

# Making the most of your Parkinson's disease clinic appointment

.....packing 6 months into 20 minutes

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25.10.22

# Talk outline

1. What the consultant would appreciate knowing at an appointment?  
What can we do to help the consultant?
2. How we can get the most out of an appointment?
3. The role of carers - the importance of a holistic approach
4. Time for Q&As

# Background

- Idiopathic Parkinson's disease (IPD) is a chronic disease
- People with IPD experience a wide range of both motor and non-motor symptoms
- Chronic disease affects not only the patient but also their family and friends
- Guidelines recommend review by a specialist approx. twice per year
- Optimal management of IPD requires input from a wide range of health professionals
- It's important for patients, their families and for health providers that patients get the most out of their review appointments





Introduction – who am I?

# Doctor patient relationship models

## Models of Doctor Patient Relationship

Model	Physician's Role	Patient's Role	Application	Prototype
Activity-Passivity	Autocratic Warm/detached Dominant	Passive	Critical care or acute Patient needs strong figure	Parent-Infant Parent-Child
Guidance-Cooperation	Warm/detached Makes plans Advises Informative	Cooperates but may be given choices	Above but more likely subacute, chronic care & minor illness	Parent-Child Parent-Adolescent
Mutual-Participation	Usually warm Discusses plan Interactive Helps patient help self Interpretive	Patient uses expert but is active in own care Interactive	Possible with most of above- more likely in chronic care and psychotherapy	Elements of above but mostly Adult-Adult



# Patient-centred care

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# The expert patient

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You are the expert about your Parkinson's disease

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Many benefit from shared experience of support groups

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Huge volume of excellent information online  
[www.parkinsons.org.uk](http://www.parkinsons.org.uk)

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Opportunities to attend scientific meetings

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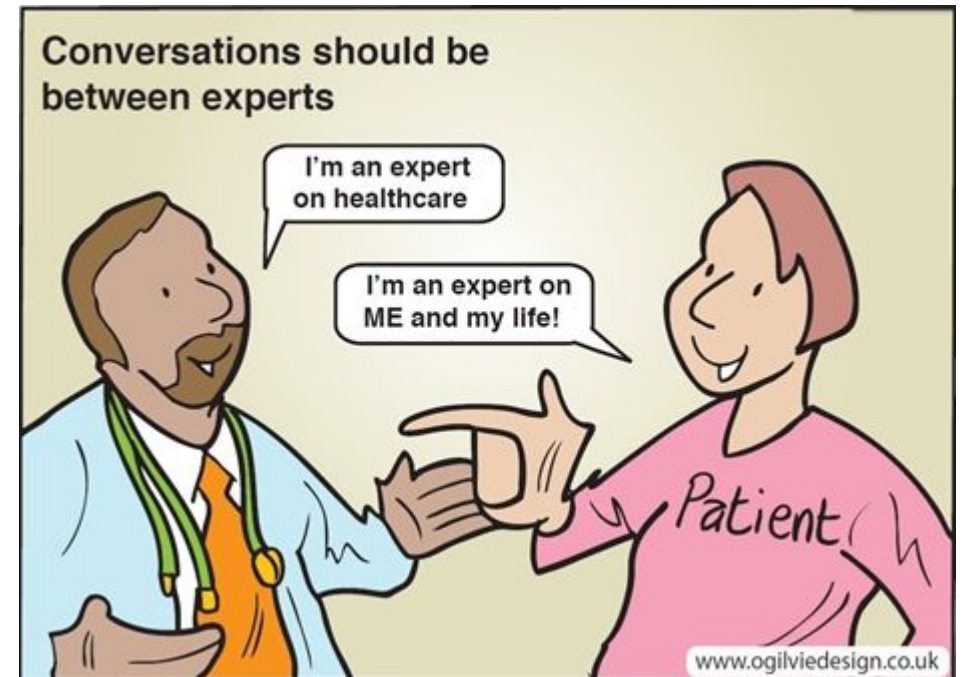
Patient empowerment sense of control

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Requires good lines of communication with clinical team - trust

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NOT for everyone



# Preparation (options)

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- Keep symptom diary
- Talk to friends/family before appointment
- Prioritise – “If you could fix one thing today what would it be?”
- Think about your expectations – medication increase, onward referral
- Write down key observations and questions
- Remember that 50% of what is said in a consultation is forgotten immediately





# What the doctor wants to know

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- General
  - Better, worse, much the same?
- Specific
  - Motor – tremor, mobility, wearing-off, falls, transfers
  - Non-motor – sleep, bowels, bladder, cognitive function, hallucinations
- Function (personal)
  - golf, bowls, child-care, getting to football, DRIVING



# Symptom diary

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- Time for pills to work
- Wearing off?
- Percentage on/off during the day
- Are on/off predictable or unpredictable?
- Dyskinesia on or off?
- Ratio of good days to bad days
- Effect of any medication changes – better or worse
- Activity log – golf, walking, bowls
- Is symptom one off or part of a pattern?
- ANYTHING!!



# The challenges and difficult questions

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- Is it the Parkinson's?
  - Pain, lethargy, apathy, low mood
- Variability, unpredictability, uncertainty, planning
- What will I feel if we increase the medication?

# Medication options

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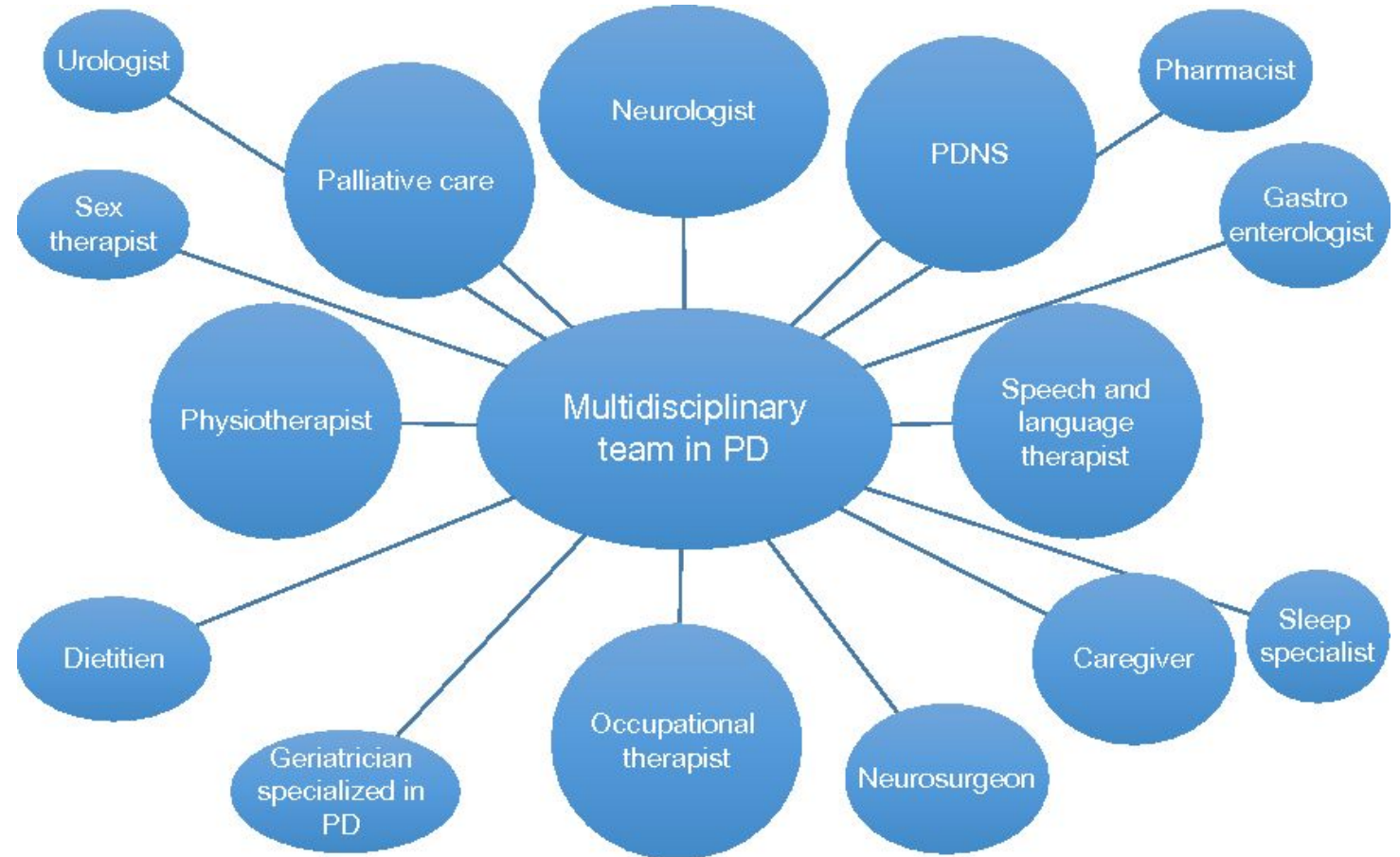
- Dopaminergic medications are predominantly for motor symptoms
- Grouped together only 3 options
  - Don't change – motor symptoms stable
  - Increase – motor symptoms progressed and no significant side effects
  - Decrease – experiencing significant side effects that outweigh any motor issues
- Drugs are only a small part of the picture



# The importance of the team

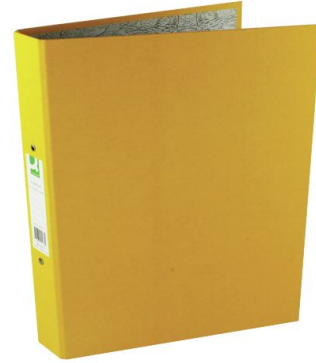
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- PDNS
- Physio
- OT
- SLT
- Mental Health Team
- Dietician
  
- PATIENT, FAMILY, CAREGIVERS



# Patient held records

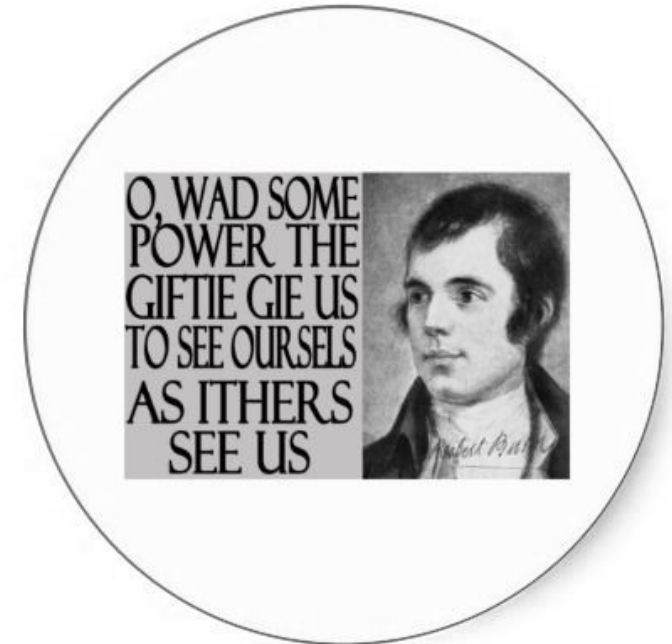
- 50% of what is said in a consultation is forgotten immediately
- 50% of what is remembered is remembered incorrectly
- Most of the 50% that is remembered is retained 2 weeks later
- The clinic letter is yours as much as anyones



# The importance of the carer

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- Carers are key
- In general it is really helpful for carers to attend appointments
- PD presents a major challenge for marriages and other relationships
- Chronic disease shifts the dynamic of a relationship
- Not everyone is suited to the role of carer
- Carer support is a key element of patient management (particularly as disease progresses)
- Shouldn't shy away from difficult conversations (anticipatory care, POA)



# Making the most of your PD clinic visit

- Prepare – talk, make notes, write down questions
- So long as you are comfortable take someone close to you with you
- Work to build a rapport with as many team members as possible
- Aim for consistency in who you see (you might have to be pushy)
- View the consultation as an opportunity to have a conversation about all aspects of your condition as two experts with different perspectives
- Prioritise to make best use of limited time
- Make sure you are seeing the right team member (remember doctors and drugs are only a small part of the treatment plan)
- Rehab requires you to be an active participant not passive
- Agree a plan that means you retain some control
- Remember optimising treatment often requires trial and error
- Consider having a copy of the clinic letter (patient held records)
- If you run into trouble don't wait for next scheduled appointment



# Questions/discussion

