NHS
Sutton
Clinical Commissioning Group

Working together to build the best affordable healthcare for Sutton

Sutton Homes of Care Vanguard Programme

UEC Improvement Collaborative Workshop: Supporting residents to stay in their care home in the last months of life

13 March 2018

Overview of session

- London perspective
- Vanguard Programme in Sutton
- Learning from the Care Home Vanguards
- EOLC Model in Sutton
- Personal experience

Background

- 2006-2016 over 65 population increase by 21%, 2016-2026 expected to rise by further 48%
- Population living longer with increasing complex co-morbidities, especially the older population living in care homes
- Independent Care Sector is expected to meet the challenge of caring for the most frail and vulnerable elderly section of our population.
- 56% of NH residents will have died within one year
- 18-24 months average LOS in residential homes
- 22% of all UK deaths occur in care homes
- There are 1/3 more care home beds then NHS beds

Central themes

- Importance of identifying, planning and managing EOLC with the resident's wishes and preferences central to decision making.
- Care Home staff need to be supported and educated to give them the confidence to deliver high quality EOLC

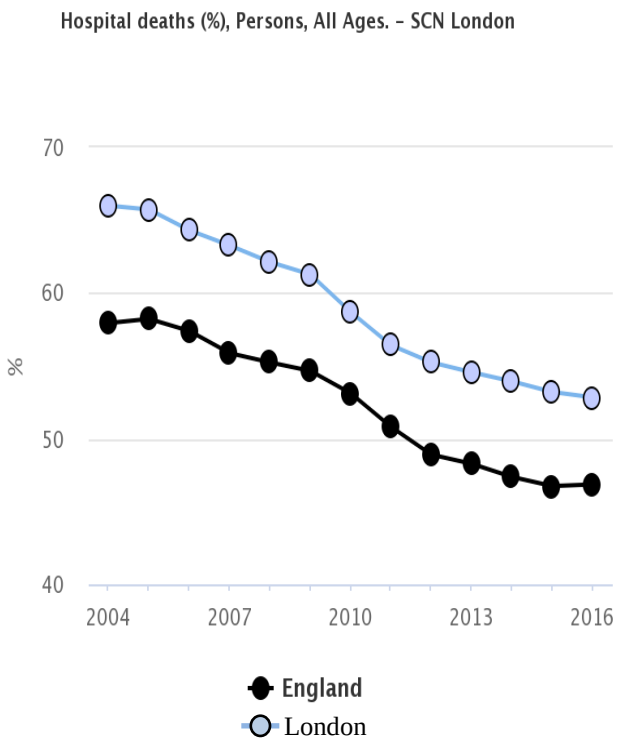
PHE EOLC Profiles
London Hospital Deaths

- Comparator table

Area	Value	Lower CI	Upper CI
England	46.9	46.7	47.0
SCN Cheshire and Mersey...	49.1	48.5	49.7
SCN East Midlands	47.5	47.1	48.0
SCN East of England	46.1	45.7	46.6
SCN Greater Manchester...	48.9	48.5	49.4
SCN London	52.8	52.4	53.3
SCN Northern England	47.3	46.8	47.9
SCN South East Coast	42.3	41.8	42.7
SCN South West	41.7	41.2	42.1
SCN Thames Valley	45.7	45.0	46.5
SCN Wessex	44.0	43.4	44.6
SCN West Midlands	49.3	48.9	49.8
SCN Yorkshire and The H...	46.4	46.0	46.8

Source: Office for National Statistics

- Trend table



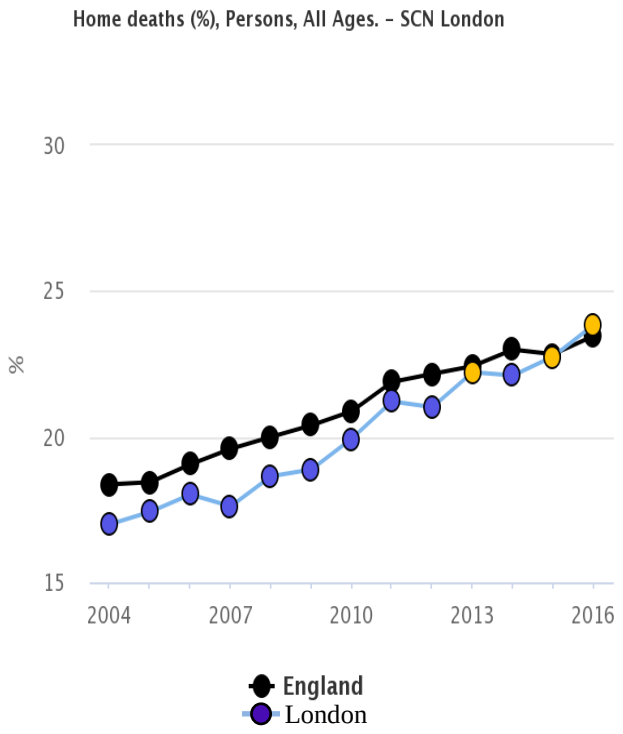
PHE EOLC Profiles
Proportion of Home deaths

- Comparator table

Area	Value	Lower CI	Upper CI
England	23.5	23.3	23.6
SCN Cheshire and Mersey...	22.9	22.4	23.4
SCN East Midlands	23.5	23.1	23.9
SCN East of England	24.0	23.6	24.3
SCN Greater Manchester...	23.2	22.8	23.6
SCN London	23.8	23.5	24.2
SCN Northern England	25.2	24.7	25.7
SCN South East Coast	21.7	21.4	22.1
SCN South West	24.6	24.2	25.0
SCN Thames Valley	23.3	22.6	23.9
SCN Wessex	23.0	22.5	23.5
SCN West Midlands	22.8	22.5	23.2
SCN Yorkshire and The H...	23.2	22.9	23.6

Source: Office for National Statistics

- Trend table



PHE EOLC Profiles

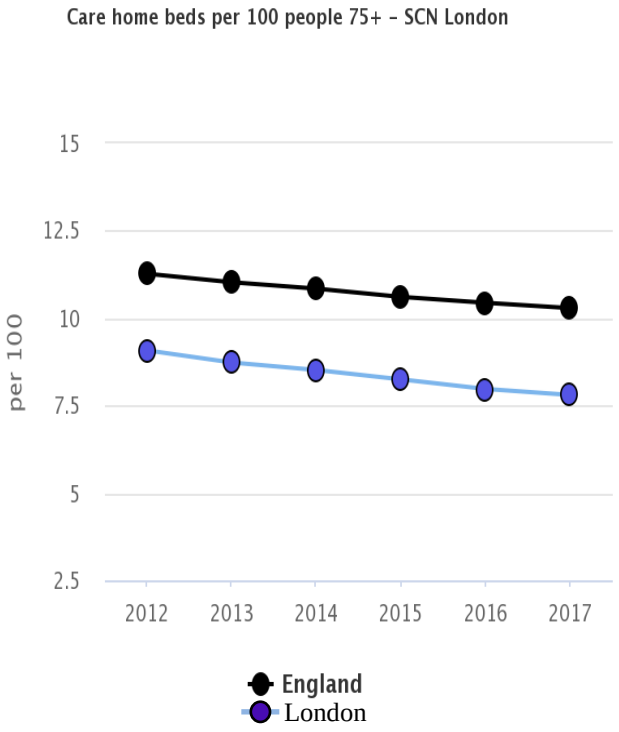
Care Home beds per 100 over 75

- Comparator table

Area	Value	Lower CI	Upper CI
England	10.3	10.2	10.4
SCN Cheshire and Mersey...	10.7	10.1	11.3
SCN East Midlands	11.0	10.6	11.5
SCN East of England	9.7	9.3	10.1
SCN Greater Manchester...	10.8	10.3	11.3
SCN London	7.8	7.4	8.2
SCN Northern England	11.1	10.6	11.6
SCN South East Coast	11.6	11.2	12.0
SCN South West	10.6	10.2	11.0
SCN Thames Valley	9.1	8.4	9.9
SCN Wessex	10.3	9.8	10.9
SCN West Midlands	9.9	9.5	10.3
SCN Yorkshire and The H...	11.1	10.7	11.5

Source: Care Quality Commission (CQC) and Office for National Statistics (ONS)

- Trend table



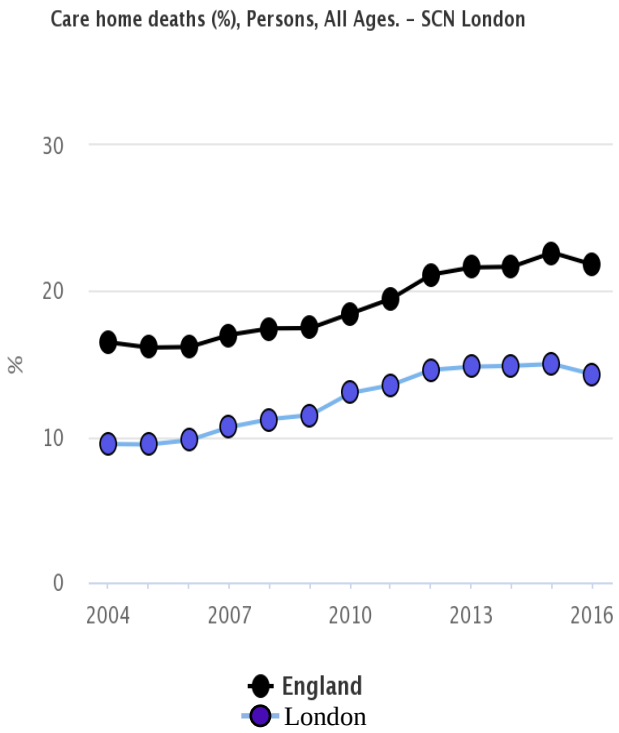
PHE EOLC Profiles
Care home deaths

- Comparator table

Area	Value	Lower CI	Upper CI
England	21.8	21.7	21.9
SCN Cheshire and Mersey...	20.5	20.0	21.0
SCN East Midlands	22.3	21.9	22.7
SCN East of England	23.0	22.7	23.4
SCN Greater Manchester...	19.9	19.6	20.3
SCN London	14.3	14.0	14.6
SCN Northern England	21.2	20.8	21.7
SCN South East Coast	25.8	25.3	26.2
SCN South West	26.5	26.1	26.9
SCN Thames Valley	22.1	21.4	22.7
SCN Wessex	25.6	25.1	26.1
SCN West Midlands	20.1	19.8	20.4
SCN Yorkshire and The H...	21.6	21.2	22.0

Source: Office for National Statistics

- Trend table



London priority

- 1500 registered care homes
- 36,000 beds
- 63,000 workforce
- 38,000 999 calls

  (Nov16-Nov17)
- 80% conveyance to hospital

Care Home 6: Enhanced Health in Care Homes Framework

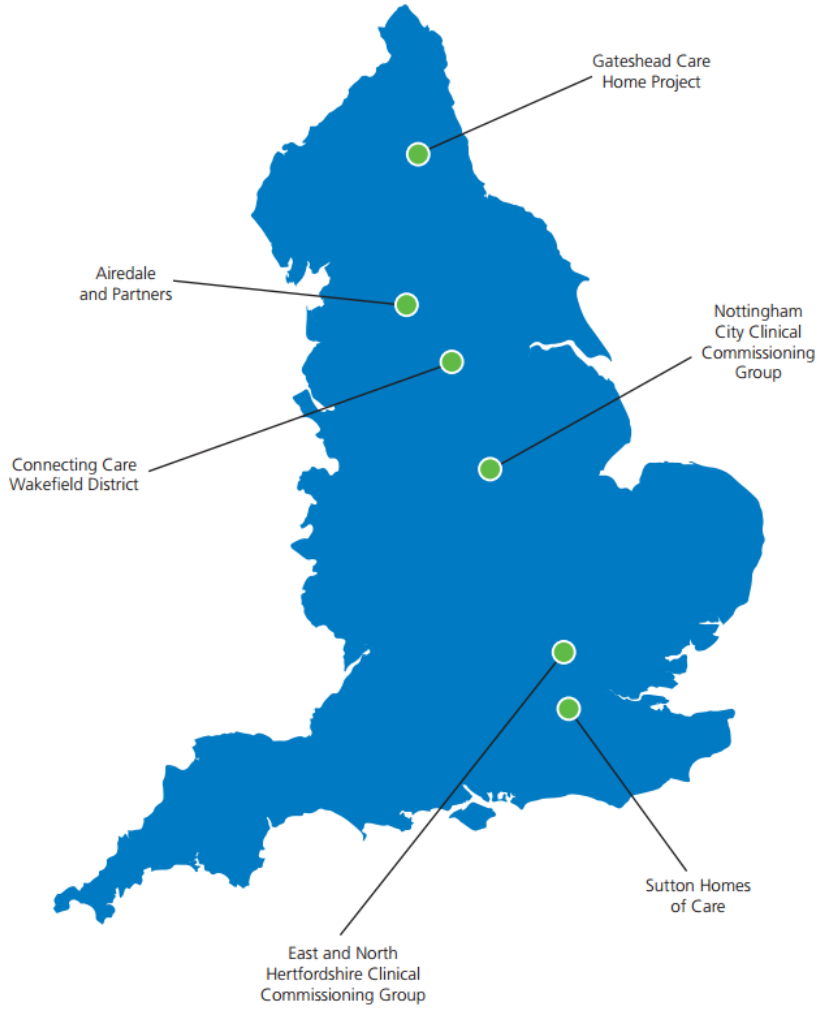


Table 1 - Care elements and sub-elements

Care element	Sub-element
1. **Enhanced primary care support**	Access to consistent, named GP and wider primary care service
	Medicine reviews
	Hydration and nutrition support
	Access to out-of-hours/urgent care when needed
2. **Multi-disciplinary team (MDT) support including coordinated health and social care**	Expert advice and care for those with the most complex needs
	Helping professionals, carers and individuals with needs navigate the health and care system
3. **Reablement and rehabilitation**	Rehabilitation/reablement services
	Developing community assets to support resilience and independence
4. **High quality end-of-life care and dementia care**	End-of-life care
	Dementia care
5. **Joined-up commissioning and collaboration between health and social care**	Co-production with providers and networked care homes
	Shared contractual mechanisms to promote integration (including Continuing Healthcare)
	Access to appropriate housing options
6. **Workforce development**	Training and development for social care provider staff
	Joint workforce planning across all sectors
7. **Data, IT and technology**	Linked health and social care data sets
	Access to the care record and secure email
	Better use of technology in care homes

Background to Sutton

81 Care Homes

594 residents in NHS Funded Nursing Home placements

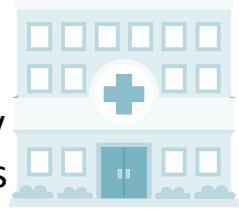
1,300 Care Home Beds (46% NH; 23% RH;31% MH&LD)

203,000
People in Sutton
15,000 aged 75+
5,000 aged 85+

Repeated safeguarding meetings
Same homes affected
No whole system approach to safety and quality

766
A&E presentations from Care Homes

493
Emergency Admissions
2013/14



The Challenge for Care Homes

Independent organisations

Barriers to engagement

Negative attitudes

Terms and conditions are not standardised

Most Frail and vulnerable members of society

What happens if a care home closes?

Myths and limitations of NHS support "*not in their own home*"

Large number of beds but limited statutory controls

Sutton Homes of Care

Our vision is to **have vibrant, high-quality care homes in Sutton** delivering care that embraces the national nursing values of patient care – Care, Compassion, Competence, Communication, Courage and Commitment (the '6Cs').

SUTTON HOMES OF CARE NEW CARE MODEL

INTEGRATED CARE

1. Health and Wellbeing Rounds
2. Hospital Transfer Pathway
3. Care Home Support Team
4. Champion Roles
5. PODs: Care homes and community
6. Dementia support
7. End Of Life Care
8. Out of Hours Support
9. Directory of Support
10. Place Based Care

CARE STAFF EDUCATION AND TRAINING

11. E-learning modules
12. Bespoke training
13. Education resources
14. Care Home Forums
15. Student Training

QUALITY ASSURANCE AND SAFETY

16. Quality Dashboard
17. Joint Intelligence Group
18. NHSmail
19. Care Home Policy Package
20. Cake, Cuppa, Chat

http://www.careengland.org.uk/news/care-england-and-itn-productions-launch-shaping-tomorrow

Our Partners

NHS Sutton Clinical Commissioning Group

Epsom and St Helier University Hospitals NHS Trust

Sutton

Leading the fight against dementia
Alzheimer's Society

London Ambulance Service NHS Trust

South West London and St George's Mental Health NHS Trust

NHS
Sutton Community Health Services

Sutton ageUK

Suttoncentre for the voluntary sector (CVS)

St Raphael's HOSPICE

… All our Care Homes in Sutton

Sponsored by:

The National Institute for Health and Care Excellence (NICE)

Working in collaboration with:

- NHS England
- New Care Model Programme
- SWL Collaborative Commissioning
- Care Quality Commission
- Health Education South London
- Health Innovation Network
- Academic Health Science Networks
- Other Care Home Vanguards

What we have achieved overall

In Care Homes with a GP from Sutton CCG…

- **Reduction** in A&E attendances
- **Reduction** in unplanned admissions
- **Increased** number of residents with an advance care plan
- **Over 80% of residents with an EOLC plan** achieved their preferred place of death
- **Reduced increase** in ambulance incidents in comparison to the Sutton average
- **Reduction** in the average length of stay of 4 days for residents with a red bag

What we have achieved

Genuine partnership and collaborative working (across sector) enabling more joined-up services

Enhanced communication across health and social care

Well attended, regular care home forums for care home mangers

Partners share detailed intelligence with each other

Positive impact on the roles of care home staff

Engagement with residents and families

Positive service user feedback

Contribute to dementia diagnosis rates

Collaborative working with other five care home vanguards: embedding EHCH Framework into practice

Widespread communication and publicity

https://itnproductions.wistia.com/medias/tz1kli6tun

Group discussion

Turn to your neighbour and share:

- *What is going on in your area to support Care Homes?*
- *Are there any gaps you are aware of?*

Setting Up an EOLC Service in Care Homes: NCM Toolkit

1) When setting up an EOLC service to support Care Homes what should be considered in advance?

2) What would be some of the benefits and impacts of setting up a service such as this?

3) What would you need to consider in terms of roles and relationships?

4) What things could be helpful in terms of learning and development for Care Home staff?

5) How would you measure success?

Setting Up an EOLC Service for Care Homes

1) When setting up an EOLC service to support Care Homes what should be considered in advance?

- Understand services in place – mapping, commissioning intentions
- Consider data and metrics – have a baseline
- Involve wider partners

Setting Up an EOLC Service for Care Homes

2) What would be some of the benefits and impacts of setting up a service such as this?

- Individuals and families: planning; improved quality of life; improved experience; support to provide care and facilitate death in preferred place; support for carers and families
- Staff: improves co-ordinated approach across system; prevent crises; support GPs to identify people
- Health and Social Care systems: greater efficiencies for capacity and funding across system; improved flow

Setting Up an EOLC Service for Care Homes

3) What would you need to consider in terms of roles and relationships?

- Care Homes and Hospices are independent;
- Do With not Do To;
- Consider roles of all partners;
- Levers to influence organisations roles;

Relationships are key!

Setting Up an EOLC Service for Care Homes

4) What things could be helpful in terms of learning and development for Care Home staff?

- Simplicity is key;
- Clarity on what needs to be done and by whom;
- Sensitivity and new for care home staff;
- Role modelling and empowerment;
- Involve families and carers;
- Raise staff profile in care homes;
- Help to build communication and trust across the organisations - care home staff know their residents best

Setting Up an EOLC Service for Care Homes

5) How would you measure success?

Consider:

- Metrics;
- KPIs;
- Financial return on investment

Setting Up an EOLC Service for Care Homes

Challenges and solutions

Challenge	Solutions
• Stigma attached and fear	• Cannot underestimate how difficult the subject is! You can demystify EOLC through teaching, make people aware of indicators, what's going to happen, and use training to let people know what to expect and how care home staff can respond. • Signpost both care provider staff and families and carers to information available online and create materials to increase awareness of what to expect (see Sutton and Newcastle examples) • Support for care homes when there are deaths – to ensure there is someone to talk to – and support for paid carers and other care home staff after a death – they will be feeling the loss as well. • Build in time for reflection as an MDT after a death - what went well, what could be done differently and better, what lessons are there to be shared.
• Sharing information on PPOD and care preferences	• Ambulance Service need to be key partners and fully aware of plan - either electronic or strong need to both record and plan - but ensure care home staff are aware and bring to attention and share with LAS when they respond
• Data	• Work with your local acute trust and ambulance trust from the beginning of your programme / initiative to ensure a joint approach to sharing care plans and recording data. • Take a look at the PHE Fingertips website – end of life care profile
• Support for end of life Care training and development	• Consider how you can get support from your Health Education England regional / locality team, local Community Education Providers Network (CEPN) and also from Skills for Care's regional support. You can also access their resources online. • Investigate how to effectively provide access to elearning for care homes, domiciliary carers and hospice staff.
• Making the case for improved end of life care and evidencing savings	• Business case - most people don't want to die in hospital – by investing to support preferred place of death (PPOD), your system can both improve quality of life and contribute to reducing NEL admissions and ambulance callouts - meaning a better use of resource overall.

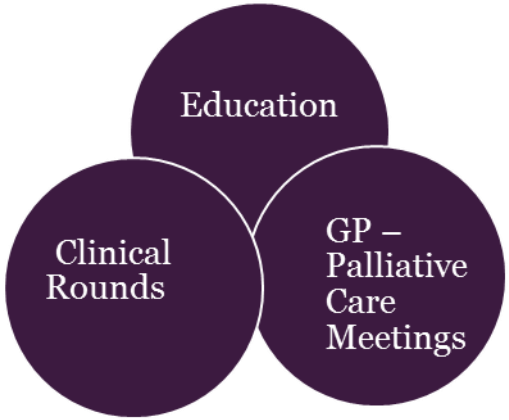
The model in Sutton

Supportive Care Home Team

The Supportive Care Home Team

- Palliative Care Service at The Royal Marsden and the Sutton Care Home Support Team
- 4 Clinical Nurse Specialists, Matron and Nurse Consultant
- Commissioned to Improve End of Life Care in Care Homes in Sutton
- Recent Sutton Vanguard pilot in Learning Disability homes

End of Life Care model for Care homes in Sutton



Outcomes

Nursing home – Key Performance Indicators (KPI's)

Key performance indicators (KPI's)	2014	Jan 2018
% of residents dying in PPD	No data	93.75% (n=30)
% of residents being offered Advance Care Plans	29.6%(n=132)	81% (n=414)
% of residents with CMC record	27.6% (n=123)	65.8% (n= 336)

Residential Care Home – KPI's

Key performance indicators (KPI's)	Oct 2015	Jan 2018
% of residents dying in PPD	No previous data	100% (n=8)
% of residents being offered Advance Care Plans	17.1% (n=18)	65.4 (n=159)
% of residents with CMC record	17.1% (n=18)	41.2% (n=97)

Recent CQC report: Inequalities in EOLC

People with a learning disability

A DIFFERENT ENDING:
ADDRESSING INEQUALITIES IN END OF LIFE CARE

Life expectancy for people with a learning disability is significantly lower than the UK average, and there is also a high incidence of premature and avoidable death.[1, 2] In addition, people with a learning disability are more likely to have unidentified health needs, which can make recognising the end of life phase difficult. This means that people are likely to be identified as approaching the end of life late, which affects their ability to plan and make choices. It can also lead to problems in coordinating end of life care and providing support to the person and their family.

We asked a group of people with a learning disability about what was important to them for good end of life care. They told us that it was important to have family and friends nearby, to have privacy, peace and quiet, preferably not to be in hospital, to be able to go outside, and to have the support of a care coordinator when needed. They thought that services should talk more to people who have a learning disability to get their views and check that they are improving and inclusive.

Lack of knowledge

The health and care staff we spoke to felt that a lack of knowledge around learning disabilities could result in late diagnosis of illness, which could have an impact on the likely success of treatment. In addition, symptoms may not be investigated because they are thought to be related to the person's learning disability.

Staff also said they sometimes had to fight to get the right care for a person with a learning disability, and that it could be difficult to organise best interests decision meetings because other professionals did not understand the Mental Capacity Act 2005.

Communication

Communication was identified as a significant barrier to good care, with health and care staff sometimes making assumptions about an individual, for example, that they may not be able to 'cope' with discussions about end of life. In addition, not being able to communicate verbally or needing specific support to communicate, presented challenges for some people. For example, health and care professionals told us that it was difficult to assess the person's pain when they have limited verbal communication. This was also a concern for people with a learning disability, who said that being able to explain or use picture cards with a nurse when they were in pain was important. Knowing the person well helped staff to understand non-verbal communication, as did using assessment tools for pain or distress, for example DisDAT, the Disability Distress Assessment Tool.[3]

1 Heslop P, Blair P, Fleming P, Hoghton M, Marriott A and Russ L, **Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD), Final report**, 2013

2 Mencap, **Death by indifference**, 2007

3 St Oswald's Hospice, **Disability Distress Assessment Tool**

MAY 2016 1

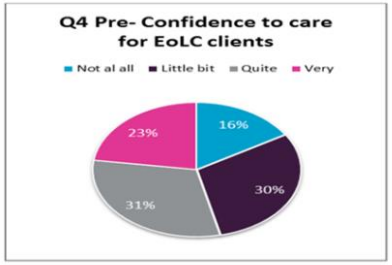
- People with a learning disability are likely to be identified as approaching the end of life late
- This can lead to problems in coordinating end of life care and providing support to the person and family
- Palliative care staff have a lack of knowledge around learning disabilities
- Communication was identified as a significant barrier to good care.
- Difficulty in assessing pain

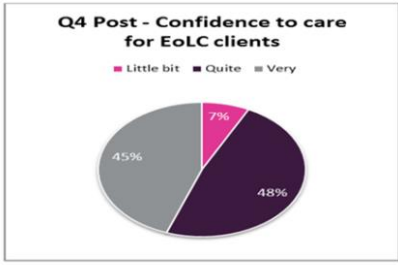
Learning Disability Homes

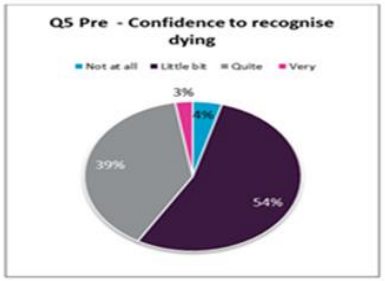
- Development of model of care based on nursing home model
- Development of teaching programme specific to learning disability
- Development of confidence questionnaire
- KPI's around PPD,ACP and CMC and pain assessments
- Attendance at relevant GP practice GSF meetings
- Regular meetings with St Raphael's Hospice, local acute hospital and continuing health care.

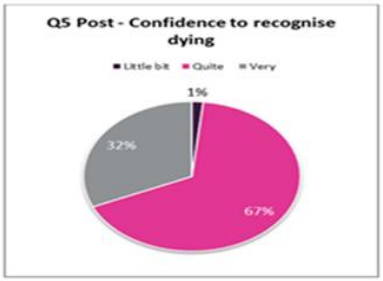
Results

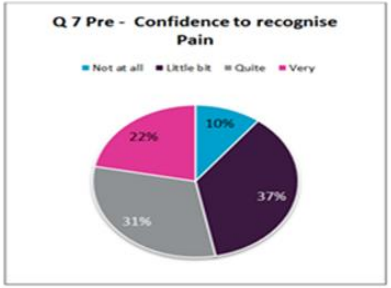
- There was a significant shift in learning disability staff confidence to care for their clients at the end of life.
- The expected deaths during the pilot died in the PPD, their pain monitored on a validated assessment tool, their wishes and preferences were captured and shared with OOH via CMC.

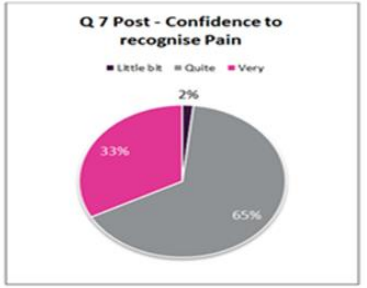












Resources we have developed

NHS
Sutton Community Health Services

Pain

If the person *can* communicate their needs:
Do they have a condition which could be painful eg osteoarthritis?

Assess for:

- Place. Where on the body is the pain? Does it spread to other areas?
- Actions tried. What has been tried? What made the pain better? What made it worse?
- Intensity. What level is the pain eg mild, medium, severe?
- Non-Verbal. What does their non-verbal/body language show eg frowning, crying etc?
- Feel. Can they describe how the pain feels eg burning, sharp, ache?
- Understanding. How does the pain impact on the person eg everyday activities, quality of life?
- Length of time. How long have they had the pain? Is it new or long standing?

Report pain to senior member of team. Team to complete the relevant pain assessment tool used in your care home

Remember to review and evaluate any actions taken such as painkillers given

If pain is not relieved – tell senior nurse/carer and/or GP.

If the person *cannot* communicate their needs, (eg advanced dementia) could the following behaviours suggest pain? For example:

- Aggressive behaviour eg pushing people away when personal care performed
- Avoids certain movements
- Change in normal routine and/or usual mobility eg walking less
- Change in appetite/eating less
- Change in usual sleep pattern
- Facial expressions eg frowning, grimacing
- Increased calling out
- Moaning, crying, etc
- Protective body postures eg 'guarding' areas
- Withdrawn.

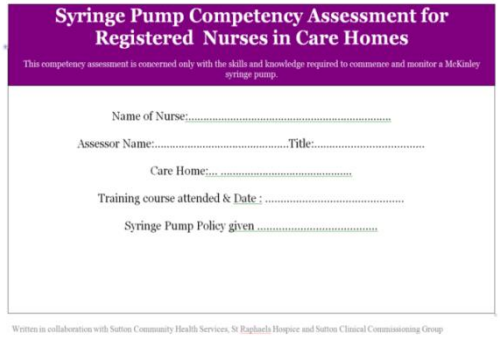
Report to the senior member of the team

Team to complete the relevant pain assessment tool for people who are unable to communicate their needs eg Abbey, Doloplus 2, PAINAD

Remember to review and evaluate any action taken such as painkillers given

If pain is not relieved, tell senior nurse/carer and/or GP.

Delivered by The Royal Marsden NHS Foundation Trust



Syringe Pump Competency Assessment for Registered Nurses in Care Homes

This competency assessment is concerned only with the skills and knowledge required to commence and monitor a McKinley syringe pump.

Name of Nurse:.....

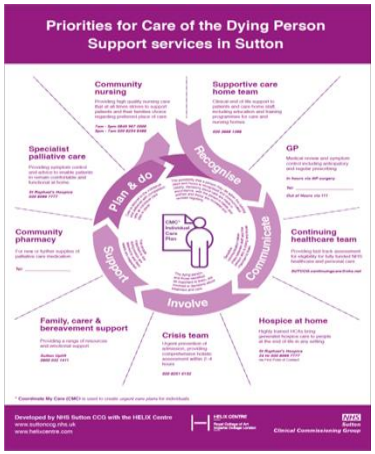
Assessor Name:.....Title:.....

Care Home:.....

Training course attended & Date : .....

Syringe Pump Policy given .....

Written in collaboration with Sutton Community Health Services, St Raphaels Hospice and Sutton Clinical Commissioning Group

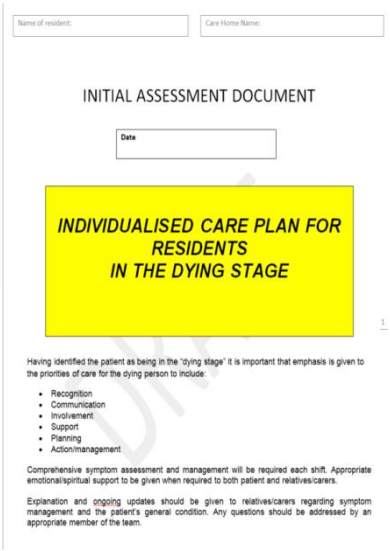


Priorities for Care of the Dying Person
Support services in Sutton

Community nursing
Supportive care home team
Specialist palliative care
GP
Community pharmacy
Continuing healthcare team
Family, carer & bereavement support
Crisis team
Hospice at home

Recognise
Communicate
Involve
Support
Plan & do

Developed by NHS Sutton CCG with the HELIX Centre
www.suttonccg.nhs.uk
www.helixcentre.com



Name of resident:
Care Home Name:

INITIAL ASSESSMENT DOCUMENT

Date

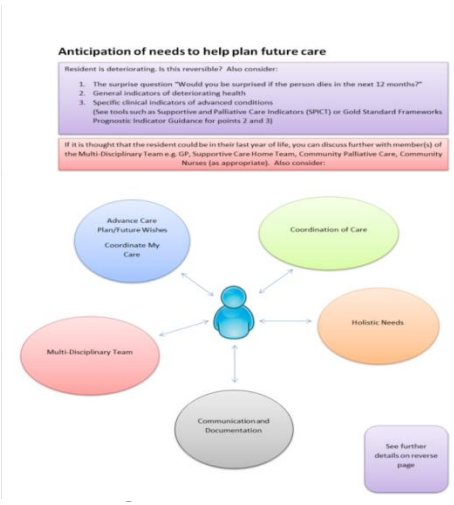
INDIVIDUALISED CARE PLAN FOR RESIDENTS IN THE DYING STAGE

Having identified the patient as being in the "dying stage" it is important that emphasis is given to the priorities of care for the dying person to include:

- Recognition
- Communication
- Involvement
- Support
- Planning
- Action/management

Comprehensive symptom assessment and management will be required each shift. Appropriate emotional/spiritual support to be given when required to both patient and relatives/carers.

Explanation and ongoing updates should be given to relatives/carers regarding symptom management and the patient's general condition. Any questions should be addressed by an appropriate member of the team.



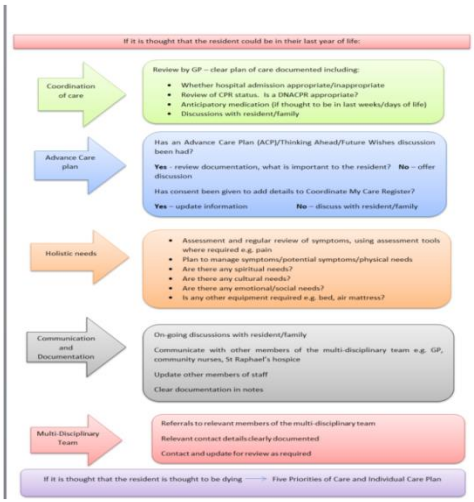
Anticipation of needs to help plan future care

Resident is deteriorating. Is this reversible? Also consider:

1. The surprise question "Would you be surprised if the person dies in the next 12 months?"
2. General indicators of deteriorating health
3. Specific clinical indicators of advanced conditions
(See tools such as Supportive and Palliative Care Indicators (SPICT) or Gold Standard Frameworks Prognostic Indicator Guidance for points 2 and 3)

If it is thought that the resident could be in their last year of life, you can discuss further with member(s) of the Multi-Disciplinary Team e.g. GP, Supportive Care Home Team, Community Palliative Care, Community Nurses (as appropriate). Also consider:

Advance Care Plan/Future Wishes
Coordinate My Care
Coordination of Care
Holistic Needs
Multi-Disciplinary Team
Communication and Documentation
See further details on reverse page



If it is thought that the resident could be in their last year of life:

Coordination of care
Review by GP – clear plan of care documented including:
- Whether hospital admission appropriate/inappropriate
- Review of CPR status. Is a DNACPR appropriate?
- Anticipatory medication (if thought to be in last weeks/days of life)
- Discussions with resident/family

Advance Care plan
Has an Advance Care Plan (ACP)/Thinking Ahead/Future Wishes discussion been had?
Yes - review documentation, what is important to the resident? **No** – offer discussion
Has consent been given to add details to Coordinate My Care Register?
Yes – update information **No** – discuss with resident/family

Holistic needs
- Assessment and regular review of symptoms, using assessment tools where required e.g. pain
- Plan to manage symptoms/potential symptoms/physical needs
- Are there any spiritual needs?
- Are there any cultural needs?
- Are there any emotional/social needs?
- Is any other equipment required e.g. bed, air mattress?

Communication and Documentation
On-going discussions with resident/family
Communicate with other members of the multi-disciplinary team e.g. GP, community nurses, St Raphael's hospice
Update other members of staff
Clear documentation in notes

Multi-Disciplinary Team
Referrals to relevant members of the multi-disciplinary team
Relevant contact details clearly documented
Contact and update for review as required

If it is thought that the resident is thought to be dying → Five Priorities of Care and Individual Care Plan

Care home manager's perspective

Sutton Homes of Care

Great care is a partnership

References

End of Life Care Profiles

https://fingertips.phe.org.uk/profile/end-of-life

Learning guide for high quality end of life care

http://www.suttonccg.nhs.uk/vanguard/Programme-Aims/Pages/Enhanced-Health-in-Care-Home.aspx

Enhanced Health in Care Homes Framework

https://www.england.nhs.uk/wp-content/uploads/2016/09/ehch-framework-v2.pdf

Sutton Homes of Care Vanguard

http://www.suttonccg.nhs.uk/vanguard