

Anchoring Patients and Families in Primary Care

making the case for joined up working between regional specialist referrals and community care



Dr Sian Jones

GP Lead for Cancer and Palliative Care in Highland





Case 1

- 68 year old lady living semi-rurally.
- WHO performance status 1-2.
- Presents with skin tumour.
- Referred from secondary care to regional centre.
- Initial review by Near-Me and arrangements made for surgery in regional centre. Letter detailing Near-Me appointment sent to GP.
- Patient had family living near regional centre so travel was not a problem.

- 3 months later presented to GP with ongoing wound healing issues. Requesting unusual Px that had been suggested by regional centre.
- GP realised had had no correspondence regarding treatment.
- Transpired her 3 surgical treatments had been extensive as tumour much larger than expected.
- She had been sending photos back and fore to regional centre, finding this difficult and disjointed, felt no-one local to turn to. GP requested information.
- 2 months later, GP partner received irate phone-call from son. His mother had been told her disease was now incurable. She was for best supportive care or “sent home to die” .
- Same day, GP partner received phone call from specialist palliative care consultant asking for information on patient as she had been referred to hospice by regional centre (“local” hospice is 110miles from her home).
- She died at home 2 days later. She was peaceful at the end.
- Complex family bereavement support.

Case 2

- Female, 16, urban setting, difficult family dynamics, resultant behavioural issues over the years.
- Immediate family very supportive but vulnerable.
- Diagnosed with devastating, incurable, rare tumour.
- Referred by secondary care to regional centre.
- For intensive palliative treatment but likely very poor prognosis.

- 
- 
- Regional centre correspondence after every appointment – both scheduled and unscheduled.
 - Recognition of likely poor prognosis from start.
 - Recognition of complex family dynamics from the start.
 - Single point of contact specialist nurse in home town from start.
 - SPOC nurse able to coordinate input from GP, district nurses, specialist paediatric community nurses and psychology (for both patient and family) in home town. Very flexible model of care.
 - Discussed regularly at primary care MDT meeting.
 - Specialist palliative consultants aware but their expertise never required.
 - Planned, coordinated, peaceful death at home.
- 
- 

Lessons learned

- **Communication** is key.
- Primary care team can be a fount of knowledge on a patients' illness behaviour, coping skills and their family dynamics (*useful before, during and after treatment*).
- Ever-improving and evolving teamwork available to support patients and families to be cared for where they choose.
- Primary care have to pick up the pieces.
- A strong community anchor is vital whether or not further specialist input is required or not.

