CareSearch Project Research Studies Register: Registration Proforma	0147

Study Title: The Palliative Management of Patients with Creautzfeld Jakob Disease (CJD)

Brief description of the study:

Retrospective review of 14 patients in outer metropolitan health service who, in 3 year period were diagnosed with the rare CJD. The aim was to collect data re presenting and progressive symptoms, the effectiveness of interventions provided and to explore the quality of psychosocial support provided to the patient and to families. With minimal published literature, we wanted to compare our findings with what is currently known and to facilitate best practice for the patient and their families. What we found is that each patient presented with their own unique symptoms, that the symptoms throughout the (usually rapid) disease trajectories were diverse and complex which made management challenging, and that family support was paramount

Study Methodology: (Please mark with an x which type of study methodology)

	Epidemiology
	Health Services / Health Economics / Quality Improvement
	Qualitative, Observational or Descriptive
	Mixed Method
X	Systematic Review
	Intervention: RCT
	Intervention: Comparative or cohort study
	Intervention: Case series

Project details:

Funding source (Optional):						
Has the study received ethics approval?	**X**	Yes		No		Not applicable
Project starting date: September 2013						
Project completion date: September 2015						
Multi site:	**X**	Yes		No		Not applicable

RESEARCHERS

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Associated publications / reports: view to submit for publication, currently in discussion

Topics (Admin only): Creutzfeld Jakob Disease (CJD)