



The PSP Association's International Medical Workshop 7th July 2009

ABSTRACT

Title of Talk: PALLIATIVE CARE

| Part 1: Speaker(s) details | |
|-----------------------------------|--------------|
| Title | DR |
| Name | DAVID OLIVER |
| Position held | |

Part 2: Abstract (Maximum 400 words) Please make your abstract easy to understand as it will appear on our website and will be read by people with PSP and their carers who are not scientists but who will want to understand your work and what it means for them.

Palliative care aims to improve the quality of life for people with life-threatening illness, and their families by the careful assessment of the differing issues facing the person:

- Physical - pain, breathlessness, mobility issues
- Psychological - the fears and emotions of someone with progressive disease
- Social - the concerns and fears of families and carers
- Spiritual - the deeper concerns about life and death, which may or may not be religious

All these aspects of care are important in the care of someone with a progressive neurodegenerative disease. Palliative care encompasses the person with the disease as families face many losses and changes as the disease progresses. This support to family / carers may continue into bereavement.

The assessment will also include preparation and anticipation of deterioration - with consideration of advance care planning, end of life discussions and ensuring the symptoms, and other issues, are managed as effectively as possible.

To ensure that all people with neurodegenerative disease receive the care they need, collaboration between services - neurological, community and specialist palliative care- is essential. Professionals may need to be encouraged to look at their attitudes towards people with progressive disease – looking at the "whole patient" in the context of the family and address the issues that the person identifies. This approach is slowly spreading but attitudes of all need to change to allow a collaborative and positive approach to the people with progressive neurodegenerative disease.

End of life

As someone with a progressive neurodegenerative disease deteriorates the discussion and preparation for end of life care is necessary. This includes:

- Awareness of the progression and the need to discuss these issues

- Preparation for and anticipation of end of life issues
- Planning care
 - Place of care and death
- Symptom management
 - Assessment and review of all medication
 - Reduction of unnecessary medication
 - Ensuring appropriate medication is available
- Support
 - Patient
 - Family and carers
 - Professional carers

Many issues need to be considered and planning has been aided, in the UK, by the Gold Standards Framework – aiding care at home – and the Liverpool care of the Dying pathway – supporting care in the final few days of life.

Advance care planning is important, as this allows patients the opportunity to make their views known, in case they are unable to make the decisions themselves, due to loss of capacity or increasing weakness and symptoms. This may include the preparation of an Advance Directive or Advance Decision to Refuse Treatment or the appointment of a lasting power of attorney to make proxy decisions.

The care of a person at the end of life depends on careful assessment and planning, with involvement and support of all involved – patient, family and carers and professionals.