The Linda McEnhill Award - 2009 and beyond!

Building bridges between palliative care and learning disability services

Dr Corinna Midgley Medical Director, Saint Francis Hospice

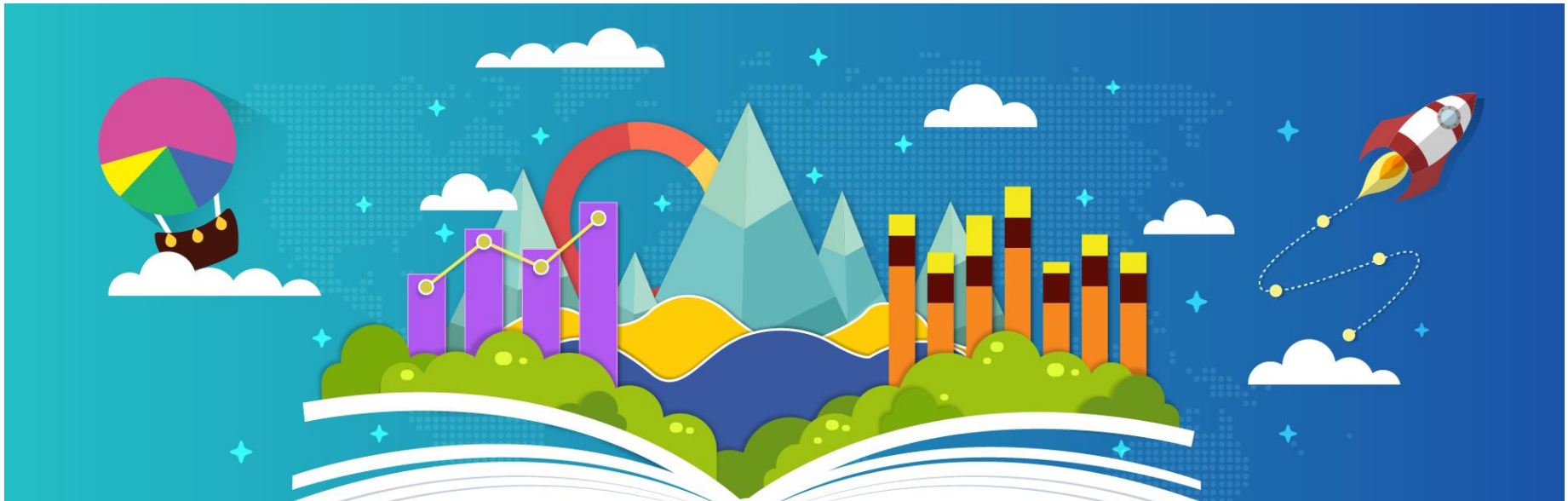
Registered Charity No: 275913

Getting started: concern and passion

Help the Hospices

2007 - 2008

- Let’s meet:
- We (working within palliative care) sought out people within the LD care field …. there were ***so many gaps*** in our knowledge!
- So much to learn, and crucially, such enthusiasm



What that led to:

- 2-3 SFH champions for people with palliative care and learning disability
- A new box on our referral form to highlight vulnerabilities
- Agreement for a Fast Track pathway for anyone referred with LD
- Sharing, studying and improving resources, and teaching materials
- Devising and delivering a Conference ‘Learning Disability: Ensuring Excellence and Empowerment in End of Life Care’

VULNERABILITY e.g. Learning Disability, dementia, hearing loss, …..

The Linda McEnhill Award 2009

JANE

PENG

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Milestones since 2009

- Palliative Care for People with Learning Disability study days - x 3 …(keeps focus and social mixing)
- Mandatory Training secured
- Route to Success pub 2011
- Resources embedded at SFH e.g. ‘This is me’
- A Champion or two at SFH
- ‘Widening Access’ made core Strategy
- Champions in our local hospital
- Care and support of people with LD
- Regular audits

Barking, Havering and Redbridge University Hospitals NHS Trust

Where are we now?

PENG
JANET

Challenges:

- Champions moving/overstretched
- Losing connections with colleagues
- Increased service pressure for SFH and DNs

JANE

Audits x 4 over 9 years have been vital to guard against complacency: what we've learnt

- Telephone support alone is not good enough.
- Find out what matters (… truth telling and asking)
- Almost everyone we have been involved with has wanted to stay at home: we need to be 3 steps ahead to help
- Most 'family' are friends, fellow residents and care staff

They feel upset, anxious, worried when a friend becomes poorly and isn't going to get better

They need much support

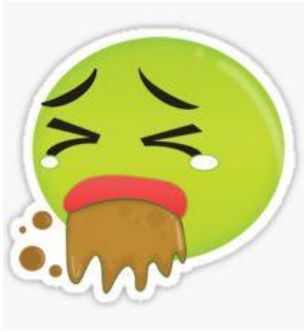
What we have been able to maintain

- Our ‘Vulnerability’ box
- The Referrals Pathway
- Champions - and (with strategy) accountability
- Strong links into and out of hospital
- Audit, and much learning through audit
- ‘This is Me’
- People’s stories

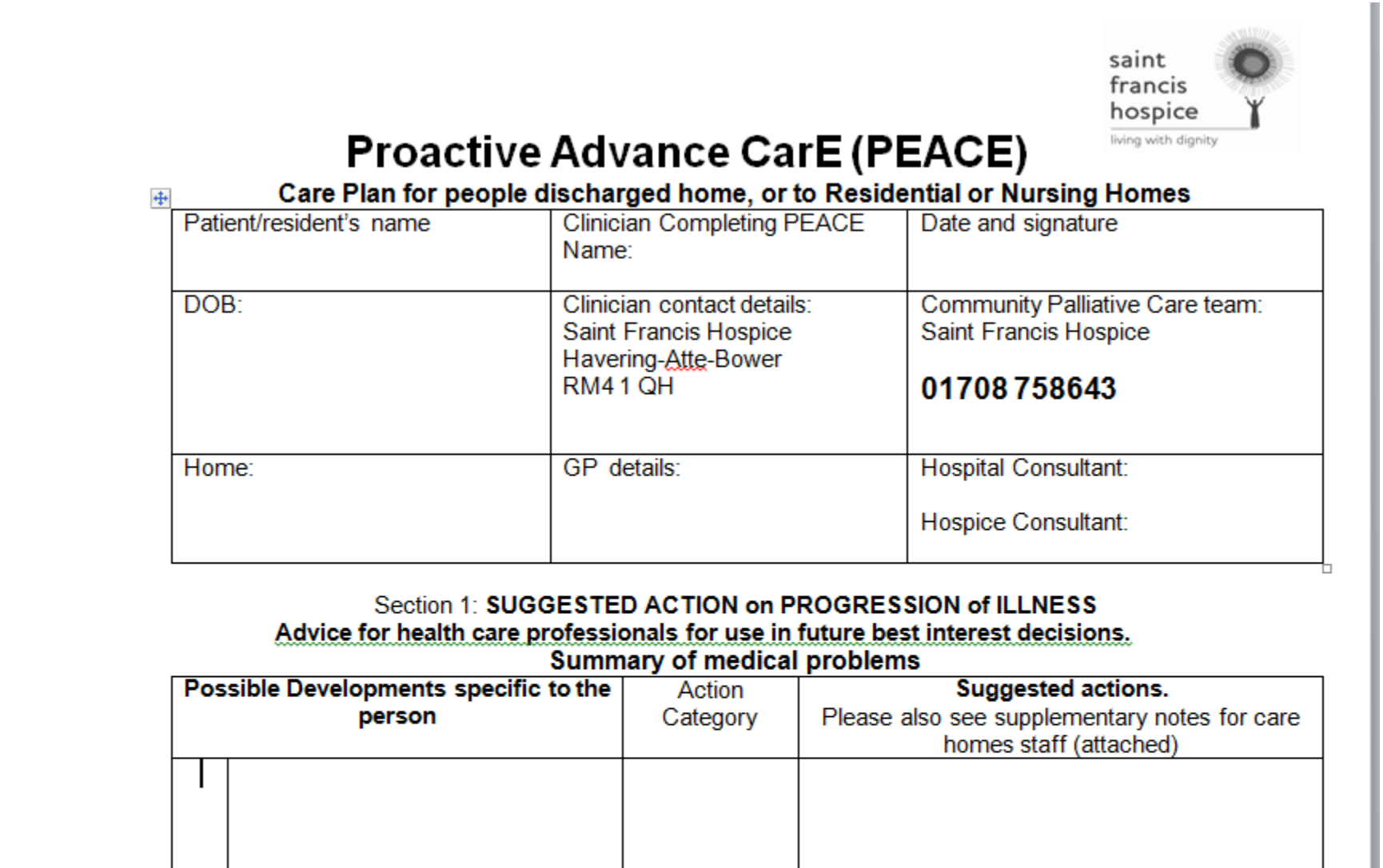
What I wish we could change …

- A strong link with LD teams in the community – but they have grown thinner and busier over time
- If we don't lead – we are forgotten – a small fish in a big pond
- Time for planned, face to face pro-active care and 'holding on' to people who temporarily stable. Audits showed that discharge causes anxiety, and key conversations often happen in more steady times – but we struggle due to workload
- CCG recognition/NHS, social or grant funding

David’s story – still learning



Latest audit: specific and focussed advance care planning would be helpful for carers



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Proactive Advance CarE (PEACE)

Care Plan for people discharged home, or to Residential or Nursing Homes

Patient/resident's name	Clinician Completing PEACE Name:	Date and signature
DOB:	Clinician contact details: Saint Francis Hospice Havering-Atte-Bower RM4 1 QH	Community Palliative Care team: Saint Francis Hospice **01708 758643**
Home:	GP details:	Hospital Consultant: Hospice Consultant:

Section 1: **SUGGESTED ACTION on PROGRESSION of ILLNESS**

Advice for health care professionals for use in future best interest decisions.

Summary of medical problems

Possible Developments specific to the person	Action Category	**Suggested actions.** Please also see supplementary notes for care homes staff (attached)

Thank you to Linda and to all at PCPLD for your inspiration and support

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