This presentation is a resource developed as part of a face to face education event or workshop.

The target audience is health and social care professionals in roles providing palliative and end of life care.

The author has agreed to share the work to enable best practice in the provision of end of life care.
Parkinson’s disease (PD) in End of Life
Vicky Queen 2019
Parkinson’s disease (PD)

What is Parkinson’s disease?
Stages of PD

- Diagnosis
- Management
- Complex
- Advanced
- Palliative
Medications in PD

- Levodopa
- Dopamine Agonists
- MAOBI inhibitors
- COMT inhibitors
- Glutamate pathway drugs
• **Neuroleptic malignant syndrome (NMS)** is a life-threatening reaction that can occur in response to the sudden withdrawal of PD medication or drugs being given that can block them.

• Symptoms include, high fever, confusion, rigid muscles, variable blood pressure, sweating, and fast heart rate. Complications may include kidney failure, seizures, and hypertension.
PD in End of Life
Advanced PD, Someone with advanced Parkinson’s may experience the following:

• Drug treatments stopping being as effective.
• A complicated drugs regimen.
• More ‘off’ periods, when the effects of medication are reduced and people experience movement (motor) fluctuations and involuntary movements (dyskinesia).
• Increased mobility problems and falls.
• Problems with swallowing.
• Mental health symptoms such as depression, anxiety, hallucinations and delusions and dementia.
• Reduced independence.
• Less control of their Parkinson’s symptoms, which become less predictable.
• Pain – management of pain is crucial at the advanced stage.
Planning Ahead

‘Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.’

International Consensus Definition of Advance Care Planning (Sudore et al 2017)
• Drug treatments stopping being as effective.
• A complicated drugs regimen.
• More ‘off’ periods, when the effects of medication are reduced and people experience movement (motor) fluctuations and involuntary movements (dyskinesia).
• Increased mobility problems and falls.
• Problems with swallowing.
• Mental health symptoms such as depression, anxiety, hallucinations and delusions and dementia.
• Reduced independence.
• Less control of their Parkinson’s symptoms, which become less predictable.
• Pain – management of pain is crucial at the advanced stage.

➢ Stopping medications*
➢ Pharmacological support
➢ Advanced therapies*

➢ Equipment
➢ Consideration of PEG
➢ Mental health team input.

Medications

➢ Psychosocial support
➢ Advanced therapies*
➢ Dopaminergic support
Advanced Treatments
Swallowing Problems

- Nasogastric tube
- Oesophagus
- Stomach
When Treatment is No Longer Affective?
• Holistic

• Person-centred approach to care.

• People with Parkinson’s and their carers (if they have them) are experts in their own condition.

• Palliative care in Parkinson’s may be supported by a number of professionals, including a Parkinson’s nurse, local hospice or specialist palliative care team, physiotherapist, occupational therapist, speech and language therapist or dietitian.

• Advanced care planning/ advanced care directive
Advance Care Decision

An Advance Decision lets you record any medical treatments that you don’t want to be given in the future.

An Advance Statement lets you record anything that’s important to you when thinking about your health, care and wellbeing, like any religious or spiritual views, your daily routine or where you would like to be cared for.

Advance Decisions are legally binding in England and Wales, as long as they meet certain requirements.
Particular Challenges?
Challenges

- Pressure are care
- Nutrition
- Hydration
- Communication
- Pain
- Complications such as NMS
Advanced Care Planning

• ‘Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.’

• International Consensus Definition of Advance Care Planning (Sudore et al 2017)
• Medications for PD are crucial.
• Advanced treatments are used in PD.
• Managing a patient who can no longer swallow.
• PD symptoms in end of life are unique to the individual.
• Understanding the challenges of PD.
• Time to explore planning
• Advanced care planning