



Leeds Palliative
Care Network

The Future of Palliative and End of Life Care in Leeds

Strategic Direction Event

21st November 2018

Weetwood Hall

Introduction to the day

Mike Stockton – LPCN Chair

Every year of our life is important but the last year often holds special significance and previously uncharted challenges that will make it different from all others.

Good morning and a very warm welcome to this day focused on developing the next palliative and end of life care strategy for Leeds.

My name is Mike Stockton and I am the chair of the Leeds Palliative Care Network. The network has been responsible for initiating and organising this event.

Thank you so much for taking time out from your busy schedule to enable us to bring together a diversity of people, professions, perspectives and possibilities. It is only together we'll we produce a strategy that is fit for the future and fit for the citizens of Leeds. You have the chance to inform and influence future strategic direction for delivery and transformation of Palliative and End of Life Care in Leeds.

Get everything out on the table: Take your chance to speak your view and truth. We want to hear the broad spectrum. Step out of organisational traditional boundaries and views. Putting the patient and the family at the centre. The irony is that the little things matter, but so do the big things.

Not one of us will understand the whole picture...health and social care is too big, too complex and continuously changing...each of us is a nodal point in that vast net; we are a part of the whole. So only between us can we catch a glimpse of the whole.

Today is the first step on a journey. There is an onward process to produce a strategy and to agree that with the CCG. I'm hoping this will be easier than agreeing the Brexit deal.

The vision and values of palliative and end of life care remain steadfast and constant: High quality person and family centred care to enable people to live and die as well as possible. And support those that remain. What has changed is the complexity and volume of need, expectations and standards plus the challenges of workforce capacity and funding.

Improving the care for people at the end of life will not only improve the outcomes and experiences of patients and families but has a much broader positive affect on the whole system. Palliative care is good for patients; palliative care is good for the system. It has the potential to improve health and care flow, reducing pressures on ambulances, GP surgeries, urgent and emergency care and hospital beds through better advance care planning, coordination and proactive care out of hospital.

Leeds has a long and strong history of developing and delivering high-quality palliative and end of life care. A service we can be proud of. We want to build on that to make services equitable, high-quality, evidence-based and sustainable. Not as standalone systems but fully integrated into all health and social care systems where people require it. How can we go from good to great? And how will we change sufficiently enough to meet the rising needs of society.

Future challenges over the next 20 years will be increasing numbers of people dying across all settings, driven by cancer, frailty and dementia. The greatest number of deaths will be in the over 85 group, making up 50% of all deaths. A prediction that there will a doubling of deaths in the community and care home will become the most frequent site of dying. How do we begin to face that challenge?

A few words about the Leeds palliative care network.

The Leeds palliative care network is a collaborative partnership all those who have a responsibility or an interest in a palliative and end of life care. This includes clinical staff social care staff and academics; in and out of hospital, NHS, third sector, YAS, social services.

We have two broad aims. One is to do better what we already do and already know. This is a kind of fixing optimising function. The other broad aim is to stimulate and facilitate more transformative imaginative thinking and development to enable us to better manage the unprecedented changes for the future.

The mention of strategy can sometimes induce feelings of dread, hopelessness and energy wasting. Previous Palliative Care strategies have been highly influential and delivered positive meaningful change.

Over the duration of the last strategy here are some of the achievements across Leeds:

- 7 day services for EOL hospital discharge, CNS in hospital and community, EOL support to nursing homes
- Neighbourhood community EOL teams
- More community nurses able to prescribe and verify death
- Additional palliative care ambulance
- Nurse led EOL beds in hospices
- Increased integration with LTC: frailty, dementia, COPD, movement disorders, heart failure
- Improved transfer of care of patients from hospital to hospice
- Agreed opioid guidelines, improved access to drugs a
- Further enhancement of EPaCCS. Completion of EPaCCS is now at 42% of all deaths
- New bereaved carers survey
- Tele education system to broaden the reach and impact of education
- Academic Unit of Palliative Care and increased research outputs

These are only a selection of developments, but as much as that, they are examples of how a vision, strategy and working together can generate improvements.

There is a great opportunity for the taking. Across Leeds the Importance of palliative and end of life care is being fully recognise that both for the benefits to patients in the benefit of the wider society. The Leeds Academic Health Partnership has become a key collaborator, alongside the Leeds Clinical Senate, Leeds Informatics Board and the Leeds GP Confederation. This is our time to be ambitious, bold and imaginative, to be logical and evidence based, but not constrained by that. It's hard for us all to let go of how we do things now and conceive of things differently. Today I'm hoping we'll have a chance to do that.

Thanks once again. Your contributions are welcomed and valued. Please give generously.

Facilitated Conversations

Myron Rogers- How Change Happens...

1. People own what they help to create
2. Real change happens, in real work places, in streets, in places where services get delivered
3. Those who do the work, do the change
4. Start anywhere, and follow it everywhere...
5. The process you use to get to the future is the future you get

Where Passion and Responsibility Collide...

What are the things we need to be talking about to inform the strategy - Open Space

What's the conversation I really want to have to be reflected in the strategy?

What are the kinds of things we need to put in the strategy to make us better?

Conversations on the day

1. How do we harness the strengths / assets of people and communities in EoLC?
2. Workforce Development Strategy for Palliative and EoLC is needed
3. Out Of Hours Access
4. How do we provide Timely End of Life Care?
5. Improving Generalist Palliative Care in the Community
6. Capacity and capability to care for Elderly in the last months of life
7. Digital Route maps
8. Single Point of Access for EoLC
9. What does a good death look like in Multicultural Leeds
10. Talk to people about what they want
11. Learning Disabilities and Palliative Care
12. How we pay for it!
13. Advanced Decisions

1. How do we harness the strengths / assets of people and communities in EoLC?

1. Generating community ownership of dying
2. Ask: 'What Can I do'
3. Neighbourhood Networks
4. Knowing what our strengths, opportunities, skills are
5. Thinking about certain age groups e.g. 45+
6. Dying Matters Campaign – Ask people - What do I want?
7. Language used 'what would you do if you had 1000 days left' or 300 days
8. Digital Networks to connect people
9. 'Better conversations'; what does this mean for End of Life Care?
10. Talk about how people want to die before they become unwell, such as practical elements, e.g. Decluttering your home, giving people time to make choices
11. When do we start conversations about death - e.g. nursery, schools, learning from other cultures
12. Reminding people of their strengths and resilience, getting more out of life
13. Personal health budgets, linked to choice and control. Also ASC budget

2. Workforce Development Strategy for Palliative and End of Life Care

Would link intrinsically to education strategy

Recruitment and retention issues demand thinking about?

Recruitment from BME and other groups + career pathway

Values based recruitment to palliative care - schools?

Retention - ensuring staff have access to training and mentoring (Health and social care academy)

Benchmark roles using HEE learning outcomes for EoLC

Allows for standardisation of knowledge + skills. Staff know what to expect of themselves, can ensure adequate training provision by identifying gaps in training + specialist roles

What does the future workforce look like?

Scope, Plan, Adapt,

Carers and patients are experts, they need training to support, care, and self-care

- How can we develop them?
- Link to Carers Leeds initiative
- What can we learn from experienced carers?
- How would this be regulated?

3. Out Of Hours access

Need to know /research project.

What are the current markers for patients being palliative e.g. Pink Stickers, Gold Standards

Framework and are these still being used/doing what they were designed to achieve?

Visible to all healthcare professionals?

Do these markers influence access to Out of Hours?

Do we limit ourselves by reducing staffing OOH?

Variable Access to hospices admission W/End and OOH

Junior Dr Contract limiting workforce availability

Leeds has a really good service

RCA of good incidents as well as poor

Understanding other services

Peer Review of pathways with providers from other organisations

Traditional roles of certain professions.

Can other people do some tasks E.g. who signs a Fast Track

4. How do we provide Timely End of Life Care?

- Challenges
- Personnel / carers limited - inequality of services, delay getting EoLC
- Clash. Best Patient v funding - (no longer fast track)
- Complex referral pathways → Single point referral
- Understanding social care / complex
- EOL v Palliative - funding / GSF
- Fast Track + Palliative funding different
- 'CAPS' Team reactive to palliative EOLC patients, all Leeds → Handing care on
- Virtual Wards?
- Flexibility of care packages
- → Money following patient, avoiding admissions, save money for care.

South Yorkshire model (?)

5. Improving Generalist Palliative Care in the Community

Impact of dependency on specialist palliative care

Optimal use of differing services without duplication

Capacity of neighbourhood teams

Empowering of GP's

Being able to describe clearly what the palliative end of life offer is for the people of Leeds

- Conversation
- SPA, Goldline etc.
- Adaptations to the home etc.
- Referrals to different specialist services
- Benefits advice

How to broach the conversation - number of different conversations

Providing front door of people's services/visiting - how to reduce needing them

Responsiveness

Building on local relationships, *shifts* rather than city wide

How to create capacity for important conversations

How do we improve generalist palliative care in care homes?

CIVAS - appropriate supportive care at home

Citywide rapid response team - composition /virtual component

Generalist support for OOH services - gaps and inequalities persist

Better anticipatory planned care (case management)

What is happening with Gold Standards Framework?

What is happening with Gold Standard Framework meetings and frail patients?

(85 people, 1 hour....)

Reactive management

Can IT info help here?

Capacity Issue making it difficult to be proactive

Local Care Partnerships - right model but capacity concerns

Villa Healthcare have been working across LCH +LTHT etc. 2-5 years

Rich source of learning; Support for workforce who can feel isolated important

Personalisation

Lack of understanding re Fast Track

Reduce Bureaucracy

Use of frailty index as a trigger? As it stands poor correlation in last year of life.

Where does self-management fit in?

Including in residential homes

Including close family

6. Capacity and capability to care for Elderly in the last months of life

Shared Records

Primary Secondary and 3rd Sector

Hand Held Records

Human Aspects of Care

Not just clinical interventions

Compassionate communities

Equity

Social Movement - Public Health Messages

Utilising 3rd Sector - Value of their additional awareness of what's available - staff/patients/family

Care of the dying, generally good, focus earlier

Place of care - Expert Nursing Homes

7. Digital Route Map

1) Access

Early Identification - structural data/risk

Stratification / self-referral /EF for EoL (*Electronic Frailty Index / End of Life index- EOLi*)

Access to data - open systems, point of care, EPACCS

2) Coordination

Lifelong ACP (*Advanced Care Plan*)

AI- decision making aid

Open Systems

Care Home Access to data and patient records, LCR.

SPA – HELM

3) Care out of Hospital

Workforce systems e-shift

Telecare Health (gold line)

4) Education ECHO

5) Service Development

Combining data sets

3D Data Analytics

6) Precision Healthcare and Medicine

Genomics

7) Apps (Alexa /Fitbit) - working with industry / open source

8. Single Point of Access

Who is it for?

Both Patients + Carers & Professionals; E.g. Paramedic

Who can access? - Last year of life?

City Wide – Could be part of Clinical Assessment Service? NB Pilot in North Leeds?

Technology - (Access to patient record is key EMIS/PPM/SI/EPaCCs)

Record conversations face to face - iPad/face time

Demand??

Staffing??

9. & 10. What does a good death look like in Multicultural Leeds & Talk to people about what they want

For BME Groups check data re groups in access

We need to go to people, can't expect them to come to us

Many issues and vulnerabilities can't design a specific service for every possible one, how do we respond via the system? Put the patient at the heart

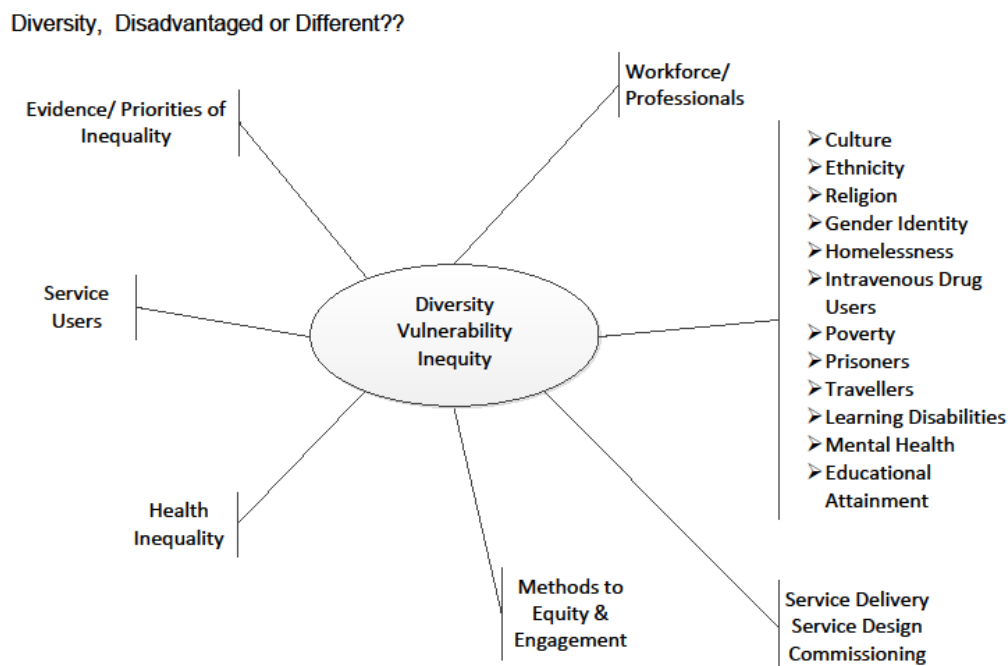
Long term

Strategy - aspirational 'Utopia'. Able to respond in the best way to all groups - have the space to do so

Shorter term

Strategy better support of identified groups

Consider - Diversity, Disadvantaged or Different??



11. Learning Disabilities and Palliative Care

- Known Group who experience inequity
- Recognition that LD services support the 'mainstream' health services
- Aging population of LD people who have outgrown children's services including hospices
- Need for collaborative inter agency working
- Need for accessible info - can we do mac easy read
- Need for education of health staff re LD
- GSF- could more LD people with palliative care needs be identified

12. How will we pay for it..?

We prevent people going into hospital

Quality - poor quality can have costly consequences

EOL bids for CCG interventions (?) have mostly been prioritised in the 1st round of decisions

Showing impact on unplanned service use using academic resource, doesn't seem to work - lack of publication

What is effectiveness of palliative care? Metric such as PPOD are over simplified

Narratives make a big difference - not just numbers

Can we see trajectories covering people in early 70's which will become causes of death?

It's an investment in wellbeing, living well until we die, and contributing, well-being of people bereaved

Good timely clinical decisions avoid all sorts of unnecessary service use

Poor quality can be costly

Changing our way of working

Experts can coach, liaise, and advise

Recognise this is the care part of the workload

We need some qualitative data as well as case studies, not sure what the data is yet

Respiratory MDT example people getting timely EoLC

Respiratory virtual ward re exacerbation of COPD - could the scope of this project include EOL

Cutting out unnecessary interventions

Especially 6-8 weeks before

Know what's happening

Stop silly tests

People don't want to spend that time in bed - giving choice

Specialists working as back up to GPs can avoid unnecessary referrals

Can we measure unnecessary tests and interventions, (e.g. DNA appointment because they'd died)

Multiple separate clinics when people have comorbidities

ACE pathway for tests that need doing without seeing multiple specialities

Simple things - having time to ring GP, say that a patient is moving - palliative

Narrative of investment for well being

Remember the People left behind

Getting & giving from life, not waiting to die

13. Advanced Care Planning

Barriers

People don't want to talk about dying

Or People Can't / too late

Professional - access to records/info electronic, e.g. Ambulance /HSWs

Over complex - all levels/info/informal

Culture - staff/patients + families

Not always end of life - growing process

Pressure to do / tick box

Documentation - 18 different versions

Different protocols in organisations

Future Plan

Leeds - Training Values/Confidence for all staff.

What it is/family complexity

Patients enter own wishes

System everyone can access, e.g. LCR

Everyone input info about advance decisions, however they gain record info

Other Thoughts, Ideas and Comments - Table cloths and Post – Its

Table 1

- Working together at our development edge – Time to think; Partnership, ‘to collaborate’ as a verb – all about relationships
- Cost of Care V’s Quality of Care
- Research having a Nursing Voice – 70@70 Research Leaders NIHR, Niche example of best practice
- CAPACITY (lack of)– Delays in discharge, Un-necessary Admission to Hospital, Hospice / Home preferred place of care, Requires multiagency approach and effective systems to access the right person at the right time.
- Waste due to box ticking.
- Difficult to reach Groups/ Inequality – MH input gap , psychology
- IT – Hospital can’t see EPaCCs, Health Tech as an enabler.
- RISK AVERSION + + – Fear of litigation, failure to understand mental capacity and advanced decisions. Learning from risk, gain share.
- Leeds providers integrated care collaborative
- Avoid over- complication
- Care Home Admissions - ACP as standard? EPaCCs as Standards?
- Early identification through digital interrogation
- Workforce Change
- Providing Key info to YAS
- Version of EFI (frailty Index) for EOL. Predictive of EOL (?) – EOLi
- Avoid us of abbreviations and Acronyms!
- Personal Health Budgets

Table 2 & 3

- **6D’s** –Definition, Demographic, Drive, Diversity, Delivery, Digital
- **ABC** – Access, Better Communication & Co-ordination, Care out of hospital, Digital Route map, Education
- What matters; retain normality V’s changing normality
- Proactive V reactive service
- Clinical need V’s personal need
- Share each other’s knowledge

Table 4

- **3Ds** – Drive, Demographic, Definition (of area e.g. EOL V’s Frailty)
- Access, Better Communication & Co-ordination, Care out of hospital, Digital Route map, Education
- Offer to people recognised to be approaching EOLC – Routine Outcome Measurement, across whole system. Symptom/ Distress outcomes in addition to place of death, hospice / hospital use.
- David’s Story: It was clear that while the support / care was important, the CHAIR made the biggest difference to the family life. Not what people might expect?
- Relationships: Honest / True/ Respect across services including non-public sector is the key to provide value based services. Most people will be provided direct services from other services in the future. Respectfully bringing other organisations to the table. I feel Leeds has taken a clear brave step in collaboration and should continue. *David RW*
- Peoples existing problems don’t go away with a terminal diagnosis.
- What is a managed risk at EOL? Who decides how risky? Risky behaviours or risk of Fall, PU,s?
- Our definition of complexity. What is complex to you may be different to what is complex to me.

Table 5 & 6

- Inequalities in Learning Disabilities population, Stats to look at LD deaths- PPD? Tie in with LeDeR? Investigation of all deaths of people with LD above 4 years.
- 'What's App' Group for LPCN?
- Digital Data; Demographic – Population needs; Drive- motivation, passion, vision; Define – who what why etc. - i.e. not frailty.
- Where is all the fluffy stuff?? 3D's as above. 'Good Death Network'
- Involve the well public- Over 65's? What do they think a good death would look like?

Table 7

- Single point of access.
- Responsive service
- Rotational jobs through different organisations
- More cross organisational roles
- What does Gold Standard mean now?
- Agree the Leeds offer to patients
- Cohort is another word for Silo so stop using it.

Start Doing, Stop Doing, Keep Doing! Post- its

Start

Using co-production in a positive, proactive, engaging way

Actually manifesting the 'Leeds Pound' - where money from all parts of the system flows with the person

Thinking of people as their own assets; thinking of their families and communities as more assets

EOLC Facilitator Care Homes – We have collected carers thoughts on how they feel when resident dies-: Developed a poster for manager to support staff – change in practice acknowledgement, book of memories, quiet area to reflect, clinical supervision

System One, IT systems, telecare- education and clinical support for care homes

Identify Champion for EOLC within care homes, provide resource files, and provide clinical support at EOL and clinical supervision after death

Using LCR proactively and develop areas that will help - e.g. LTHT seeing EPaCCs

Consulting with the People of Leeds

Continue to bring 'different people' to the table.

If you always hear the same voices how can you then create something different?

Stop

Thinking there will ever be one IT system across all the divergent providers and focus on using what there is (LCR) better! ☺

Talking about people as: patients, cohorts, body parts/illnesses

'Managing' risk – whose risk? Try enabling proactive risk taking, i.e. life

Replicating Services

Thinking telling people what the system is going to do is neither engagement OR co-production

Meetings that hold no value or purpose

Keep

Networking

Talking to each other AND talking to the people of Leeds

Focus on individualised patient care

Provide education and clinical support in Care Homes

Pushing forward Provider/ Group led outcomes for people NOT task focused services; as people are not just tasks.

Closing Remarks from the Room

- Use Clinical Experts from across the Whole System
- Leeds Is Good 😊
- Understand others views – keep networking and building relationships
- Define who we are and what we do / don't do
- Demographic Challenges
- We have drive, passion and motivation!
- We looked at Generalist Care in Community but may need to consider future model for Specialist Palliative Care in Leeds
- Professional in Leeds are so passionate and care about EOLC
- Match the £ to the demand!

Closing Remarks from Mike Chitty...

- We hope that we gave you a taste of what it's like to work well in a network together. Messy, inspiring, creative, frustrating...
- The challenge is to keep working as a network between formal meetings
- We think you should meet more often, perhaps 4-6 times a year for 2-3 hours each to keep having the open space conversations about what is important NOW and what do we do about it, as well as where are we trying to get!

Remember

People own what they help to create – so involve those who should have ownership in the creation process...

Real change happens, in real work places, in streets, in places where services get delivered – let's keep the network close to the 'real work'

Those who do the work, do the change – don't try to impose change

Start anywhere, and follow it anywhere – messy emergent – but make a start and keep going!

The process you use to get to the future is the future you get – so make it joyful, innovative compassionate and inclusive!

Loved working with you! Thanks to LPCN for inviting us in to help!

Mike and Emma