Primary palliative care

• Generalist palliative care provided by primary care
World population 7,700,000,000
Irish Population stats 2015-2040

• Population rises 4.57m to 6.35m
• Number of deaths rises 29,000 to 48,000
• Dependency ratio rises from 49% to 75%
• (2006) 11% >65yo (2036) 25% >65yo
• Old dependency ratio doubles
  (>65 / 15-65) x 100%

• Approx doubling of disease rates e.g. Invasive cancers (excluding NMSC) incidence rises by 84% for females and by 107% for males
Where do Irish people actually die(%)?

- Hospital: 43%
- Home: 26%
- Nursing home/long stay residential: 25%
- Hospice: 6%
Preferred place of death Ireland - at palliative care referral 2001

- 81% want to die at home
- 25% die at home
- 20% die in nursing homes
- (43% die in hospital) (2014)

- Place of care: 90% of time is spent at home in this last year
Place of Death in Ireland, 1885-2013
Based on original analysis by McKeown and updated by Irish Hospice Foundation, 2016)

- Proportion of Deaths at Home
- Proportion of Deaths in Hospitals and Institutions
Dying at home 2011

Ireland
Belgium
Czech Republic
England
Italy
Netherlands
Norway
Portugal
Wales
### Irish General Practices

<table>
<thead>
<tr>
<th>Service</th>
<th>1992</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>GMS+PRIVATE</td>
<td>91%</td>
<td>89%</td>
</tr>
<tr>
<td>OOH Co-op/deputising service</td>
<td>58%</td>
<td>93%</td>
</tr>
<tr>
<td>Single-handed</td>
<td>62% (1982)</td>
<td>18%</td>
</tr>
<tr>
<td>3+ GPs/practice</td>
<td>No figures</td>
<td>52%</td>
</tr>
<tr>
<td>Practice nurse (FT/PT)</td>
<td>17%</td>
<td>82%</td>
</tr>
<tr>
<td>Practice Manager</td>
<td></td>
<td>58%</td>
</tr>
<tr>
<td>Electronic records</td>
<td></td>
<td>94% (100% &lt;40yo)</td>
</tr>
<tr>
<td>Corporate practices</td>
<td></td>
<td>3%</td>
</tr>
<tr>
<td></td>
<td>1992</td>
<td>2015</td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>------</td>
<td>------</td>
</tr>
<tr>
<td>Fulltime (FT)</td>
<td>97%</td>
<td>84%</td>
</tr>
<tr>
<td>Male</td>
<td>85%</td>
<td>58%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(91% FT)</td>
</tr>
<tr>
<td>Female</td>
<td>15%</td>
<td>42%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(72% FT)</td>
</tr>
<tr>
<td>Irish undergradu ate-trained</td>
<td>98%</td>
<td>94%</td>
</tr>
<tr>
<td>Vocational postgraduate trained</td>
<td>&lt;10%</td>
<td>62%</td>
</tr>
<tr>
<td>Irish postgraduate trained</td>
<td>34%</td>
<td>75%</td>
</tr>
<tr>
<td>UK postgraduate trained</td>
<td>62%</td>
<td>24%</td>
</tr>
</tbody>
</table>

“Let’s try two apples a day and see how that goes.”
The rise of the Corporates!

Ranelagh Medical

- 3% in 2015, rising?
- Centric health 31 different practices
- Home Visits?
- Less time per consultation
- Continuity?
- Loss of emotional attachment
Irish general practice in need of palliation??!
Irish GP shortage

Shhh! Don't disturb him... there aren't many left in the wild...

Endangered Species
UK GP shortage

NHS CRISIS: 500,000 FORCED TO FIND NEW GP
Record number of families move surgery as smaller practices are axed

Will the last practice to close please turn out the lights?
Palliative care in General practice

Tate Gallery

Luke Fildes 1890

• ‘The character and bearing of the doctor throughout the time made a deep impression on my father...’.
Cradle to grave medicine
GPs assessed by patients/carers

Best if
- Ease of getting appointment
- GP willing to make home visits
- GP takes time to listen and discuss (communication)
- GP makes efforts at symptom relief
- Gp and PHN and SPC in tandem
- Routine contact after death

Worst if
- Poor communication
- No home visits
- Dismissive
- Works in silo
- No contact with carers post death
GP-Patient communication
Slort et al BJGP 2011

facilitators
- Accessibilty
- Taking time
- Listening and empathy
- straightforwardness
- Commitment
- Respect for dignity and autonomy of patient
- Friendliness
- GP led initiative taken to discuss end of life issues

barriers
- Lack of time
- Former doctor’s delayed diagnosis
- Strongly held relatives’ views
- Geographically distant surgery
20 DEATHS IN A GP PRACTICE
Murray, Scotland

- CANCER = 5
- ORGAN FAILURE = 6
- DEMENTIA/FRAILTY = 7
- SUDDEN DEATH = 2
Figure 1 Different disease trajectories for different illnesses
Issues for the GP

- Identification of patients at practice level likely to die in the next year
- Access to IT support
- Access to further education
- Access to specialist advisory service
- Adequate recompense for care with advanced illness
- Access to syringe drivers/equipment
- Out of hours provision of palliative care
Suggested Structured GP role in palliative care includes...

- Patient identification (SPICT, PIG)
- Advance care planning (“THINK AHEAD”/MODIFIED ‘POLST’)
- Symptom management (holistic)
- Anticipatory care - prescribing/out of hours information handover
- Avoiding unnecessary hospital admission
- End of life care medical/legal/family
- Bereavement
GP House calls less common if

- GP is salaried, living geographically distant  
  Senior BMJ

- GP is urban, female and part time  
  Mills BJGP 2019

- The only positive correlation in general practice with regard to enhancing numbers of people dying at home was for availability of **GP home visiting** and this was a strong association  
  Neergard BJGP 2009
Medical cards for palliative care patients

- Cabinet approval 2014
- End of life (full) medical cards issued if prognosis less than 6 months.
- No renewals will ever be necessary once issued
- Card number issued within 24 hrs
Gold Standards Framework 2000

Kerry Thomas
The 7 c’s

- Communication
- Co-ordination of care
- Control of symptoms
- Continuity of care
- Continued learning
- Carer support
- Care at end of life
Gold Standards Framework
-Keri Thomas

• To provide a framework for bettering the care of palliative care patients by the primary care teams-

  • **Identifying** clearly this group of patients and their carers
  • **Assessing** their needs
  • **Planning** their care
Primary care professionals have the potential and ability to provide end of life care for most patients, given adequate training, resources, and, when needed, specialist advice. They share common values with palliative care specialists—holistic, patient centred care, delivered in the context of families and friends.

S Murray 2004
Professor Scott A Murray
St Columba's Hospice
Chair of Primary Palliative Care, Primary Palliative Care Research Group
PRIORITISED RECOMMENDATIONS

• Create a system for primary care teams to identify patients with palliative care needs and respond appropriately.

• Develop and implement a palliative care summary for communication with out of hours services

• Clarify the extent and means of access to 24 hour SPC advice/information.

• Provision of information supporting PPC
IDENTIFICATION-REGISTER

• “FIND YOUR 1%”

• CODING??

• In UK, only 29% of patients dying are actually on the GP’s register

• 68% of patients with cancers and 20% of patients with non-malignant diseases

• Those on register more likely to die at home (50% v 25%)
Quality and outcomes framework (QOF) 8/1000 for palliative care (UK)

- 1000 points max
- Keeping a **register** -3 points
- At least **quarterly meetings** to discuss patients on register - 3 points
- Filling and sending **out of hours handover form** -2 points
- Up to 50 other related points e.g. for dementia care
Irish GP reimbursement 2020

- Payment available to GMS and non GMS GP’s.
- Payment available for the care of GMS and non GMS patients
- Register on “palliative care notification” form (green)
- Claim on “palliative care claim” form (blue) on the death of the patient.
- 242 euro per patient
- Available for cancer/end stage HIV/ progressive end stage neurological disorders
- ONLY CLAIMED BY 8% OF GPs
1948-1951

Mother and child scheme
Primary palliative care scheme

- **All patients** with serious chronic or progressive disease dying in primary care
- Defined tasks, capped payment.
- Initial advance care planning-e.g. THINK AHEAD
- Palliative care Special type consultations (STC) from a structured care menu (over and above routine primary care)
STC – examples

- Maintaining a register of patients
- Periodic discussion of same
- HOME VISIT
- FAMILY MEETING
- END OF LIFE CARE
- SYRINGE DRIVER CHANGE
- Complex grief/bereavement
- SYMPTOM MANAGEMENT
- STRUCTURED MEDICATION REVIEW
- Palliative care educational course?
Aims of PPC scheme

• Alleviate suffering by incentivising focus on palliative care needs
• Enhanced patient directed care
• Reduce over medicalisation
• Reduce unnecessary hospital admissions/ A+E
• Incentivise primary care team involvement with GP
• Allow for patient’s wish to die at home
OUT OF HOURS (OOH)

“The best medicine is practised at the worst of times”
What is the outcome of a GP OOH call for a **home** visit?  

L Rainey, Unpublished

- CAREDOC .....1.06million covered
- *Preliminary figures*

- 185 calls to the service identified as palliative and triaged in 2 separate months of 2012
- 47 (25%) advice only
- 8 (4%) centre visits
- 130 (70%) required visit
Outcome of GP OOH palliative care visits

- 10% referred to hospital
- **90% treated at home** (similar to UK figures)

Commonest symptoms: pain/dyspnoea/vomiting/agitation/dying

Commonest drugs prescribed: Buscopan (6%), Co-amoxiclav (4%), Tramadol (4%), Morphine (3%)
Survey of GP views on OOH info

Kiely et al. :BMJ supportive and palliative care  2013

• 212 GPs responded

• 82% do not *routinely* transfer information to OOH service

• 96% would welcome method of doing so

• 67 % felt they unnecessarily referred to A/E in the absence of information
Kiely et al.
Form information valued by OOH GPs

- Diagnosis 96%
- Medications 94%
- Patient insight 91%
- Patients wishes re place of end of life care 90%
- Anticipated problems and suggested management 90%
Development of OOH handover form

- April-Sept 2014: Packs sent to GPs in Southdoc area (information leaflet/Guidance document/forms)
- Formal pilot done of 60 forms submitted and used over a 6 month period
- 2015 Independent evaluation (Weafer et al.) done of this pilot comprising 22 interviews and quantitative analysis of data from these 60 forms
- Form further refined
- Main barriers – awareness of it and GP handwriting!
GP OOH Palliative Care Handover Form

- CARE Doc still pursuing development of e-version of the form

- Audit of use in 2019 found that 3 OOH services are actively using the form CAREDOC, SOUTHDOC and KDOC

- The form is also being used in Community Hospitals, Residential Centres and Nursing Homes
Electronic Palliative care summary

- Increase chance of home death x2 if form in place Finucaine BJGP 2020
GP out of hours future

- Out Of Hours (OOH) electronic Palliative Care Summary (ePCS) to include advanced care plan and DNR status

- ePCS Available to all relevant practitioners in OOH setting

- On call SPC advice to OOH

- Access to medicines OOH

- Education module for OOH GPs
GOLD STANDARD ePCS

- ePCS (with consent!) allows automatic twice daily updating of GP records to central repository
- No faxing!
- Allows for review dates
- Allows anticipatory care planning
GP assessment of their own care

**good**
- Rewarding and satisfying
- Co-ordinating role
- More comfortable with care the longer in general practice

**poor**
- Symptoms other than pain
- Managing patient’s and relatives’ psychological distress
- Managing transition to palliative from curative phase
Levels of Palliative Care

- Level 1 - palliative care approach
- Level 2 - General palliative care
- Level 3 - Specialist palliative care
Health Service

There! All fixed.

Health Care Reform
Tate gallery