UK Hospice and Palliative Care

- Similar history & system to ours for hospice services
- Cancer focus plus MND, slowly changing
- Moving towards shorter LOS and d/c planning focus, renaming of hospice to PCU
- Some long term stays continue in hospices
- Community teams & consult services well developed
- Macmillan nurses and Marie Curie nurses provide more care, especially after hours care, plus better domiciliary services in UK than here
Transition to ACF

- Recent changes in funding for palliative patients moving to ACFs...continuing health care not social care
- No fees for these residents, acknowledgement of health care needs
- Various approaches to f/u in ACFs by pall care teams; Link nurse model in ACFs
- Gold Standards Framework rolling out: EOL care pathway for all dying residents
- Single or double rooms are the standard for ACF accommodation!!!
USA scene

- More recent history based on Hospice benefit in last 6 months of life, aggressive treatments forgone, e.g. chemotherapy: “sign up”
- Less inpatient focus: care at home & in ACFs
- Small short stay PCUs and acute consult services
- Multidisciplinary hospice care for all enrolled patients, 4 visits weekly from team common
- 56% non malignant and 44% cancer (2007)
- Explicit national referral criteria to hospice, including NMDs and Alzheimers Disease
Hospice in ACFs in USA

- ACFs are growing market for hospice organisations, especially “for profits”
- High proportion of end stage dementia patients enrolled: prognosis a problem, many survive over 6 months, re-enrolled or d/c
- Hospice provides great supplement to basic care in ACFs
- Accommodation is single or double rooms, impressive facades and entrance areas!
- Cats commonly live happily in ACFs (Oscar!)
Transition to ACF

- Palliative patients moving to ACF are “SNF” patients and Medicare pays ACF fees
- Ineligible for hospice care unless able to pay ACF daily fee $250-$300 (double dipping)
- Hospice teams developing pall care services for ineligible patients in ACF or at home
- Nurse practitioner model with doctor & SW
- Recognition that not all can accept they are dying but still need care
USA medications

- Little use of syringe drivers at home or in ACFs
- Sublingual morphine and ativan are main meds in terminal care, 2 hourly dosing by family at home common practice… seen as adequate and good outcomes
- Inpatient PCUs may use syringe drivers and other sedation, but no expectation for use in community
GP Services to ACFs

- Universal weak area of care
- “Missing in action” finding in USA study re ACF care: limit of 1 visit per 30 days to ACF
- Difficulties with after hours GP and urgent medication access

Exceptions

- in small village ACF in Nottingham with 1 GP
- Netherlands and Belgium have physicians trained for NH role and that is their job
Psychosocial care in ACFS

- NSW has no Social Work in ACFs except Jewish Aged Care & UK similar lack of SW
- Pall care outreach to ACFs does not include SW in Australia and UK
- USA ACFs must have a SW if over 120 beds and less beds must have social services designee
- USA hospice teams always provide qualified SW & chaplain to ACF, highly valued roles
Commonalities for ACFs

- Low paid, low status, poorly trained care assistants deliver most daily care in ACFs in Australia, UK and USA (high turnover)
- Poorly funded residential aged care systems, but UK and USA have higher standards of accommodation than us and their governments pay for care of the very ill in NH
- Admission to NH is still the least desirable outcome for most