

Reflective Practice

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- Work with people affected by all forms of CJD, their families and carers
- Sporadic, acquired and inherited forms
- Rapidly progressive disease: cognitive, physical and psychological symptoms
- Affected people often under 65 years old
- Inherited forms tend to have a longer disease progression

Case Study

- Mrs A is a 42 year old woman affected by inherited prion disease
- Lives at home with husband and two teenage children
- Historically in denial of diagnosis and resistant to care
- Physically very effected, 'challenging behaviour'

Need for reflection?

- Isolation of carers
- Resistance to care
- Denial of extent of physical dependence
- Altered states of consciousness
- Different responses to different carers
- Verbal abuse
- Caring for someone own age / younger

Outcomes

- Opportunity to share information, techniques, ideas
- Teach and learn
- Exploration of approaches to care
- Validation of care given
- ‘get things of your chest’, good and bad
- Meet other carers and create a supportive network
- Ask questions about the disease

Personal Reflections

- Move from formal teaching sessions – need to be a usable resource / facilitator
- Agency Nurse
- Most affected people still older than me
- Role of the nurse as a therapist
- Can't replace local team – must not become a barrier
- Will never have all the answers!

Information and resources

➤ National Prion Clinic:
www.nationalprionclinic.org

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➤ Department of Health
www.doh.gov.uk

➤ National CJD Surveillance Unit
ph. 01315 373 037
www.cjd.ed.ac.uk

➤ CJD Support Network
ph. 01630 673 973
www.cjdsupport.net