# Palliative Care Case Studies-Some Challenging Young patients

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#### Introduction

- Our service for over 18s
- Some patients might transition from children's services e.g CF, M.D.
- Children's Hospices largely deal with children with long term conditions, respite, day care.
- Patients with cancer rare
- They will often keep patients beyond the age of 18 if they are already known.
- There can be challenges with some patients as their needs might seem better met by paeds

#### Our Young Patients

- YOU at Christie
- Most of our young patients are thankfully not as young as this.
- Recently feels that we have had increasing numbers of patients aged 25-35.

- These patients present with similar palliative care issue to any patient but also have some unique challenges.
- What do you think some of these could be?

# Not an exhaustive list but some examples!

- Increased levels of distress
- Tricky symptom management
- Distressed parents and siblings
- A dependency on family
- Chaotic lifestyles
- Only making contact when in crisis
- Childlike behaviour

- A feeling that the hospice is not for them
- Staff distress
- Staff avoidance
- 'Transference'
- Complicated bereavement issues

- SG 28 year old man
- Testicular cancer
- Benign tumour in teens. 'Watch and wait' policy adopted.
- Now metastatic disease.
- Not sensitive to chemotherapy.
- No response to radiotherapy.
- Lymph node metastases.

- Presents with sporadic abdominal pain
- Repeated scans do not explain the severe loin pain described
- When in pain calls an ambulance and gets taken to AandE
- In AandE he demands IV morphine and is often given it.
- Abusive to staff.
- Abusive to other patients.
- Get admitted for pain management.
- Often leaves before a management plan can be implemented

• Difficult to engage with at home. If well is out. If unwell either hides under duvet and refuses to engage or is in AandE

- Receives 10-20mg IV morphine when in AandE but at home tends to swig doses far in excess.
- Unable to comprehend that there is no reason that the IV should be 'Better'
- Any ideas as to how we should proceed??

- Liaison with AandE team
- Implemented plan-abstral, lorazepam.
- Worked to an extent.
- Reduced AandE attendance for a time
- Now excessive abstral and oxycodone use.
- GP and community teams 'Concerned'
- Looked unwell before Christmas? Dying
- Commenced Syringe pump. Threw it at the district nurses
- Now more stable

- Now has bone mets
- Increasing pain at times
- What else might we be able to do?

- CB 35 year old woman
- Dilated cardiomyopathy.
- Genetic condition
- Witnessed her mums collapse and death
- 2 children
- ICD
- Referred to palliative care Dec 2019
- 'Is there anything we could do to avoid her children suffering the same experience?'

- ICD activating regularly mostly in early hours of the morning and patient unaware at that point.
- Only option transplant but recent history of alcohol excess and continuing to smoke
- Continued uncertainty as to whether this would be an option should she stop but increasingly unlikely and patient increasingly unwell. Very difficult to have this conversation with patient
- Suggestions made re hospice –declined
- Refused to have DNACPR on grounds that ICD continues to activate and then she recovers
- Refusing deactivation of ICD

- Continued episodes of arrhythmia and delayed shocks.
- One episode witnessed by HF nurse on a visit
- Liaison with AandE. Not for escalation to ITU
- Attemped further discussion re DNACPR. Refused to consider
- Discussed concerns for kids. Challenged her re experiences with own mother
- Any ideas as to what we might have done differently?

- RIP in weeks following Christmas.
- Did not answer phone to partner.
- Found dead on sofa by young son.
- Resus attempted and prolonged attempt in AandE
- Could we have done anything differently?
- Did we do right by her?
- Did we do right by her kids?

#### Summary

- Palliating younger patients comes with unique challenges.
- Patients often have a complex range of issues
- Emotionally challenging
- AS YOU GET OLDER YOUR PATIENTS GET YOUNGER!!
- Importance of team-working and support
- If you get it right it can be very rewarding