Compassionate Communities: using robust methodology to rocket boost results for people living and working in UK

Dr Catherine Millington-Sanders
Kingston CCG EOLC Clinical Lead and Macmillan GP
SWL STP EOLC Clinical Lead
RCGP/ Marie Curie National EOLC Clinical Champion
31st October 2017
Population approach

National policy

Kingston example

Frome Compassionate Communities Model

Transformation through Compassionate Communities
Population approach
Rise in multi-morbidity
And complexity

Percentage of patients with each condition who have other conditions:
- This condition only
- This condition +1 other
- +2 others
- +3 or more others

Conditions:
- Heart failure
- Stroke/TIA
- Atrial fibrillation
- Coronary heart disease
- Painful condition
- Diabetes
- COPD
- Hypertension
- Cancer
- Epilepsy
- Asthma
- Dementia
- Anxiety
- Schizophrenia/Bipolar
- Depression

RCGP Royal College of General Practitioners
Marie Curie Care and support through terminal illness
Some day, we will all die, Snoopy! True, but on all the other days, we will not.
Compassionate Community’s Aims

- Personalised Care + Support for all, through serious illness and end of life care, irrespective of diagnosis + age
- Includes all forms of crisis, loss + grief – significant diagnosis, sudden death, suicide, accidents, pet loss
- Integrates chronic illness with death and bereavement
- Integrates with CCG and LA plans
- Transforms communities – inclusive of neighbourhoods through to institutions and workplaces
Population

- 7.7 million people
- 500,000 deaths per annum (to increase by 17% by 2030)
- 500,000 carer prevalence for EOLC (c 10%)

Total EOLC spend c25% of total expenditure

c£3,000 per emergency admission (average 2-3 in the last year of life)

Cost: £3-4.5bn (c4% of total expenditure)
National policy
Interest in the public health approach

The impact of a new public health approach to end-of-life care: A systematic review

Libby Sallnow¹,², Heather Richardson³, Scott A Murray² and Allan Kellehear⁴

Abstract

Palliative care, since its inception over 40 years ago, has set the standard of how to care for people who are dying. Key features among these standards have been the professional development of clinical specialties such as palliative medicine and palliative nursing; the essential addition of the multidisciplinary team to these new specialties that included social, spiritual and allied health workers—an outgrowth of the recognition that managing work with the dying, their care, and the bereaved required more than solely clinical skills; and the unique partnership with communities that yielded the volunteer movement within palliative care. Professional, evidence-based symptom management and the importance of supportive care and the unique partnership with communities that yielded the volunteer movement within palliative care. Professional, evidence-based symptom management and the importance of supportive care and the unique partnership with communities that yielded the volunteer movement within palliative care.
Six ambitions to bring that vision about

01 Each person is seen as an individual
02 Each person gets fair access to care
03 Maximising comfort and wellbeing
04 Care is coordinated
05 All staff are prepared to care
06 Each community is prepared to help

“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).”
Each community is prepared to help

The building blocks for achieving our ambition

<table>
<thead>
<tr>
<th>Compassionate and resilient communities</th>
<th>Public awareness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public health approaches to palliative and end of life care need to be accelerated and support given to people and communities who can provide practical help and compassion.</td>
<td>Those who share our ambition should work to improve public awareness of the difficulties people face and create a better understanding of the help that is available.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Practical support</th>
<th>Volunteers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local health, care and voluntary organisations should find new ways to give the practical support, information and training that enables families, neighbours and community organisations to help.</td>
<td>To achieve our ambition more should be done locally and nationally to recruit, train, value and connect volunteers into a more integrated effort to help support people, their families and communities.</td>
</tr>
</tbody>
</table>
UK General Practice:
Quality Improvement Standards

- For Advanced Serious Illness + EOLC
- Free, self-directed resource for practices
- Robust, evidence based quality improvement
- *To inspire, support and enable general practice to improve EOLC quality and outcomes, at scale.*
The 8 Standards

Standard 1: Professional and competent staff
Standard 2: Early identification
Standard 3: Carer Support - pre and post death
Standard 4: Seamless, planned, coordinated care
Standard 5: assess unique needs of the patient
Standard 6: Quality care during the last days of life
Standard 7: Care after death
Standard 8: General Practice being hubs within Compassionate Communities
Update on process so far

- Senior leadership sign-off concept by RCGP and Marie Curie – October 2016
- Consultation period with key stakeholders – Autumn 2016
- Alignment with EOLC Curriculum review - Autumn 2016
- Feedback from Academic Peer-Review Group – January-February 2017
Next steps?

- Working Group of practicing clinicians for independent review and challenge – Sept/Oct 2017
- Pilot practices/ CCGs to commence – Nov 2017
- Evaluation and model evolution – March-April 2018
- Wider implementation May 2018
Kingston example
Why do we need to do something different?
Home death rates England and Kingston
Kingston population data*

- Kingston borough population size = 173,525 (2015)
- Kingston CCG registered patient population size = 204,510 (Jan 2017)
- Older People age 65 + years borough population = 23,012 (2015)

- BME (ethnic minorities) = 29.6%, and rising each year (2015)

- Life expectancy at birth is 81.5 years for men and 84.5 years for women (2013 - 2015)

- Numbers on disease registers (March 2016)
  - cancer = 3,837, dementia = 1,012,  COPD= 2,334,  Heart failure = 918

*estimated data
In Kingston, an ageing population is set to increase each year. In 2015, Kingston had 1,114 deaths.

KCCG PHE data:
- Hospital deaths = 48.2% (537)
- Care Home deaths = 21.5% (240)
- Home deaths = 21.5% (239)
- Hospice deaths = 6.9% (77)
- Other places = 1.89% (22)
- Variation in the ratio of GPs use of palliative care/s registers to the number of all deaths = 29.5%
  (Av SWL 46.6%)
Serious Illness and EOLC are a priority for Kingston CCG and SWL STP

- c1,100 deaths per annum (to increase by 17% by 2030) [NEOLCIN]
- c1,100 carer prevalence for EOLC alone (c 10%)
- Total EOLC spend c25% of total expenditure
- Assuming c£2,213 per emergency admission (average 2-3 in the last year of life)
- Av Cost = £6.16 Million [£4.93 - £7.39 M]
Serious Illness and EOLC are a priority for Kingston CCG and SWL STP

- Kingston CCG total allocation = £248M
- Emergency admissions 18+ = £23.8M (9.60% of total allocation)
- Emergency admissions 00-17 = £2.3M

- Cost & number of GP consultations on comorbidity + EOLC (TBC)
- Cost & number of community nursing consultations on comorbidity + EOLC (TBC)
- Cost of social care for comorbidity + EOLC (TBC)
Frome Compassionate Communities
Quarterly admissions Frome 2013/4 – 2016/7

Source: Abel
Monthly admissions Somerset 2013 - 2017

Source: Abel
Monthly NEL admission cost Frome 2013/4 – 2016/7

Source: Abel
## Cost implications of Frome Model

<table>
<thead>
<tr>
<th></th>
<th>Frome</th>
<th>Somerset (excl Frome)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>30,000</td>
<td>540,000</td>
</tr>
<tr>
<td>Total NEL costs (2013 – 2014)</td>
<td>£5,7M</td>
<td>£86,5M</td>
</tr>
<tr>
<td>Total NEL costs (2016 – 2017)</td>
<td>£4,5M</td>
<td>£104,8M</td>
</tr>
<tr>
<td>Change in NEL costs (13/14 – 16/17)</td>
<td>➖£1,2M</td>
<td>➕£18,3M</td>
</tr>
<tr>
<td>% change</td>
<td>21% ➖</td>
<td>21% ➕</td>
</tr>
</tbody>
</table>

Source: Abel

- Early Implementation Mendip – results within first 6 months
- Application of Frome model could have saved Somerset > £36 million
Outcomes: Health Connections Mendip Patient and Professionals

- 81% - patients saw improvement in wellbeing (WEMWBS)
- 83% - patients saw increase in PAM (patient activation)
- 93% - patients felt more able to access support in the community
- 94% - patients were more able to manage their health and wellbeing or LTC
- 92% - GP practice staff feel confident their patients benefit from being signposted to HCM
- 91.4% - GP practice staff feel HCM adds value to the service they provide to patients

Source: Abel
Transformation through a Complex Intervention – Compassionate Communities; the principles
Compassionate Community; the principles

1. **Reliable system of identification** of those in need in GP surgeries and hospitals – training to internal community led hubs; practicing robust, proactive MDTs and use of QI methodology with real-time response to data to review and achieve outcomes.

2. **Care + Support planning:** evidence-based, personalised mapping of support + goal setting – streamlined process in place for scale, e.g. standardised ‘life plan’, transferable codes across settings.

3. **Robust network mapping + enhancement:** training for community development groups, using QI methodology and active participatory approach to enable the ‘community muscle’. Activate connections between health and community resources, community development workers are part of the internal hub team.

4. **Implementation of Compassionate City Charter:** using QI process to review and achieve outcomes.
‘Community is central to the wellbeing of individuals’ Abel

Ecomap of network and relationships

Network organiser

Frequency of visits F
- Relationship type eg son/daughter R
- Strong relationship
- Weak/vulnerable relationship
- Stressful/adverse relationship

Practical support = P
Emotional support = E
Compassionate Community Programme - Essential Components of the Complex Intervention

1. Specialist Care
2. Generalist Care
3. Compassionate Communities
4. Civic Programme for Compassionate City Charter

Adapted from Palliative Care – The New Essentials. Source: Abel
Hierarchy of Well Being

**NEGATIVE CONSEQUENCES**
- Poor work experience, increased social isolation, stress, civic societal impacts
- Carer exhaustion, morbidity and mortality, emergency admissions, long term psychological trauma & ill health
- Poor care planning, poor coordination, emergency admission to hospital, poor symptom control
- Poor symptom control, lack of equity, poor death outcomes, increased institution usage

**POSITIVE OUTCOMES**
- Bedrock of support, engagement post bereavement, increased social contact, social cohesion & inclusion
- Resilient supportive networks, strengthened relationships into bereavement, increased home deaths
- Every death captured, good symptom control, good bereavement care, coordinated care
- Good symptom control, integrated with primary care, good coordination

**Source:** Abel
GP MDT

Hospital Discharge
MDTs and Hospital Discharges become...
Compassionate Communities

- **Builds on what is already there.** Many areas have components in place but not applied in all areas systematically.
- The same principles can be applied across the CCG populations.
- Links joint working between health and social care and the ‘community muscle’.
- Allows GPs and professionals in the community to practice the medicine they are striving for.
Built on Institute of Health Improvement
QI Methodology

1. Team to lead project across CCG

2. Meet with primary care, CCG operational and strategic leaders, existing community development/social prescribing schemes and county councils to determine what is already being done

3. Identify champion training site(s) in the first instance, develop early adopters

4. Provide on the ground expertise, mentoring and support to these sites to develop their projects.

5. Plan a programme of role out based around achievement of successful outcomes in each area, running primary care homes’ programmes sequentially.

6. Expansion of project dependent on demonstrating improved outcomes from first wave sites
Community development done with not to communities

- Robust methods to enable community development skills
- Build resilient networks of support around families + communities
- Skilling up of caring networks
- Increasing neighbourhood capacity to care for those who experience crisis, death, dying and loss
- Integration and building of trusting relationships with health and social care teams
- Community capacity building in different environments – schools, communities, workplaces etc
- Community development worker as professional role
Compassionate Cities are communities that recognise that all natural cycles of sickness and health, birth and death, and love and loss occur everyday within the orbits of its institutions and regular activities. A compassionate city is a community that recognizes that care for one another at times of crisis and loss is not simply a task solely for health and social services but is everyone’s responsibility.
Compassionate City Charter

- Systematic way of ensuring we build compassionate communities in all sectors
- Educational institutions, workplaces, trade unions, health and social care institutions, religious institutions, neighbourhoods, homeless and vulnerable amongst others
- Incentive schemes and awards at civic level
- Policy change to support compassionate communities
6 Key Points

1. Implement all the functions of the model
2. Ownership of change must be in primary care
   NOT TOP DOWN CHANGE
3. Population Approach - No criteria for identification
   other than clinical impression – not relying on
   databases
4. Do what is best for the patient
5. ALWAYS use quality improvement methodology
   for change
6. COMMUNITY DEVELOPMENT WORKERS
   attached to General Practice
Risks of NOT doing Kingston Compassionate Communities

1) General Practice and Nursing workforce crisis – reducing numbers
   - Builds the ‘community muscle’

2) Workforce – reducing resilience & burnout with increasing non-health needs being presented to health and care professionals
   - Reducing non-health needs being presented to health and care professionals

3) Efficiencies not being realised
   - QI methodology robustly enables aims and outcomes
   - Real-time monitoring of data to ensure programme is successful and challenges are tackled to enable progress
Dr Catherine Millington-Sanders
RCGP & Marie Curie National Clinical End of Life Care Champion

For more information:
Email c.millington-sanders@nhs.net
Acknowledgements

- Dr Julian Abel, Consultant Palliative Medicine Cornwall & Compassionate Communities UK Founder
- Frome Medical Practice and Health Connections Mendip
- Kingston Public Health team