Palliative Care & Haematology:
Known Unknowns or Unknown Unknowns?
Working towards a better collaboration.

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ANZSPM Update June 2013
Epidemiology of Haem malignancies – in brief

- 4th most common cancer diagnosis in Vic.
- Greatest risk factor: increasing age*
- Increasing rates 1998-2008, esp DLBCL, follicular lymphoma, plasma cell disorders
- Increasing survival

1. CanStat 2011
Outcomes

**AML:**
- Median onset 65 years
- Overall mean survival 20 months
- In the elderly:
  - Intensive chemo cures <20%
  - If not fit enough for chemo mean survival 4/12

**Myeloma:**
- Median survival 3-4 years
- Higher for younger patients
- Many lines of treatment, many trials
- (But essentially incurable)
What’s the big deal?

• Symptoms:
  – Pain
  – Haemorrhage
  – Fever
  – Dyspnoea
  – Fatigue, drowsiness
  – Delirium
  – Psychological symptoms
  – Distress
  – CNS disturbance
  – Insomnia
  – Diarrhoea
Pain in haematological malignancy

- Incidence in advanced disease: 52-76%
- 69% moderate or severe
- Aetiology:
  - Bone marrow expansion
  - Osteolysis
  - Lymphadenopathy
  - Mucositis
Bleeding at EoL – patients with haem malignancy

• Incidence 26-44%
• Italian study, 469 patients with advanced HM at home\(^1\):  
  – 26% had bleeding episode ≥WHO G1  
  – 88% resolved, 81% transfused plt at home (!)  
  – 6% died b/c of bleeding complications

1. Cartoni et al, Leuk Lymphoma 2009
Our (PC) idea of a good death

- Preferred location
- Symptoms controlled
- Chance to prepare, attend to ‘bucket list’
- Unencumbered by technology
- etc
What do haematology patients want?

• Not a lot of information:
  
  – Some would refer to be at home; may find it difficult to raise this with treating teams if they don’t initiate the discussion.
  
  – Others would prefer to remain in the familiar environment of the haematology ward
    > HBAPCC becomes an important provider of PC
  
  – How well are patients/families informed about their prognosis?
Palliative Care and Haematology today

Patients with haematological vs other malignancies:

- are less likely to have PC involvement
  - 27% Acute leuk vs 75% CRC \(^1\)
  - RR 0.46 vs other cancers \(^2\)

- Have a reduced time from PC referral to death
  - 14 vs 47 days

- are >twice as likely to die in hospital

\(^1\) Maddocks. Ann Acad Med Singapore 1994
\(^2\) Howell et al. Palliative Medicine 2011
What are the factors at work here?

• Trajectory of disease
• Unclear goals of care
• Lack of knowledge about PC
• Inadequacies of PC system

Manitta V, Zordan R, Cole-Sinclair M, Philip J, Nandurkar H.
J Pain & Symptom Manage 2011; 42 (3): 432-442

Much in common with non-malignant diseases.
Disease Trajectory

- Multiple acute episodes
  - High-tech, generally effective therapeutic interventions.
  - Except for one!

- Deterioration is sometimes sudden, eg haemorrhage, and may be unpredictable
Be careful what you wish for!

Current workload

With some of the additional referrals!
Clarity around goals of care

• Multiple lines of therapy
• Multitude of studies
• Focus on cure – doesn’t trigger PC referral.

• Can patients parallel process different ideas?
Incomplete understanding of PC

• Equated with terminal care
• Is there a self-fulfilling prophecy element?

• Personal factors for some clinicians:
Don’t mention the war....
Maybe I can get away with this:

- Some doctors seem to find it hard to accept an impending death
  - Avoid discussion
  - Avoid referral

- Over-optimism in prognosticating is routine
  - Worse the longer a physician has known a patient

- Scenario of iatrogenic illness
  - Treatment SE’s
  - GvHD

- Clearly some negative outcomes of this avoidance
Inadequacies in the PC system

• Lack of experience in managing haematology patients.

• Reluctance of some PC physicians to use blood products

• Need for high level medical support in the late phase of disease
Inadequacies in the PC system

• Difficult and/or variable referral processes
• Lack of hospice beds
• Unnecessary referral from CPCS nurses back to hospital
• Reliance on time frames for determining eligibility
Toward a better collaboration

- PMCC data 2007-10
  - Rising number of ham referrals, 9.7 → 13.7% of total referrals
  - 54% inpatient Haem deaths referred to PC
  - Main increase seen in O/P referrals

- Symptoms a common trigger for referral
  - Less confronting for referrers and ? Patients
  - Allows time to build relationships
  - O/P referrals had longer survival

Corbett et aJ Pall Med 2013
Toward a better collaboration

• Haematology Supportive Care Plan at Alfred Health
  – Best practice model for transition from curative to more palliative care
  – Communication document
  – Activated following MDM decision that aims of care are now palliative
# HAEMATOLOGY SUPPORTIVE CARE PLAN

**DATE**
The use of this form is for all patients deemed appropriate for palliative care, where no plan for further aggressive therapy has been agreed upon, there is no curative intent and patient is not for further active management, including clinical trials.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Haematology Registrar</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NFR:</strong></td>
<td>Patient documented NFR:</td>
</tr>
<tr>
<td>(If yes, ensure patient is documented not for CPR, DCR or intubation and a current MR 89 form has been completed. If no, must provide rationale)</td>
<td>Y  N</td>
</tr>
<tr>
<td>Comment:</td>
<td></td>
</tr>
<tr>
<td><strong>Referrals:</strong></td>
<td></td>
</tr>
<tr>
<td>Palliative Care Registrar:</td>
<td>Y  N</td>
</tr>
<tr>
<td>Palliative Care Coordinator:</td>
<td>Y  N</td>
</tr>
<tr>
<td>Psychology:</td>
<td>Y  N</td>
</tr>
<tr>
<td>Social Work:</td>
<td>Y  N</td>
</tr>
<tr>
<td>Grief Counsellor</td>
<td>Y  N</td>
</tr>
<tr>
<td><strong>Patient/Family/Carer informed of referral</strong> (If yes, agreement and discussion of palliative care intent and management plan has been had with patient/family/carer. If no, must provide comment)</td>
<td></td>
</tr>
<tr>
<td><strong>SUPPORTIVE CARE MANAGEMENT</strong></td>
<td></td>
</tr>
<tr>
<td>Blood Product Support (please indicate rationale for blood tests and procedures. You must provide rationale for blood test monitoring)</td>
<td>Blood Tests</td>
</tr>
<tr>
<td>Weekly:</td>
<td>For Red Blood Cell transfusions for symptomatic patients with Hb &lt; ___</td>
</tr>
<tr>
<td>Fortnightly:</td>
<td>For platelet transfusions when symptomatic (ie: bleeding) with platelet &lt; ___</td>
</tr>
<tr>
<td>When symptomatic:</td>
<td></td>
</tr>
<tr>
<td>Comment:</td>
<td></td>
</tr>
</tbody>
</table>

**MEDICATION** (medication regimen focus is the relief of distressing symptoms – unless indicated)
If medications are documented elsewhere, please record document, ie: see MR M 50

| Oral antibiotics | Details: |
| Oral fungal medication | Details: |
| Tranexamic Acid | Details: |
| Allopurinol | Details: |
| HSV (herpes simplex virus) prophylaxis | Details: |
| Emergency medications prescribed | Details: |
| Analgesia | Details: |
### HAEMATOLOGY SUPPORTIVE CARE PLAN

**FEVER EPISODES**  
(a temperature greater than or equal to 38°)  
Discussed: Y □ N □  
Comment:  

**INTRAVENOUS ACCESS**  
(please give details of IV access, how long it has been in situ and management plan, such as who will continue to care for line)  
Y □ N □  
Comment:  

**OUTPATIENT APPOINTMENTS**  
(Ensure patient has at least one follow up appointment arranged)  
Haematology: Y □ N □  
Palliative Care: Y □ N □  
Community Palliative Care: Y □ N □  

**COMMUNICATION OF CARE PLAN**  
(Ensure care plan has been faxed to GP or local health care provider)  
Y □ N □  
Details:  

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**MEDICATION**

**Analgesia**  
Patient is advised to contact the palliative care team for pain and symptom management needs

**FEBRILE EPISODES**  
If patient is stable yet with fevers, patient should be informed they do not need to notify medical team and may take antipyretics unless contraindicated.  
If patient is unwell with fevers, patients should be informed to contact their palliative care contact or present to ED.

**INTRAVENOUS ACCESS**  
Intravenous access may be maintained for symptomatic management of the patient and/or where poor venous access is evident and patient is requiring transfusion support frequently.

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Completed by:  
Signature:  
Print Name:  

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Patient Information

Q & A format

Definitions of pall care, hospice

Haematology involvement

When to come to hospital

Limits of care e.g. transfusion support, febrile episodes, investigations, treatment of infections with high cost antibiotics

Contact details
Haematology Supportive Care Plan

• Evaluation
  – **Nurses:** Patients were still not always referred in a timely manner and were seen as challenging to palliate
  – **BUT** communication of the care plans improved

  – **Patients:** Were all aware that goals of care was no longer curative and recalled discussion of care plan.
  – Saw PC as an important point of contact and part of care team
  – Retained some mis-perceptions of how often they required tests and interventions
Time for Palliative Care v2.0?

• Involvement at an earlier point in the illness trajectory
  – needs vs prognosis
• Expand involvement to non-malignant conditions
  – needs vs diagnosis
• Expand the range of therapies offered
  – needs vs ‘dogma’
Oils ain’t oils...
Toward a better collaboration

• PC must recognise that the majority of primary PC has been and will be done by non-specialist carers.
  – Resource rather than replacement

• Core set of PC competencies for all physicians (and other health professionals) to be incorporated in under and post-grad curricula.
  – Communication
  – When to involve specialist PC.
Toward a better collaboration

- PC need to reorganize/reconceptualise interaction with non-onc fields
  - Reconsider the training requirements
  - Review mission statements
The End