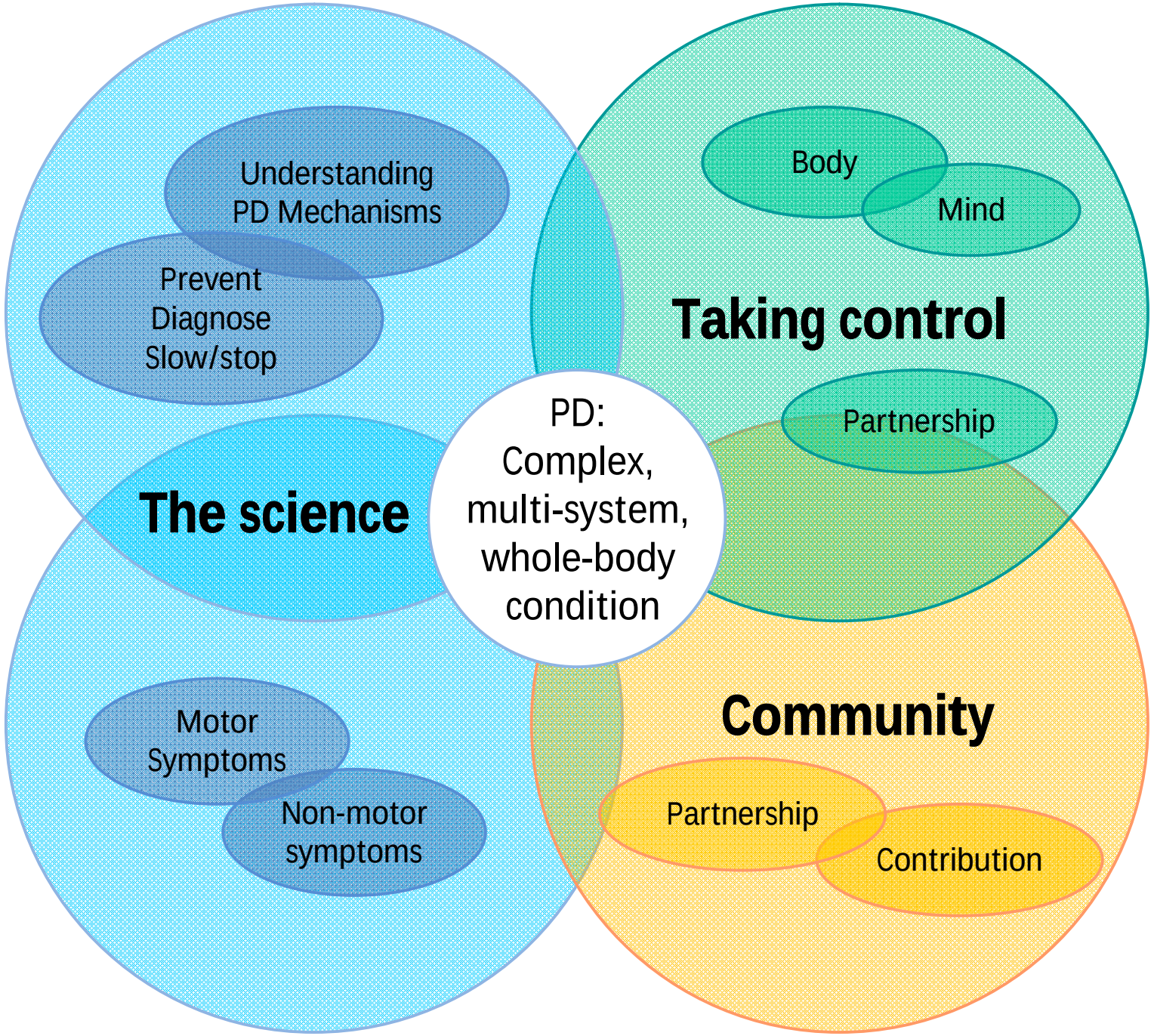
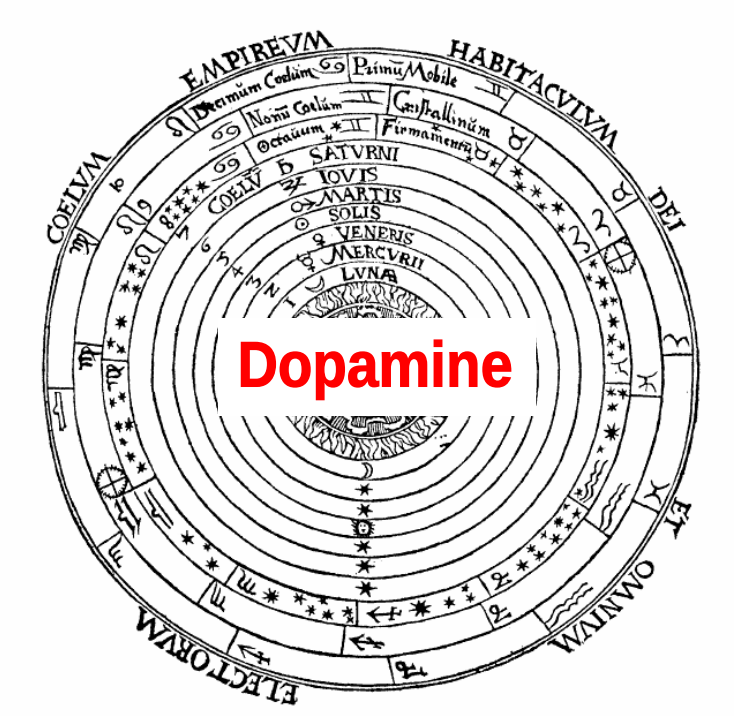
Understanding them, dealing with them, thriving beyond them

NON-MOTOR SYMPTOMS (MOSTLY!)


Understanding
PD Mechanisms
Prevent
Diagnose
Slow/stop
Body
Mind
Taking control
Partnership
The science
PD:
Complex,
multi-system,
whole-body
condition
Motor
Symptoms
Non-motor
symptoms
Community
Partnership
Contribution

Beyond Dopamine



Ptolemaic View of the
Universe: Earth at the centre

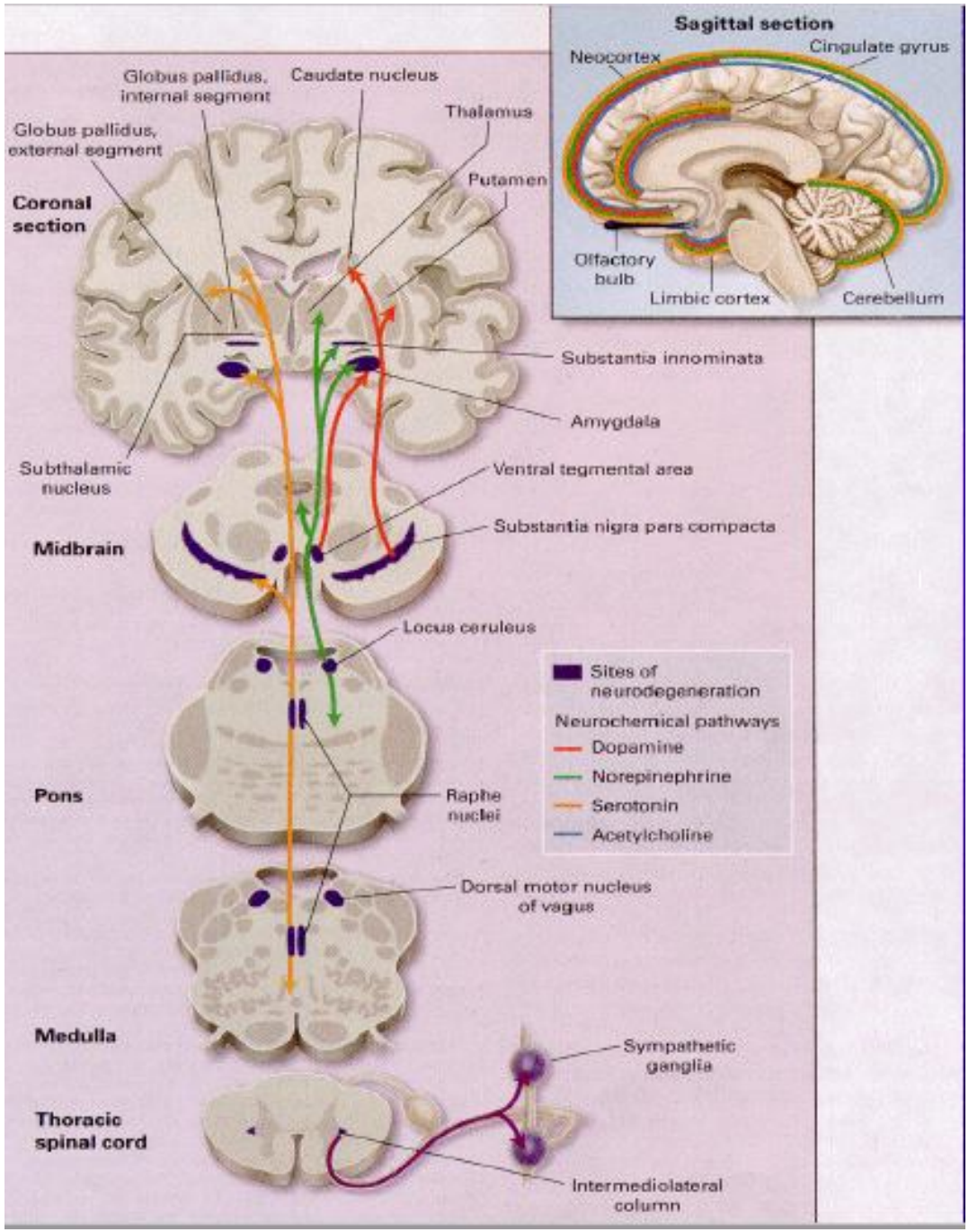
Halliday et al *Movement Disorders* 2014

Source: Ray Chaudhuri; Anthony Lang slides

Sites of neurodegeneration

Neurochemical pathways

- Dopamine
- Norepinephrine
- Serotonin
- Acetylcholine



Source: Anthony Lang slides

Deficiency in Dopamine + 3

New-to-us information

Motor symptoms

Dopamine:

- Slowness, freezing, tremor

Seratonin:

- Dyskinesias

Acetylcholine:

- On freezing

(**Noradrenaline**)

Non-motor symptoms

Dopamine:

- Depression, apathy, pain, RLS

Seratonin:

- Depression, apathy, fatigue

Acetylcholine:

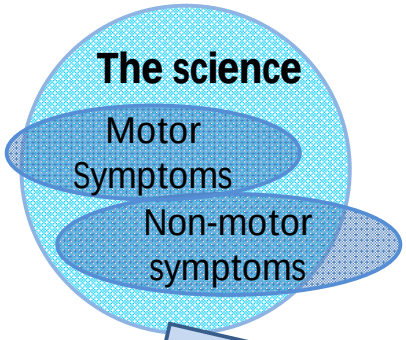
- MCI (mild cognitive impairment)
- Dementia

Noradrenaline:

- Autonomic dysfunctions
- Sleep

Source: Ray Chaudhuri slides

Halliday et al *Movement Disorders* 2014



(Some!) Non-motor symptoms

Memory loss MCI

Psychological

Apathy; Depression; Anxiety

Obsessive compulsive

Sleep & EDS

Gastro-intestinal

Pain

Motor symptoms

Urinary problems

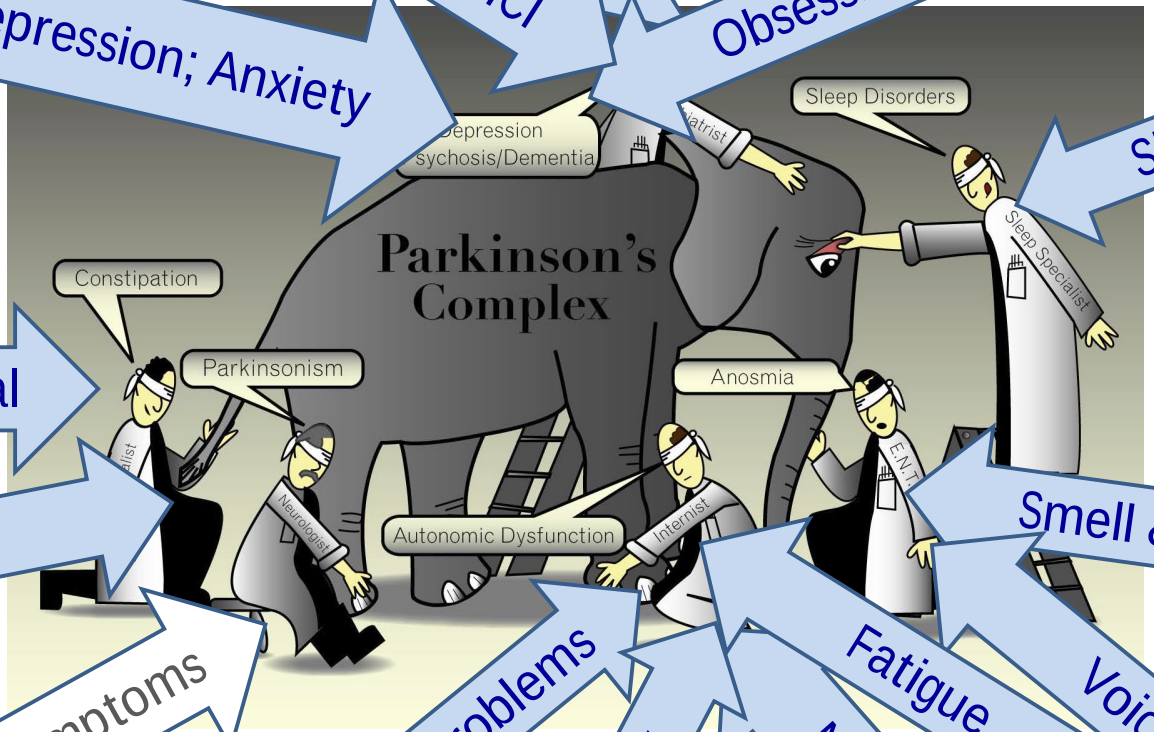
Intimacy

Fatigue

NMS symptoms

Voice

Smell & taste



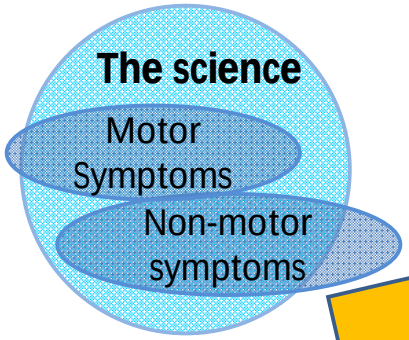
Anthony Lang

NMS Impact

- Non-motor symptoms have “a strong impact on patients quality of life and caregiver’s burden (CB)”

- “Non-motor symptoms can remain undeclared by patients due to misconception or embarrassment, for example, and undetected by doctors due to lack of a systematic search.”

Ron Pfeiffer abstract



Measuring and evaluating NMS

Just some of the.....

TABLE 2. *Domains include*

Number	Domain	
1	Gastrointestinal tract	
2	Urinary tract	
3	Sexual function	
4	Cardiovascular	
5	Apathy/attention/memory	
6	Hallucinations/delusions	2
7	Depression/anxiety/anhedonia	2
8	Sleep/fatigue	5
9	Pain (unrelated to other causes)	1
10	Miscellaneous (e.g., diplopia, weight loss)	3

Non-motor symptoms questionn

This questionnaire should be completed and **given to your GP, specialist or nurse at your next appointment.** Please **do not** return it to Parkinson's UK.

Name: ..... **Date:** .....

Centre ID: Male ☐ Female ☐ **Age:** .....

Have you experienced any of the following in the last month?

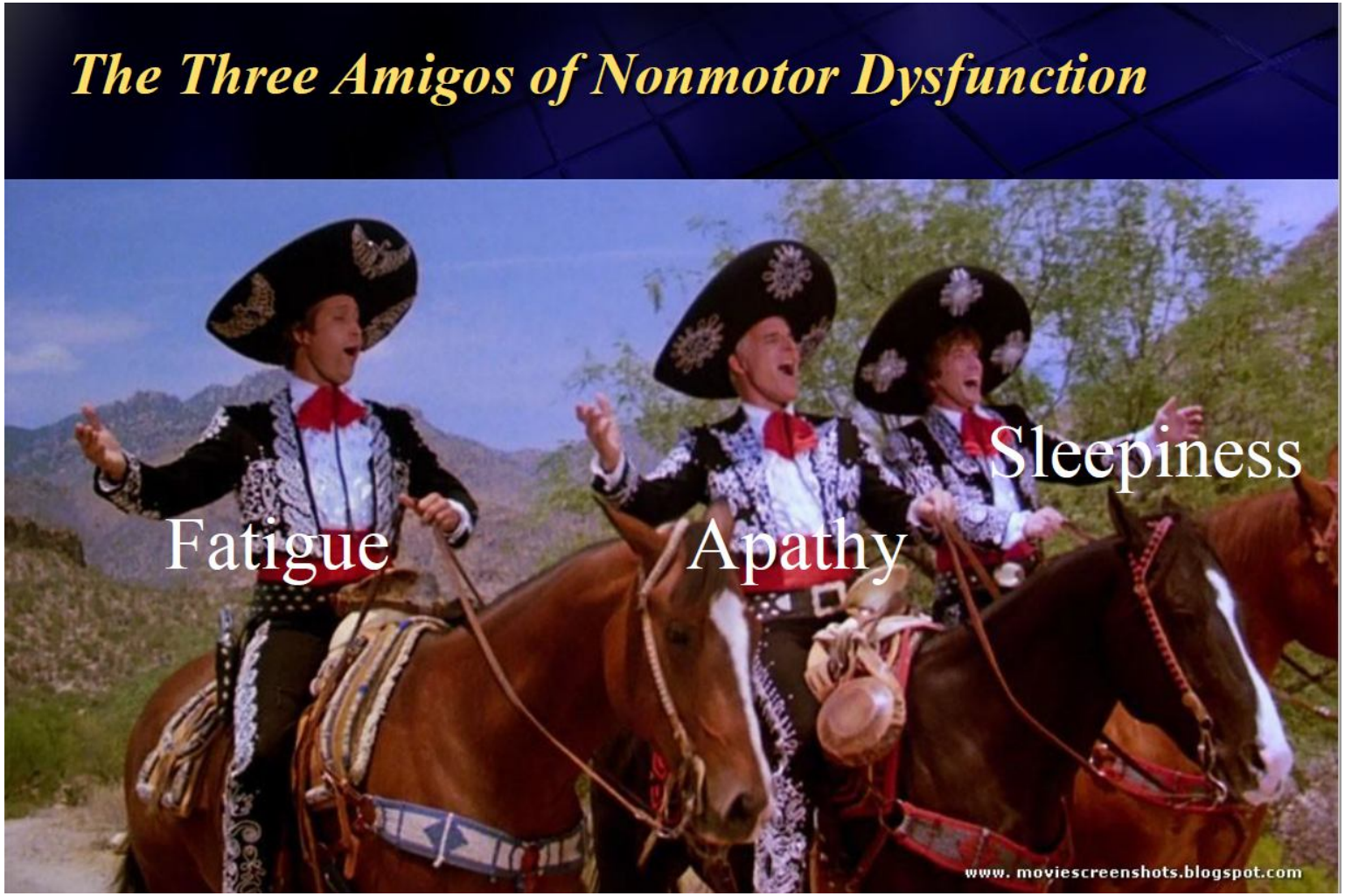
All the information you supply through this form will be treated with confidence and will only be us the purpose for which it has been collected. Information supplied will be used for monitoring purpo Your personal data will be processed and held in accordance with the Data Protection Act 1998. Developed and validated by the International PD Non Motor Group.

Non-movement problems in Parkinson's

The movement symptoms of Parkinson's are well known. However, other problems can sometimes occur as part of the condition or its treatment. It is important that the doctor knows about these, particularly if they are troublesome for you.

No NMS measures until 2004

Source: Ray Chaudhuri slides
Chaudhuri et al 2006 *Movement Disorders*



Ron Pfeiffer slides

Ron Pfeiffer slides

Sleep: *Excessive Daytime Sleepiness & Rapid Eye Movement*

Falling asleep at the wheel: Motor vehicle mishaps in persons taking pramipexole and ropinirole

S. Frucht, J. D. Rogers P. E. Greene, M. F. Gordon, S. Fahn, Neurology 1999

EDS: *"Tendency to fall asleep, or nod-off during daytime without prior planning to go to sleep"*

Possible treatments:

- Adjust PD medication
- Reduce/eliminate sedating medications
- Treat night time problems
- Prescribe stimulant medications

REM Sleep: The mechanism that separates the brain from the muscles during sleep doesn't work properly – hence 'dream enactment'

New-to-us information

Ray Chaudhuri and Ron Pfeiffer slides (Höglund et al 2015)

Fatigue

"Difficulty initiating or sustaining physical or mental voluntary activity" is present in around 30-60% of PD patients

Ron Pfeiffer slides

Fatigue

"A sense of exhaustion unexplained by drug effects, other medical or psychiatric disorders, and associated with other fatigue-related symptoms, such as reduced motivation and non-restorative rest, or constraints on activities."

Friedman JH, et al. NPJ Parkinsons Dis 2016;2:.doi:10.1038/npjparkd.2015.25

Types of Fatigue

- Physical
  - A feeling of physical exhaustion & decreased energy for physical tasks or activities
- Cognitive (mental)
  - Struggling to start and sustain mental tasks
- Fatigability
  - Muscle loses strength with repeated contraction

New-to-us information

Treatments

- Often improves with exercise *(Friedman 2013)*
- Protein at lunchtime helps *(Zwickey)*

Lack of energy- Tips & Tricks for living with Parkinson's - Bob Kuhn.mp4

Ron Pfeiffer slides

Apathy

Apathy is NOT depression

- Emotional (withdrawing from people)
- Cognitive (mental)
- Auto-activation (getting going)

"Patients' and caregivers' QoL decreases, increasing CB."

Treatments:

- Psychotherapy (including CBT)
- Exercise ("dopamine-eliciting activities")
- Drugs (e.g., piribedil, ropinirole)

(May appear or increase after STN-DBS)

Source: Ronald Pfeiffer slides; Bernal-Pacheco & Fernandez 2013)

Caregiver comments

- Not the same
- More and more lazy
- Does nothing unless pushed
- Does not start things or finish them
- Just sits alone all day and does nothing
- Very quiet – has nothing to say
- No curiosity or initiative
- Does not show and emotions
- Stares blankly at the TV all day
- No interests or enthusiasm
- Has become a couch potato

Does not care about anything anymore

Source: Ronald Pfeiffer slides; Weiss & Marsh (2013)

Depression

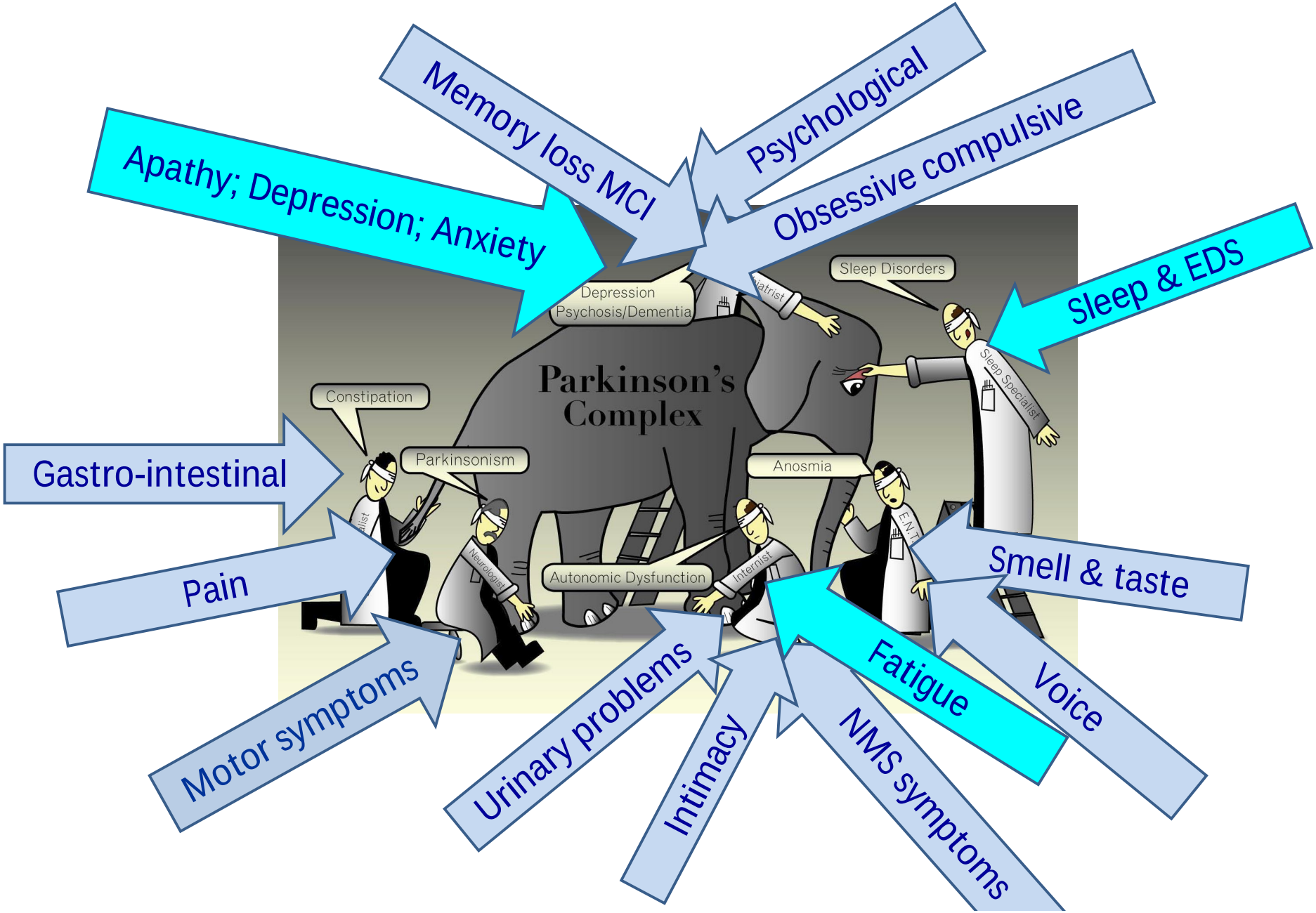
Non-pharmacological treatment

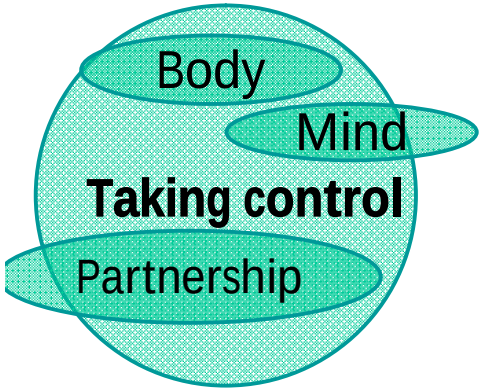
- CBT & psychotherapy
- Increasing meaningful and social activities
- Exercise
- Problem solving for physical limitations
- Light therapy
- Caregiver participation matters

- Conclusion: “Your mood is one critical aspect of living with PD that you can control!”

Source: Roseanne D. Dobkin slides

And all the rest.....





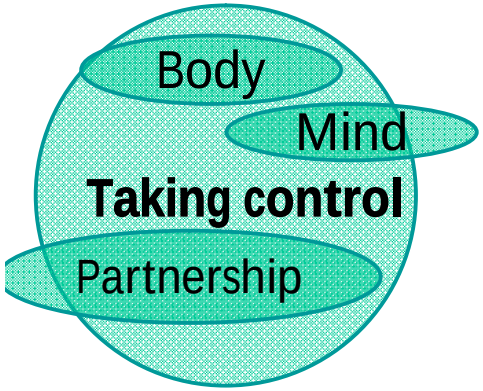
What can we do in partnership?

Health professionals, PWPs & Care Partners

Moving from passive recipient to active participant

- Our bodies
- Our minds & emotions
- Our lives

☼ *Exercise* ☼ *Nutrition* ☼ *Attitude* ☼ *Community*



Exercise works for NMS

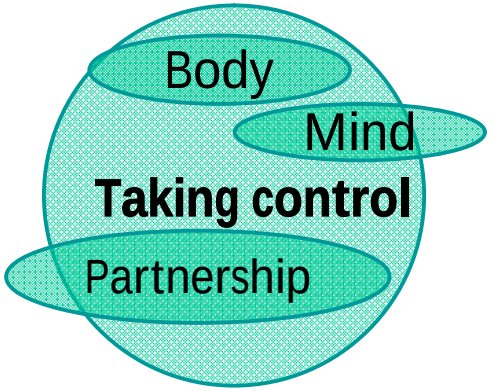
(and motor as well!)

Making a change

Physical	Cognitive, mental, & emotional
• Fatigue • Gastro-intestinal • Blood sugar levels • Voice • Heart and lungs	• Depression • Apathy • Anxiety

New-to-us information

Source: Roseanne D. Dobkin; Gizelle Petzinger; Gammon Erhart; Lynne Rochester



Let's Get Moving

- Skills-based learning
- Aerobic
- Strengthening
- Resilience

Tai Chi
Pilates
Dance
Walking

Exercise
AT ALL LEVELS
Gentle as well as strenuous:
eg gardening, housework, shopping

- Those with PD who exercise regularly (>150 minutes per week):
  - Higher quality of life
  - Better mobility and physical function
  - Less disease progression over one year
  - Less cognitive decline over one year
  - Less care partner burden

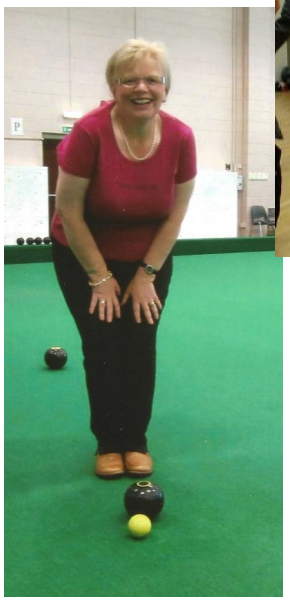
Inspiring

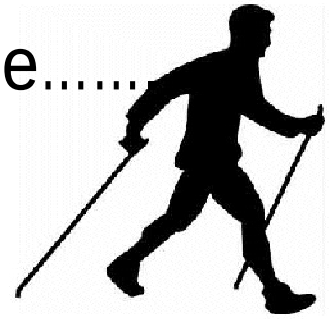
Source: Roseanne D. Dobkin; Gizelle Petzinger; Gammon Erhart; Lynne Rochester; Oguh et al 2014

Exercise works.....even better when done in company!

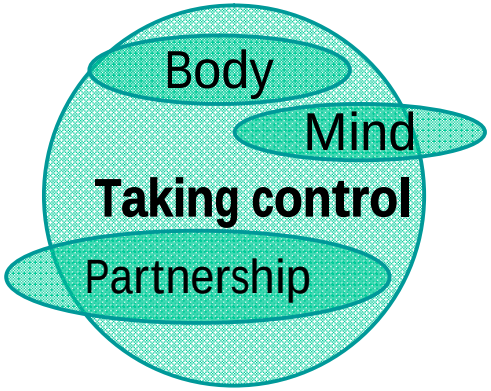
EDINBURGH BRANCH
PARKINSON'S UK

Singing
Swimming
Aquafit
Bowls
Gentle exercise classes
and many more.....





Source: Roseanne D. Dobkin; Gizelle Petzinger; Gammon Earhart; Lynne Rochester



Nutrition: Why is this topic important?

Health professionals, PWPs & Care Partners

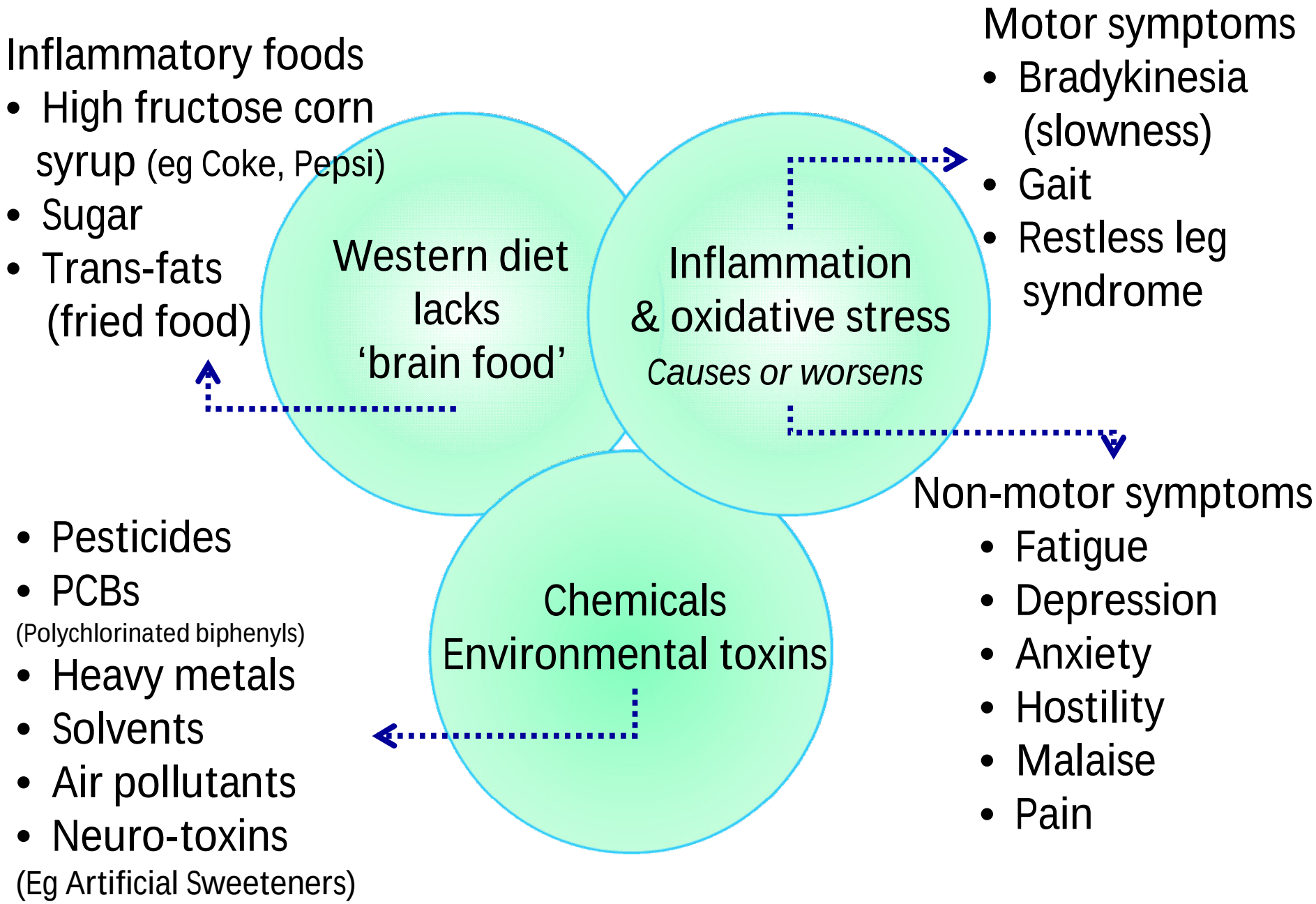
- Proper and appropriate nutrition may play an important part in:
  - o Preventing PD
  - o Medical therapies for PD
  - o Slowing the progression of PD
  - o Counteracting malnutrition

New-to-us information

Medical Nutrition Theory: How & Why?

PD Affects	Nutrition Addresses
Whole body	Whole body
• Brain	• Neuronal health
• Systemic inflammation	• Systemic inflammation
• Digestive system	• Oxidative stress
• Blood glucose	• Chemical toxicity
	• Microflora
	• Blood glucose

Heather Zwickey slides



Information from slides by Zwickey, Duda & Brodsky

Nutrition and Malnutrition in PD: Prevalence, Importance & Ramifications

Prospective study of dietary pattern and risk of Parkinson disease[1–3]

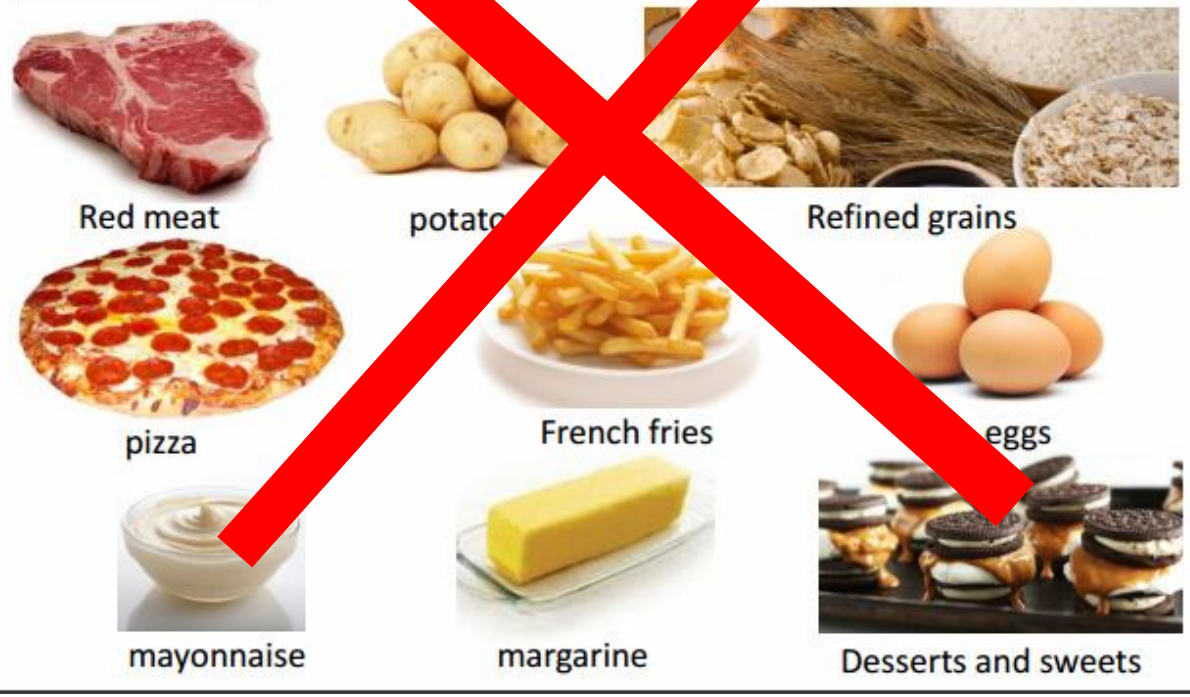
Xiang Gao, Honglei Chen, Teresa T Fung, Giancarlo Logroscino, Michael A Schwarzschild, Frank B Hu, and Alberto Ascherio

Methods:

Two large cohorts:

- Health Professionals Follo Up Study (HPFS) = 51,529 males
- Nurses' Health Study (NHS) 1,700 females
- Dietary intakes

"Western Diet"

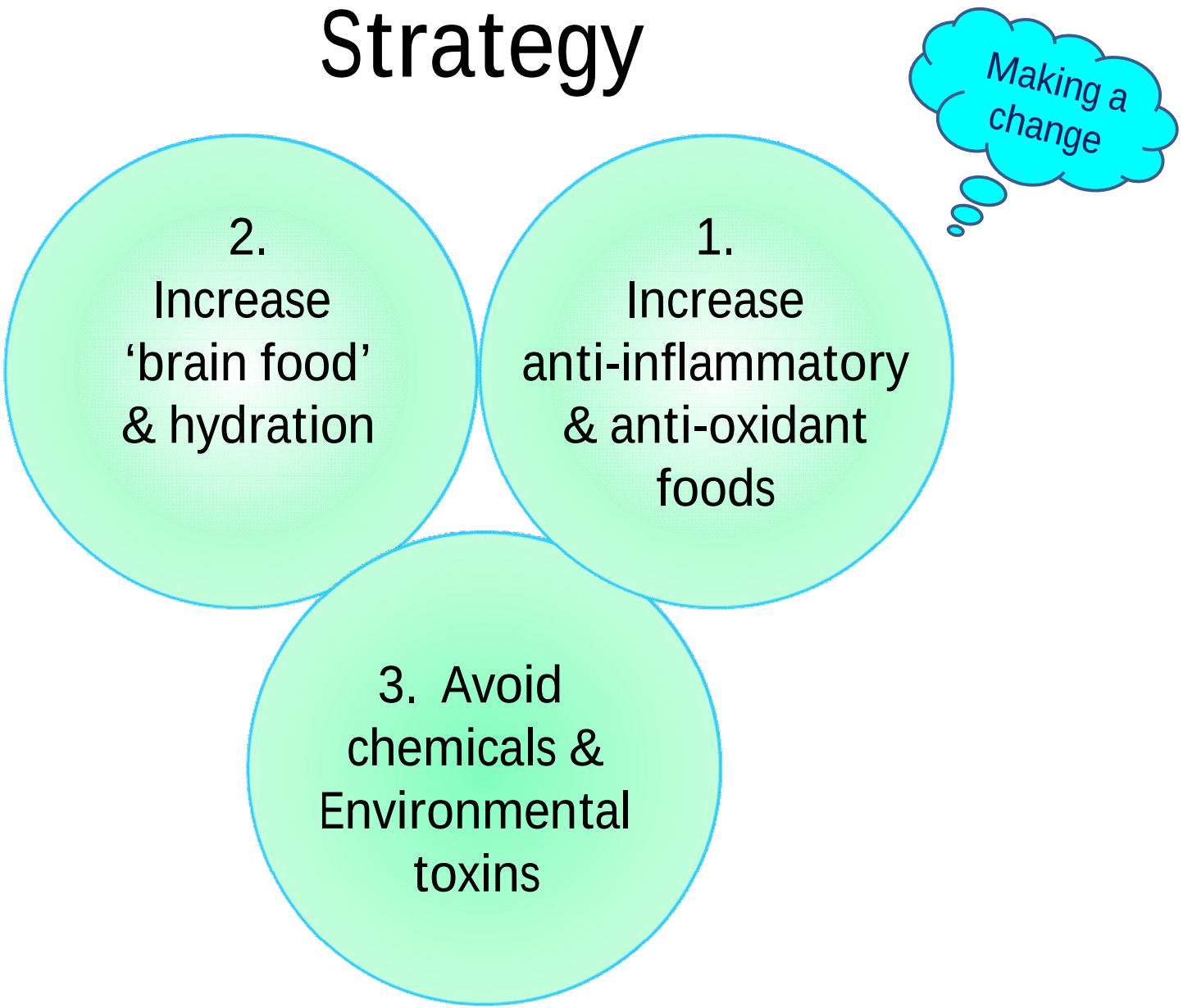


Source: Matthew Brodsky slides

What CAN we eat?

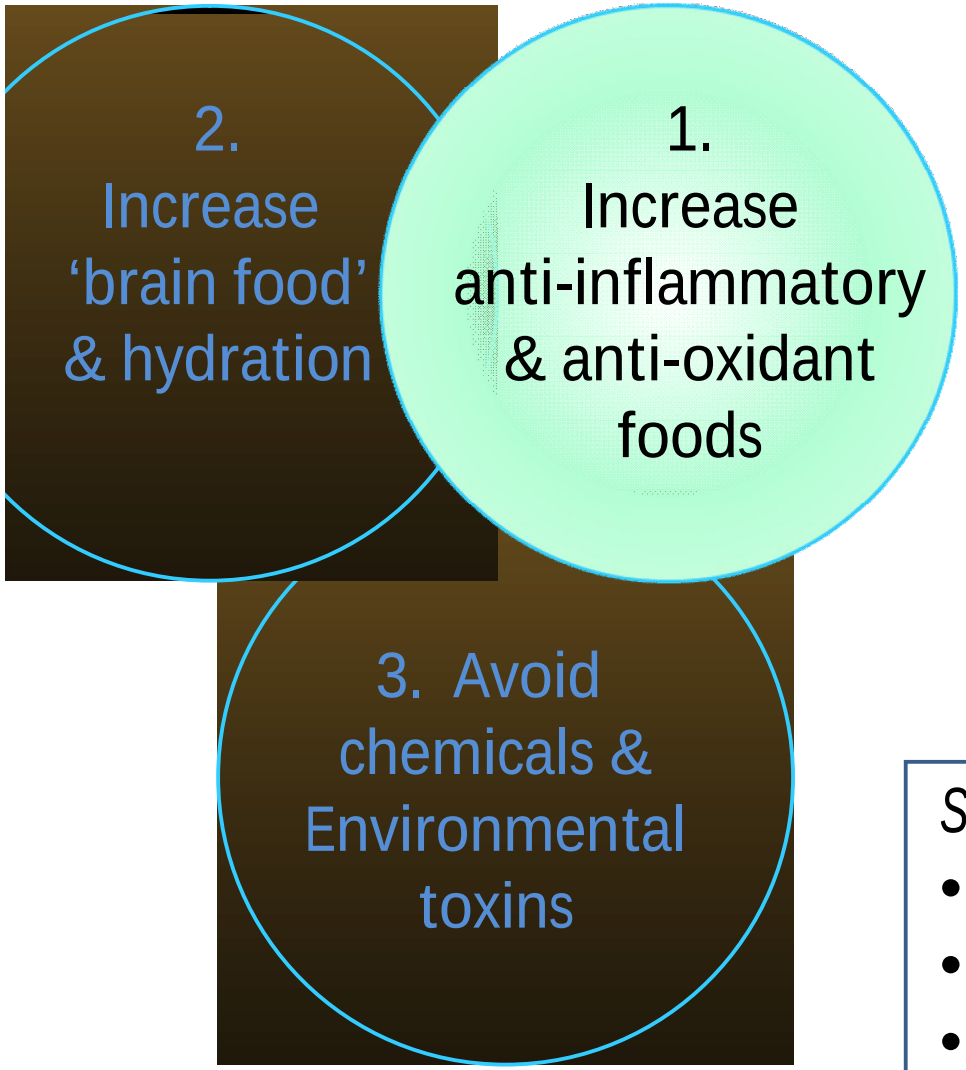
Source: slides by Zwickey

Strategy



Information from slides by Zwickey, Duda

Strategy



Berries & citrus fruits

Nightshade family

- Tomato
- Aubergine
- Peppers

Spices (especially)

- Curcumin
- Cinnamon
- Rosemary
- Turmeric

Oily fish

Fibre & dark green veg.

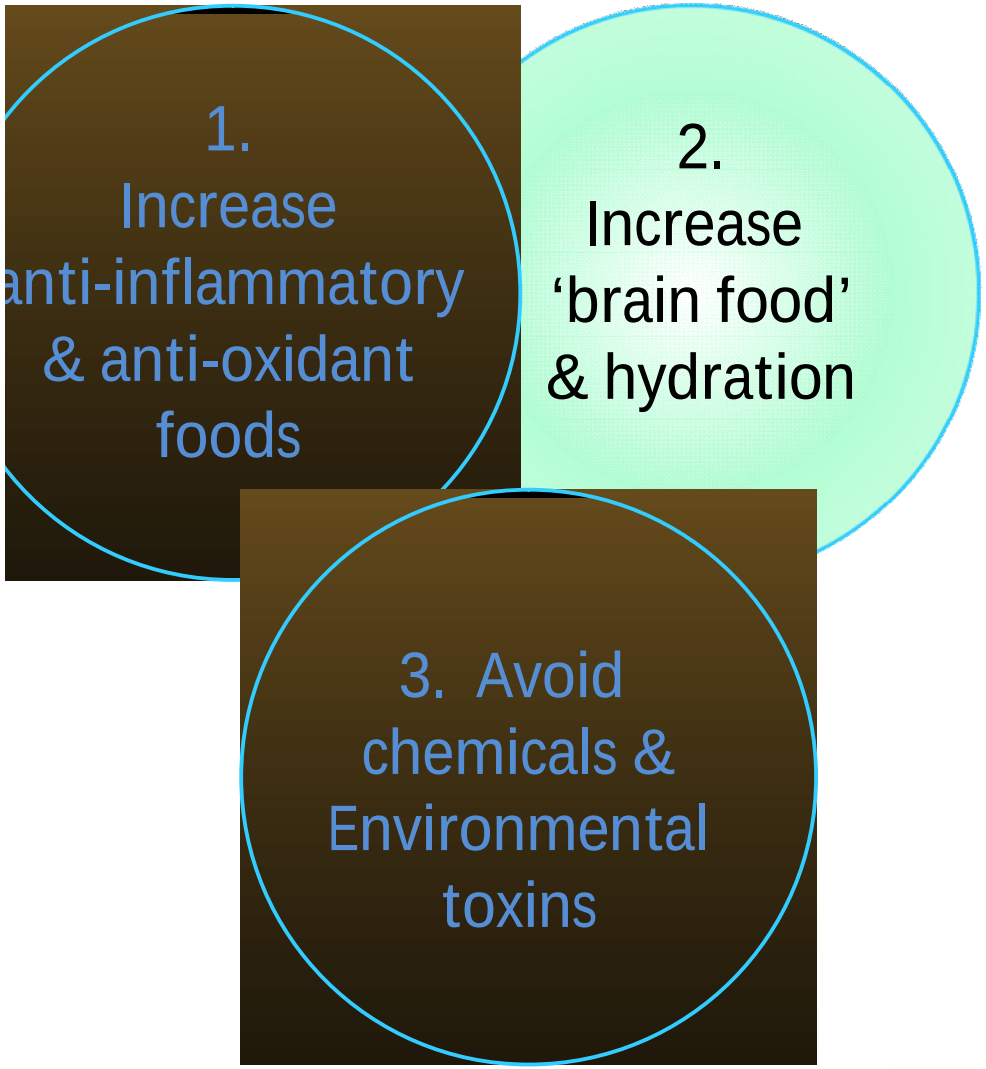
Supplements

- Vitamins B12, D, C, A
- Ginseng
- Spirulina
- CoQ10
- Glutathione

Making a change

Information from slides by Zwickey, Duda

Strategy



Water – 8 glasses per day

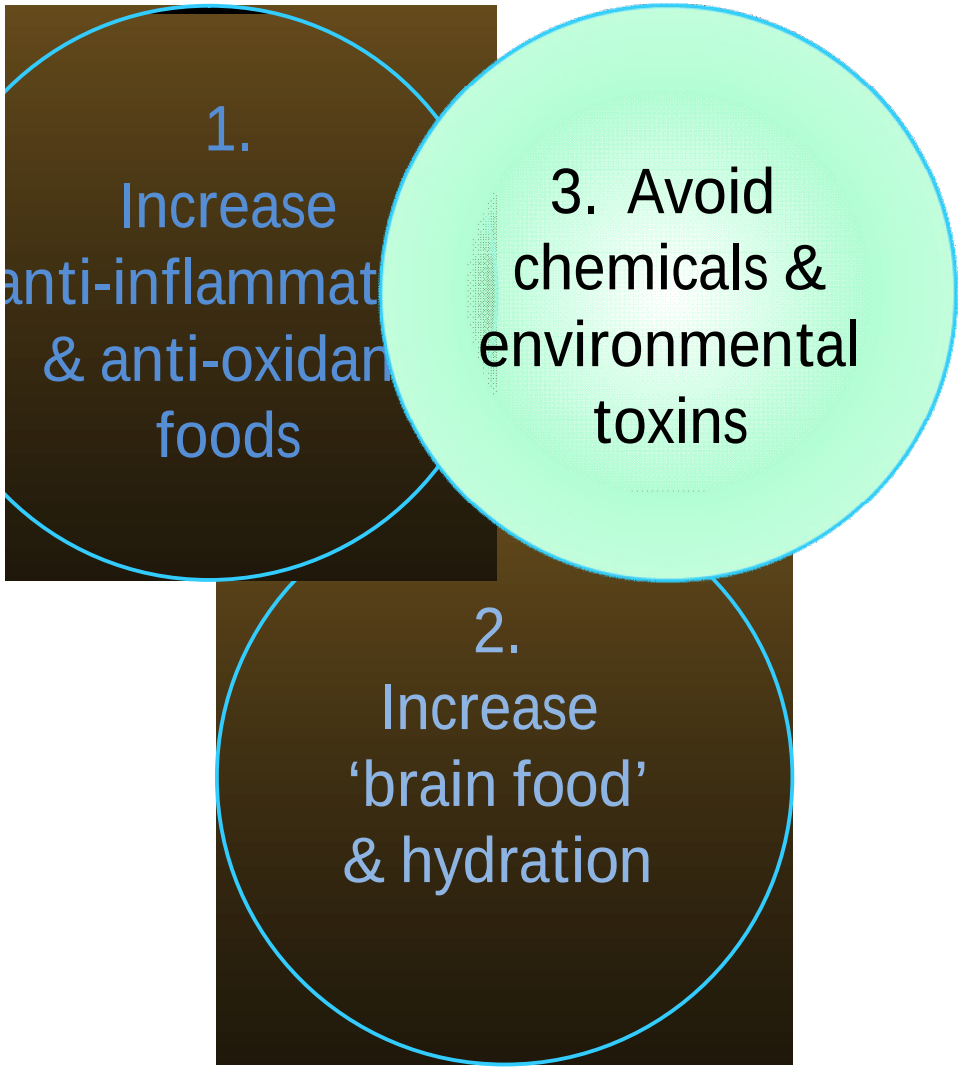
Caffeine
Red wine (NOT white)
Green tea
Nuts – Brazil nuts, walnuts

Cook with
- Fish oil
- Olive oil
- Coconut oil

Making a change

Information from slides by Zwickey, Duda

Strategy



Making a change

Buy organic:

Wash other fruit & veg

Limit milk and dairy

(breaks down uric acid)

Avoid some fish (mercury)

Use eco-household cleaners

Don't cook in aluminium

Don't use pyrethroid insecticides

Source: Malú G. Tansey Neuro-Inflammation in PD
And slides by Zwickey, Duda

"Prudent Diet"

fish

poultry

legumes

Leafy vegetables

w vegetables

Whole grains

omatoes

garlic

Olive oil

"Improved nutritional status is related to improved quality of life in Parkinson's Disease"

Source: Matthew Brodsky slides

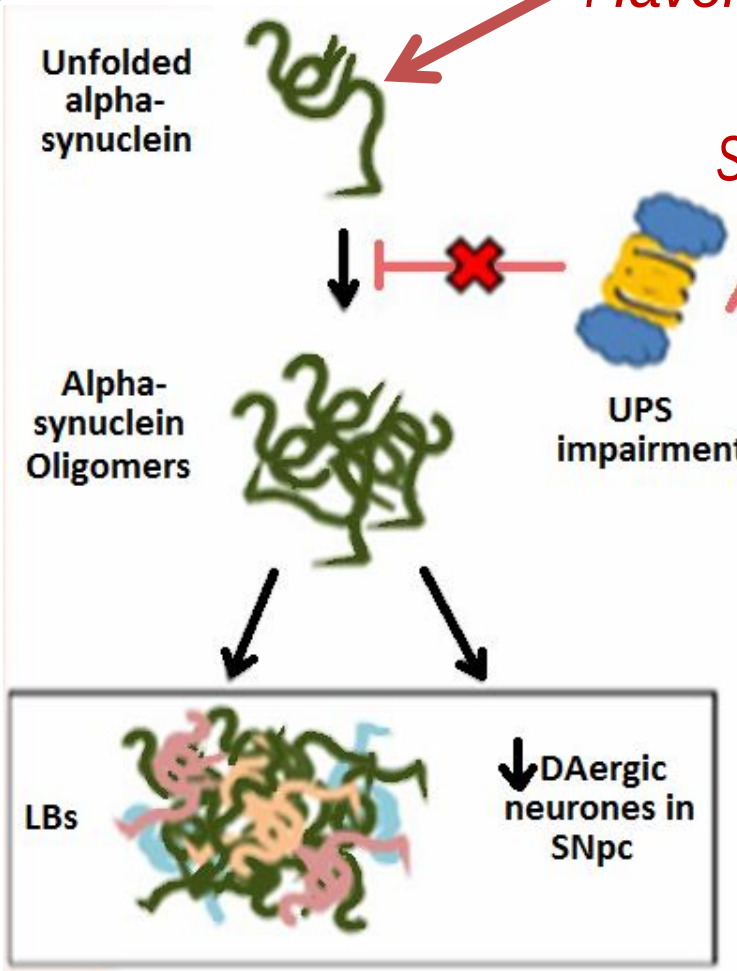
Why do plant chemicals work?

Phytochemicals protect plants

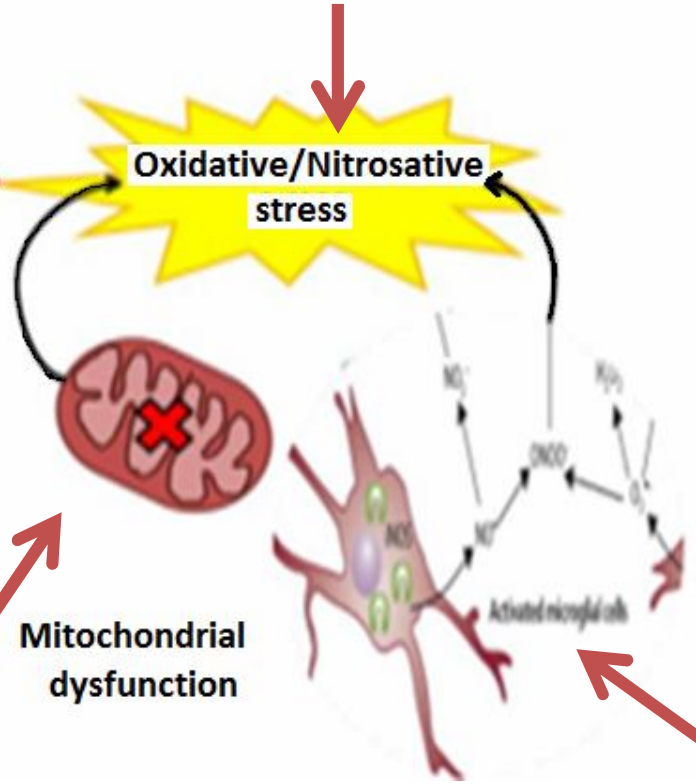
- Stimulate passive immune systems
- Anti-bacterial and anti-fungal responses
- Anti-oxidants
- Repair cell damage

New-to-us information

Flavonoids shown to stabilise αSyn in vitro



Some flavonoids directly scavenge ROS

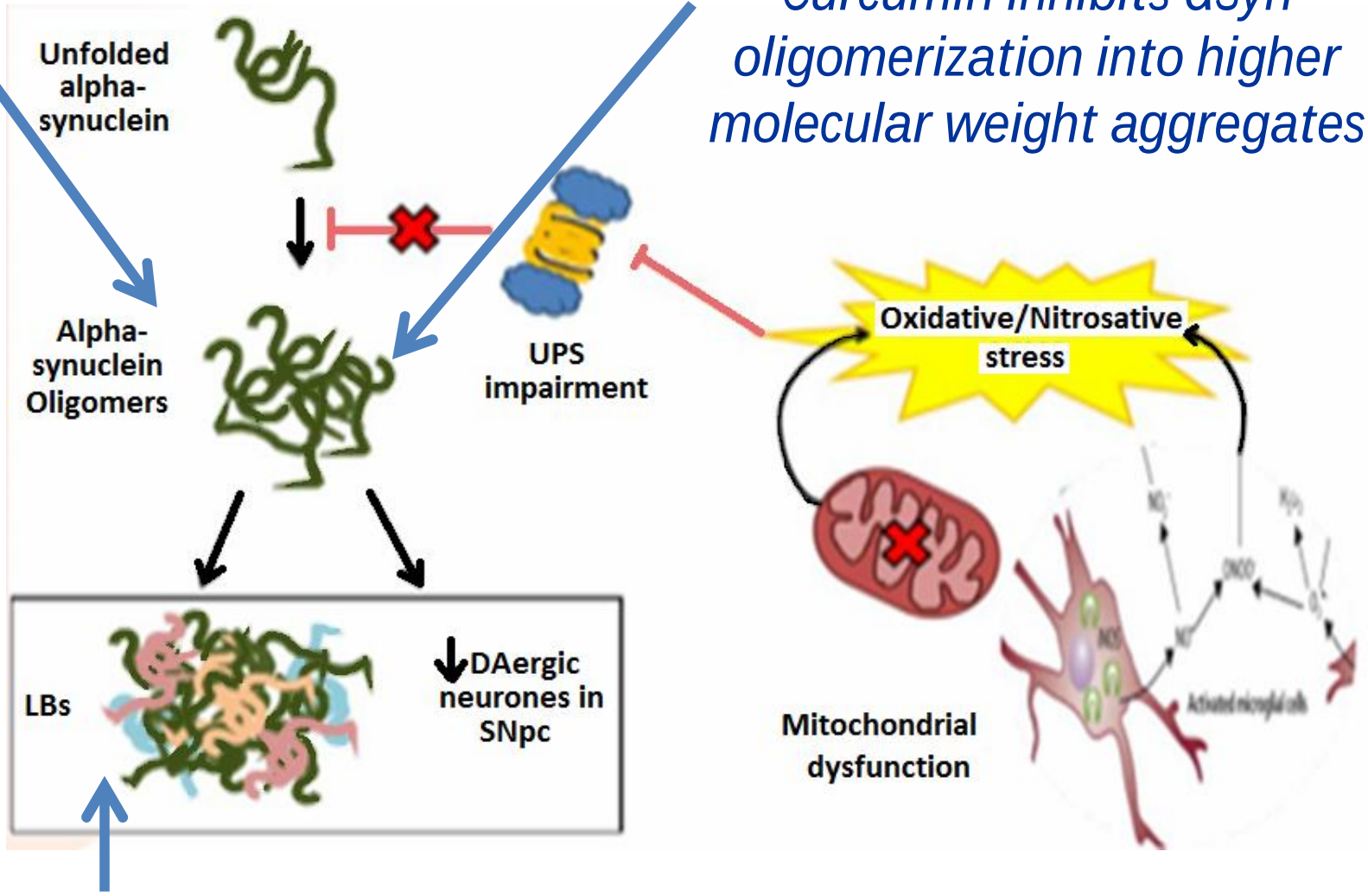


Quercetin augmented ETC complex 1 in rotenone treated rats

Flavonoids inhibit inflammation by inhibiting NO & cytokines

EGCG converts large αSyn aggregates into small non-toxic ones

Curcumin inhibits αSyn oligomerization into higher molecular weight aggregates

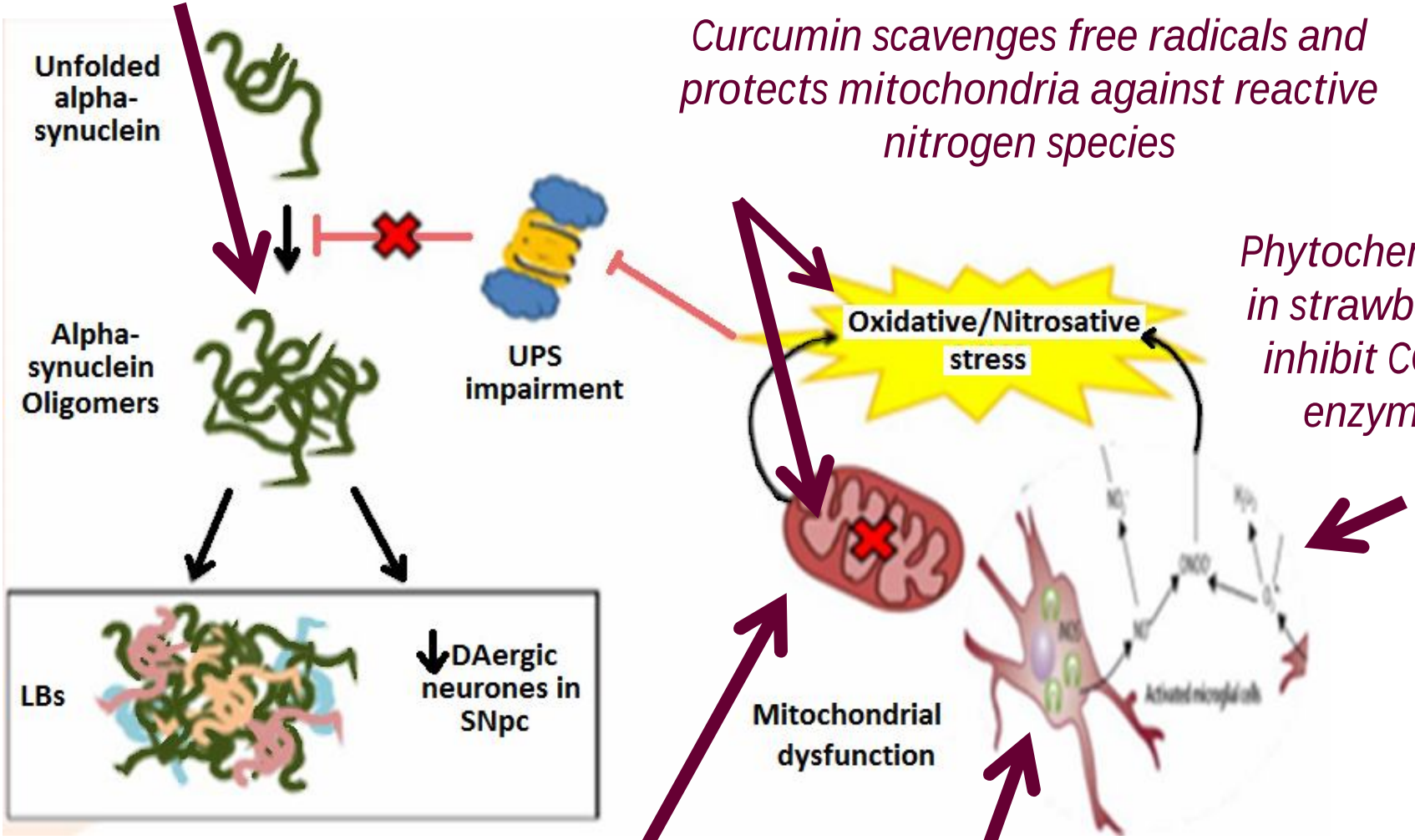


mTOR inhibition results in increased autophagy that may help to clear αSyn aggregates. Caffeine, curcumin and resveratrol inhibit mTOR

L-ergothioneine protects against protein accumulation

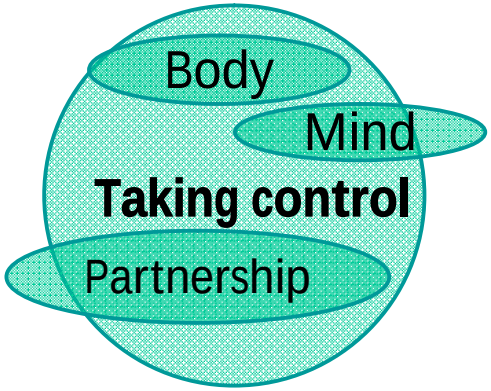
Curcumin scavenges free radicals and protects mitochondria against reactive nitrogen species

Phytochemicals in strawberries inhibit COX-2 enzymes



L-ergothioneine protects mitochondria against oxidative stress

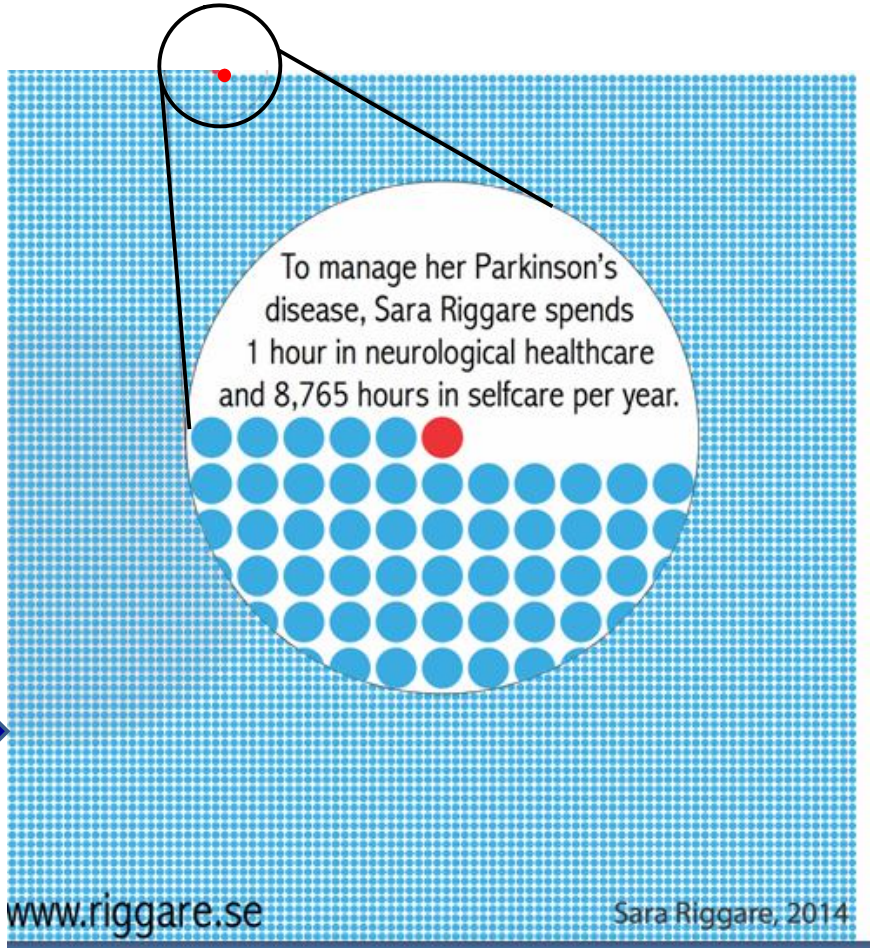
An isoflavone found in soya beans protects dopaminergic neurones by inhibiting microglia activation



Taking control of our lives: Why?

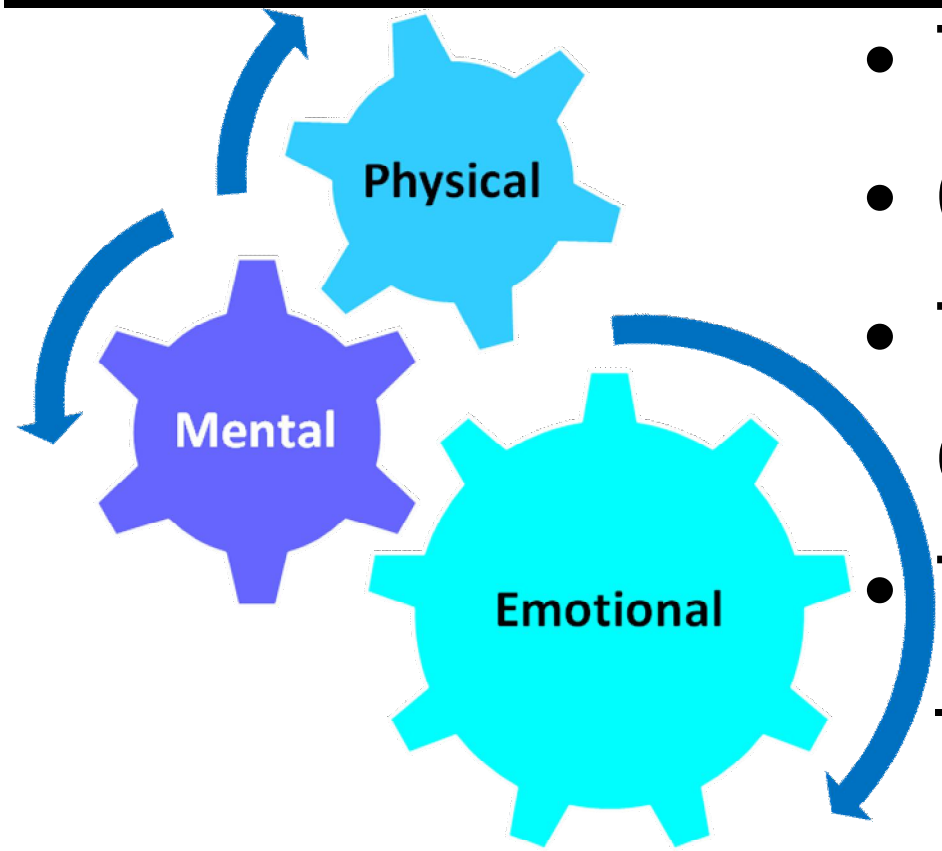
- Managing our PD is 50% the medication, and **50% up to us** (Petzinger)

- Making the most of those 8,765 hours



Source: Riggare; Petzinger

Taking control of our lives: How?



- The choices we make
- Our day-to-day lives
- The stories we tell ourselves and others
- The stories we listen to – and the ones we don't

Brian Grant

Anger, depression, denial, loneliness

"What am I doing?"

- Doing the Man Thing
- Cursing

- Embracing my new best friend who I hate
- Embracing it as a blessing – good for me, good for those around me
- Give back to the community

Tremor- Tips & Tricks for living with Parkinson's - Brian Grant.mp4

Jane Busch: 5 keys for self-care

1. Nutrition
2. Supplements
3. Exercise
4. Mindfulness
    - Paying attention non-judgementally, moment to moment, appreciating others
    - We cannot change the past – *put it on the raft and let it float off down the river*
    - Who knows what the future will bring “Live NOW!”
5. Volunteering
    - Volunteers are healthier, happier & build stronger relationships

Bob Kuhn:

"We have complete control over one thing: our attitude"

Choosing a positive attitude gives:

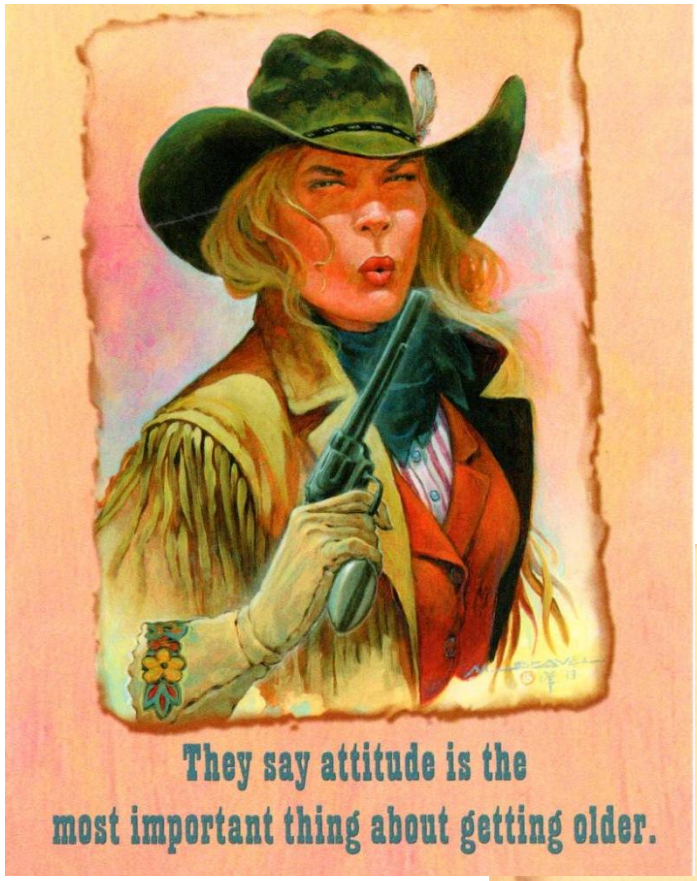
- Strength & hope to others – friends & families
- Strength & hope to ourselves – a renewed sense of confidence

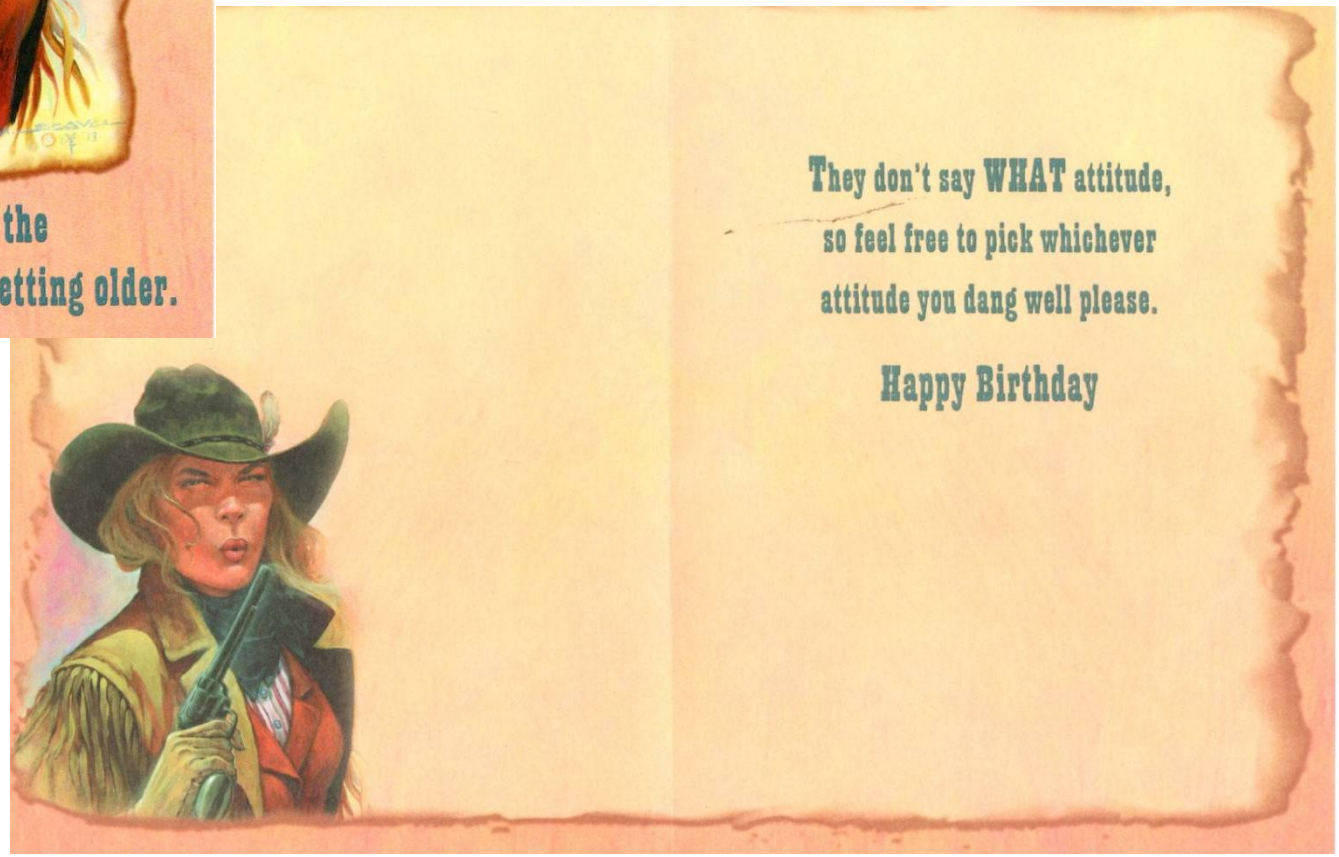
Sustaining a positive attitude requires:

- A passionate purpose
- Choosing a challenge
- Inner strength, getting up again, learning from it
- Going beyond our own needs and wants

Engage ☼ Encourage ☼ Inspire

"It's the only logical way to play the cards we are dealt"



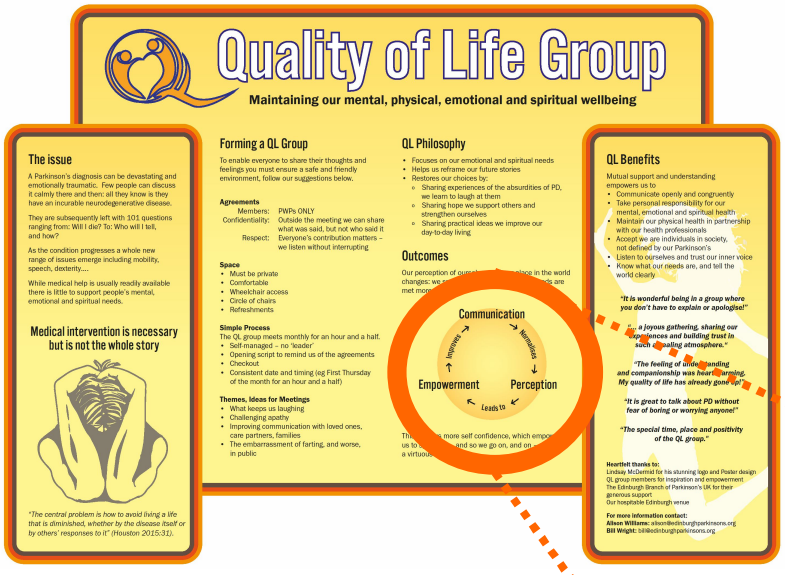


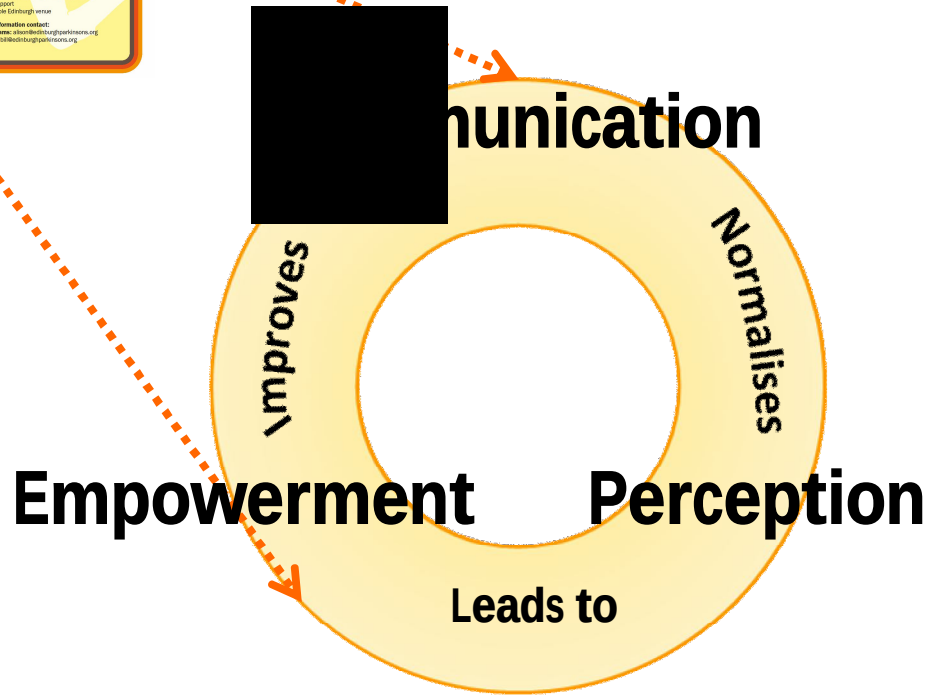
"Attitude Cowgirl"
by Mike Scovel

Dilys Parker: Communication

- Our words define us and our world – to empower or disempower. What do I tell myself?
- Challenges of non-verbal communication and putting thoughts into words
- The person is not the problem – the *problem* is the problem

“We’re all in this together – stay cool!” (Tom Isaacs)





Poster content: Alison Williams & Bill Wright. Design: Lindsay McDermid

Learning

The unwanted visitor doesn’t rule my life – I do

The importance of:

- Mutual support and encouragement
- Clear, transparent communication

Taking control of our treatment

"It is important to listen to patient's and the carer's voice."

Changing how we relate to each other

- Beyond the power imbalance & paternalism
- From passive recipient to active participant
- Partnership – patient as teacher; doctor as partner
- What we want from our consultants:
  - Building confidence and trust by listening, taking time and care in an unhurried way, and active involvement
  - Active listening and shared understanding

Source: Dilys Parker; Bastiaan Bloem; Ray Chaudhuri

Quote of the day….

"The patient will never care how much you know, until they know how much you care."

Terry Canale, Vice President
The American Academy of Orthopaedic Surgeons

Taking control of our lives, our treatment, our selves

DISCUSSION