



# The challenges of palliative care for children with chronic renal failure and learning difficulties

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# Julie

- 13 year old girl
- Learning difficulties and impaired communication due to Dandy Walker malformation
- Shunted hydrocephalus

# Julie's presentation in CRF

- Presented in October 2007 with signs of blocked VP shunt
- Pre-operative bloods before shunt revision showed severe renal impairment
- Biopsy showed chronic tubulo-interstitial nephritis

# Difficulties for treatment

- Distance from the unit
- Intolerance of medical procedures
- Behaviour
- Uncertainty of outcomes
- Quality of life

# Discussions with family

- Explanation of CRF
- Description of treatment options
- Practical implications of each option
- Possible outcomes of each option
- Support

# Impact of the diagnosis

- Shock
- Assimilation of information
- Understanding the information
- Adjusting to implications of diagnosis
- Consideration of options

# Planning for palliative care

- Local hospice
- Julie's school and school nurse
- Multi-agency meeting at family home:
  - Community occupational therapist
  - Community nurse
  - Respite carer
- Local GP

# Impact of learning difficulties on dialysis and transplant programmes

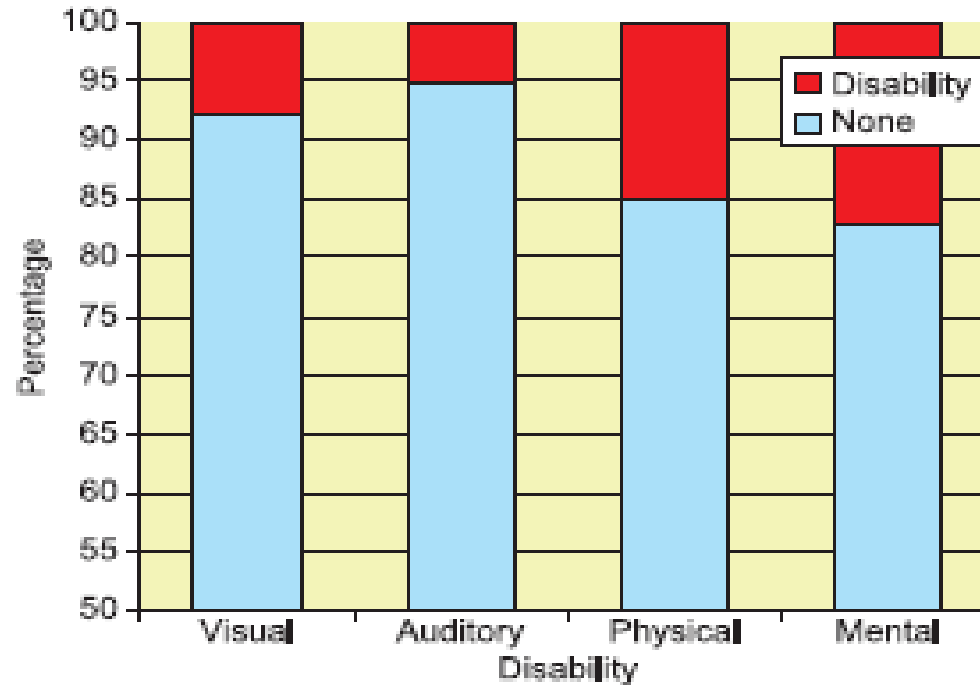
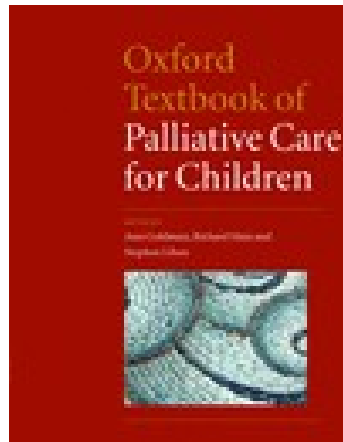


Figure 18.18: Prevalence of disability in the ERF population

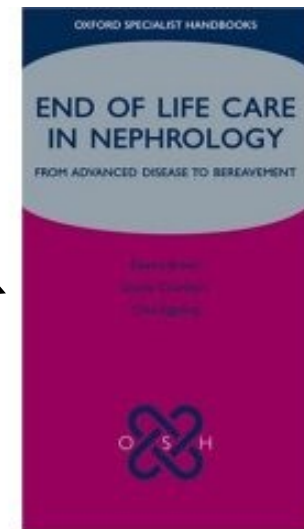


# Conservative management of CRF in children



No chapter on children

No chapter on chronic renal disease



# End of life issues

- Julie died at home in January 2008
- SW attended the funeral
- Further contact with family
- How the family have coped so far

# Summary

- Importance of psychosocial support from diagnosis to end of life care
- Renal teams involved at each stage
- Large supportive families make a positive difference!

# Issues for discussion

- Do others have children on D&T programmes in their units for whom:
  - conservative management may be appropriate?
  - parents have refused non-active treatment?
- Would prior positive experience of conservative management have helped in recommending this option?