The Poor Prognosis Letter Project

University Hospitals Bristol
Supportive and Palliative Care Team
The Poor Prognosis Letter (PPL) journey

Problem → Process → Future
The problem

- Recognising the end of life
- Communication
- Patient choice
Process

GP end of life leads (information)

Specialty teams (indicators of poor prognosis)

Palliative care team

IT

Patients
The Poor Prognosis Letter

Top box – admission to hospital

3. Prognostic criteria

9. Patient’s understanding

11. Preferences for future treatment
Patient notes

PATIENTB ZZTESTB

NHS number: 1234554321  Hospital Number: RA77264337

University Hospitals Bristol NHS Foundation Trust

This form is sent to you because your patient has a chronic condition and has been reassessed in the clinic/on the ward today. He/She has been found to have poor prognostic markers for their condition and therefore may be in the last year of life. This would make them eligible for the extra support that you provide via your practice supportive care register. (Gold Standards Framework or similar).

Admission to hospital for active treatment remains appropriate
(Unless the patient has an advance decision to refuse treatment)

GP Letter. Please check before wider distribution. This letter is confidential.

Outpatient Letter

Patient Identification
PATIENTB ZZTESTB
4 HENLEAZE AVENUE
BRISTOL
BS9 4ET

Appointment Date: 07/05/2016 15:30

Sex: Male
Date of Birth: 01/01/2000
Marital Status: Unknown
NHS number: 123 455 4321
Hospital Number: RA77264337
He/she is thought to be in the last year of life by the medical team and has the following poor prognostic criteria for advanced disease.

1. Poor prognostic criteria for cancer
   World Health Organisation Performance Status 3 or 4
   Metastatic disease with no anti-cancer treatments available

2. Poor prognostic criteria for chronic respiratory diseases
   Forced Expiratory Volume in 1 second (FEV1) < 30% predicted
   Very limited mobility due to breathlessness
   Needed more than 2 hospitalisations during the previous year

3. Poor prognostic criteria for heart failure
   NYHA Class IV
   Presence of treatment-resistant peripheral oedema
   Renal impairment (eGFR <30ml/min)
   Repeated hospitalisations with decompensated heart failure or ICD shocks

4. Poor prognostic criteria for renal disease
   Unintentional weight loss (non-fluid) > 10% over past 6 months
   Serum albumin < 25mg/dl
   World Health Organisation Performance Status 3 or 4
   Conservative management patients (i.e. not on dialysis) with CKD 5

5. Poor prognostic criteria for neurological conditions
   Progressive deterioration in physical and/or cognitive function in spite of optimal therapy
   Muscular weakness leading to aspiration pneumonia or respiratory failure in spite of respiratory support

6. Poor prognostic criteria for dementia
   Unable to walk without assistance
   Urinary and faecal incontinence
   No consistently meaningful verbal communication
   Reduced ability to perform activities of daily living

7. Poor prognostic criteria for frailty
   Multiple comorbidities with deteriorating day to day functioning
   Combination of at least 3 symptoms of: weakness, slow walking speed, low physical activity, significant weight loss,
8. Poor Prognosis Criteria for Chronic Liver Disease
Childs-Pugh C
>2 admissions in last 6 months
Ongoing alcohol usage
Unsuitable for transplant
WHO performance status 3-4

9. This prognostic information has been discussed with the patient - Yes

10. This prognostic information has been discussed with the carer - Yes

11. There have been discussions about preference for future treatments - Yes

12. Details of discussions...e.g Preferred Place of Death - Home if possible

13. A Do Not Attempt CPR (DNACPR) order in place during this admission - Yes

14. This form was sent home with the patient? - Yes

15. Significant social factors e.g. patient lives alone or is a carer - None

Consultant: Mr E ENT
Clinic: OP ENT
Specialty: ENT
Letter Ref: 411257/0
Date Printed: 27/02/2017 13:04
Signed: Colette Reid [Requester + Doctor]
Nick Harvey [Administrator]
The opportunity

- Quantifying Impact
- Improving Communication
- Improving the patient experience
- Involving GPs, DNs OOH
- Changing culture

University Hospitals Bristol
NHS Foundation Trust

Respecting everyone
Embracing change
Recognising success
Working together
Our hospitals.
Embedding in UHBristol end of life care initiatives

- DNACPR
- Communication skills training
- Treatment Escalation
- Personalised Plans
- End of life CQUINs
- PPL
Impact

National

Primary care

Trust

Patient

1500
Data so far – poor prognosis letter audits

<table>
<thead>
<tr>
<th>Date</th>
<th>No pts with PPC</th>
<th>Pts with PPC discharged</th>
<th>No (%) with PPC with PPL to GP</th>
</tr>
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<tbody>
<tr>
<td>Jul 2014</td>
<td>56</td>
<td>43</td>
<td>8 (19)</td>
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<tr>
<td>Mar 2015</td>
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<td>28 (93)</td>
</tr>
<tr>
<td>Sep 2016</td>
<td>22</td>
<td>18</td>
<td>9 (50)</td>
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</tbody>
</table>
Audit of PPLs in general surgery

Retrospective audit of patients from 2015/16

- 26 patients had letters sent; all had died
- All patients had been referred to community palliative care services

Prospective audit Sept-Nov 2016

- 16 patients identified as having a prognosis of less than 12 months
- 12/16 patients survived until discharge; 6 had PPLs sent to GP
Impact so far – examining a sample of PPLs

- 185 patients had a letter completed April – October 2015
- All patients had died – median survival 31.5 days
- 68/185 (36%) patients died in hospital  
  - (Bristol CCG average = 46% currently)
- 13/24 GPs of patients who had PPLs sent October 2016 contacted successfully
  - 7 positive
  - 3 neutral
  - 3 ‘out of area’ GPs
## Feedback from the GPs

<table>
<thead>
<tr>
<th>Really good letter, really clear… makes a GP stop and think I need to do something.</th>
<th>Her son is forceful about what he wants done for his mother and the letter has helped with that.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Useful and thought provoking.</td>
<td>I sat down and spoke to the patient regarding his wishes…it made me think about what’s going on and what I need to do next.</td>
</tr>
</tbody>
</table>
Integration of palliative and supportive care in the management of advanced liver disease: development and evaluation of a prognostic screening tool and supportive care intervention

Benjamin E Hudson,1,2 Kelly Ameneshoa,1 Anya Gopfert,1 Rachael Goddard,1 Karen Forbes,2,3 Julia Verme,2 Peter Collins,1 Fiona Gordon,1 Andrew J Portal,1 Colette Reid,3 C Anne McCune1

<table>
<thead>
<tr>
<th>Poor prognosis screening: cirrhotic patients only</th>
<th>Total score:</th>
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<tbody>
<tr>
<td><strong>Criteria</strong></td>
<td><strong>If total score &gt; 2, consider:</strong></td>
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<tr>
<td>Child Pugh Grade C</td>
<td>Poor prognosis discussion with patient/family</td>
</tr>
<tr>
<td>&gt; 2 liver-related admissions last 6 months</td>
<td>Poor prognosis letter to GP</td>
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<tr>
<td>Ongoing alcohol use (ARLD patients)</td>
<td>Advance care planning discussions</td>
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<tr>
<td>Unsuitable for transplant work-up</td>
<td>Specialist palliative care referral</td>
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<tr>
<td>WHO performance status 3-4</td>
<td>Allocation of hepatology specialist nurse</td>
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</table>

Hudson BE et al. *Frontline Gastroenterology*  http://dx.doi.org/10.1136/flgastro-2016-100734
Challenges

• Median survival only 31 days – prognostication still overcautious

• Some teams remain resistant to identifying patients with poor prognosis
Aspirations for the future

- Prospective database to allow us to monitor median survival and place of death

- To shift the care of patients in the last year of life from the ‘technological imperative’ to a ‘good death imperative’
Aspirations for the future

• Prospective database to allow us to monitor median survival and place of death

• To shift care of patients in the last year of life from the ‘technological imperative’ to a ‘good death imperative’

• To remind us that the only person who can tell us what is important at the end of their life is the patient
What’s happened since May 4th?

- Numerous requests for the letter across the UK
- Invitation to speak at the Hospice UK conference in November
- Loss of End of Life CQUIN – so no resources
- Personal feedback from ITU consultant about a PPL being used to make a decision re ITU admission
- Teaching feedback from senior doctors about its usefulness in recognising the dying patient and shifting goals of care to end-of-life care
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<tr>
<td>Apr</td>
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<td>32</td>
<td>2</td>
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<tr>
<td>Jun</td>
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<td>Jul</td>
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<td><strong>1573</strong></td>
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• Lessons learnt
  – Anything worth doing takes time and effort (the only place success comes before work is in the dictionary)
  – Use junior medical colleagues as allies – they see everything and go everywhere
  – Don’t give up