

# Seacroft – Dying Well in the Community End of project report

**Leeds Palliative Care Network** 

May 2024



### **Background to the Project**

#### Leeds Palliative Care Network - Dying Well in the Community

Leeds Palliative Care Network is leading a project to improve Palliative and End of Life (P&EoL) Care in the Community in Leeds called "Leeds Dying Well in the Community." The aim of this project is: to improve the transfer of patients between all providers and to ensure continuity of care and the quality of end of life care experience.

The main focus of the project is community (out of hospital) services and how they interact with each other and hospitals to meet patients and their family's needs. The project is split into two key phases:

- Phase 1 was a process, using Whole Systems Approach and using other methods to obtain different views, to scope out the services on offer across Leeds and look for areas of duplication and gaps.
- Phase 2 to ensure that there is effective service redesign to make the best use of the resources available to deliver the most effective and compassionate care outside of hospital for those people who are dying and for their carers and families.

#### Summary of key areas for actions from Phase 1 of Leeds Dying Well in the Community

Within Phase 1 we accumulated a large amount of information. The recommendations can be summarised as

- Updating the service offer
- Scoping the need for a Citywide Single Point of Access for P&EoL care to support people who are dying and their families and carers but also as a hub for information for professionals.
- Agreeing a clear process for recording one up to date Advanced Care Plan (ACP) that is updated and kept as a single version
- Maximising efficiency and increasing resources available to support death in the community.
- Improving timely prescribing

Within the work on "updating the service offer" we wanted to test how integrating services could improve the quality of P&EoL care in a specific community setting. The LPCN worked with the Local Care Partnerships Development Team to identify geographical areas where there would be interest in looking at end of life work and also some capacity to consider the work needed to integrate teams. After an initial meeting with the Seacroft area we agreed to pilot the work in this area.

#### Seacroft Project June 2022

The project started in June 2022, and looked at how key services could be integrated in the Seacroft area for P&EoL care. The key services considered were: community health care, primary care, hospice care, third sector involvement and social care.

The theory being tested was that better integration of services will lead to closer working and, in turn, this will reduce duplication. The increased efficiency of working together more closely will allow the right member of staff to visit people who are at the end of life, and their carers, and offer a more timely and better quality services. We also aimed to clarify the service offer so that each service can describe to people what another service can and can't offer. We know that lack of clarity between services causes confusion for professionals and the public alike and can raise expectations beyond what is achievable.



A "kick off" meeting was held in July 2022 where key people were asked to identify areas of concern and the locality data from the Leeds Planning Ahead document was shared. A follow up meeting to clarify the aims of the project was held a few weeks later. From this, the group identified the following key aims:

- Focus on people who are in the dying phase as first cohort
- Focus on 18 years and over (co-terminus with approach in Leeds and acknowledgment that a different group of partners/services would need to be engaged for a focus on children and younger people) whilst acknowledging that different age groups across an adult population will have different needs
- Increase understanding of the pathway and explore pathway redesign and new models of care working with the community, building upon community assets and strengths and enabling better integration across partners
- To include the role of the GP and senior clinicians in the final phase of life
- Manual of dying/how to have a good death in Seacroft including a glossary of terms (as something the group would like to develop but there may be other things that fall out of the mapping and redesign phase)

A business case was approved by the LPCN executive to provide back fill for a range of clinical and administrative staff to support the project for the following six months.

Over Summer 2022, attempts were made to arrange further meetings and progress the work but this was challenging as people were struggling with competing priorities alongside taking time for holidays after the difficult COVID years. This meant that the group was not able to meet face to face as often as hoped and that the back fill money was not utilised to free partners up to attend.

More positively, the work on developing community assets started to move forward with some momentum. Local residents/bereaved residents and local grass roots and third sector organisations (including local businesses/funeral directors/faith groups) showed an interest in supporting the work and sharing what is important to them. The LS14 Trust/We are Seacroft Alliance started bringing together this group and holding space for meaningful discussion.

In Autumn 2022, a group of senior clinicians were brought together to describe the pathway for death and dying in Seacroft. This meeting proved challenging as what emerged was a complicated picture depending on issues relating to the patient (such as where they were diagnosed and the diagnosis of their illness) and which teams were involved in their care.

At this point it was recognised for the project to move forward local project management was needed to focus on the work and support partners to move at a pace.

#### Project structure and resources January 2023 onwards

In January 2023, a part-time project manager (1.5 days a week) was commissioned by the Local Care Partnership to support the partner organisations in Seacroft to deliver the project. This was commissioned from funding provided by the Leeds Palliative Care Network. After meeting with individual stakeholders, the project manager established a Seacroft Dying Well in the Community Core Group inviting local Primary Care Network, Leeds Community Healthcare, Adult Social Care, Public Health and Third sector partners (for list of members/attendees see Appendix 1).



The purpose of the Core Group was to set the locally agreed priorities and steer the actions that would best improve the experience of people dying in the community at home in Seacroft and their families and carers. The Core Group met monthly (March 2023 - March 2024) at the LS14 Trust building in Seacroft, this venue having the added benefit of a wider professional network learning about the third sector work in Seacroft that would help them to deliver better End of Life outcomes for their patients.

The project manager reported back into Leeds Palliative Care Network's Community Improvement Group, which in turn reported to the LPCN Executive Group and the LPCN Group.

In addition to the regular core group meetings, an external facilitator was brought in to run two workshops; held in June and July 2023, for wider stakeholders interested in the project in order to get a stronger steer on the more clinically-focussed workstream of the project.

Working in collaboration with LS14 Trust, conversations about death, dying and End of Life were held with members of the Seacroft community to understand what would be important to them.





### **The Three Project Work Areas**

The Core Group, working in collaboration with the Leeds Palliative Care Network, agreed 3 broad areas of work for the project:

- 1. Clinical pathways and service integration
- 2. Information offer for the Seacroft Community
- 3. Conversations about death and dying with the Seacroft community

#### Work Area 1 : Clinical pathways and integration

A challenge throughout the Seacroft project has been where to focus attention when working with people at end of life. From the formation of the Seacroft Core Group it was clear that the Project's intended focus on the very last days and weeks of life was not where the biggest gains were to be made in Seacroft. Rather, the group wanted to focus on the last months/last year of life as it considered that this is where the greatest co-ordination was needed and where consistency was most challenging. The group felt that, in their professional experience, the very end of life was not an issue and that there was clarity at this point around respective roles and responsibilities for professionals and for the patients and their family and carers.

This provided a challenge to the project as it brought into scope a greater number of community services, including disease-specific specialist teams, and blurred the distinction and boundary between end of life and living with complex long-term conditions/frailty. It also, naturally, meant that a much larger number of people living in Seacroft came into scope. It called into question what can be the arbitrary nature of the boundary between complex frailty and end of life.

Listening to the feedback from the core group, the project moved its previously intended focus on the very end of life to the broader scope. At this point, a pragmatic decision needed to be made as to what tangible pieces of work could be carried out. Otherwise there was a risk that we would be trying to find solutions to issues across of the whole health and care community system. Two externally facilitated workshops were held in June and July 2023 to support this conversation. One outcome of which was to agree to focus in on a specific cohort of patients/people and to conduct a clinical review of how well these people were supported at the End of Life and also what could be done to improve this experience.

In parallel, around this time, a new city-wide Health & Care priority emerged that provided this focus for the project in Seacroft. The Leeds Partnership Executive Group (PEG) (accountable to the Leeds Health and Wellbeing Board) had identified a number of areas to explore as part of the actions from the Leeds Healthy Plan. One of the cohorts in this was people at End of Life who had a respiratory condition and who lived in the 'most deprived' super output areas of the city (IMD1). Three localities were identified for this: Middleton, Crossgates and Seacroft. Integrated data sets held by the ICB showed that a high number of people in this cohort were experiencing unplanned hospital care. The ICB wanted to explore the reasons for this to see if there were actions that could be taken to maintain people within the community and manage fluctuations in their conditions there. The project worked closely with ICB colleagues to use this data as an area of focus that could then be used for learning across other cohorts of people at end of life (details in the table below).



#### Work Area 2 : Information offer for the Seacroft Community

The Core Group identified the benefits for both people living in Seacroft and professionals working in Seacroft of having a reliable source of local information on opportunities, support and care for people at end of life and for their families and friends. They identified the need for this to include information about getting advice on advanced planning for the future (e.g. wills, POA, funeral plans); support and care at the end of life; and bereavement support. In May 2024, the We Are Seacroft Collective (third sector organisations and community members) will produce and distribute the Dying Well in Seacroft information in leaflet form and digitally (details in the table below) as part of a 'Living Well in Seacroft'.

#### Work Area 3 : Conversations about death and dying with the Seacroft community

The Seacroft Core Group and local residents told us they want to live and work in a community where people feel confident, comfortable and competent in having conversations about death and dying. As well as being healthy and beneficial in its own right, the core group believed this will also help people to take a more preventative approach to illness and End of Life and to seek the right support at the right time. A number of community events and discussions have taken place during the life of the project and more are scheduled as part of the legacy. From April 2024 onwards, the Dying Well in Seacroft Network (which is the new form of the Seacroft Core Group) is holding monthly evening 'Life and Loss Cafes' with potential for themed sessions and attendance by organisations who provide EoL/palliative care services (details in the table below).

For each of these three work areas, the tables below show what was achieved during the dedicated project time (up to March 2024) and what is planned and continuing as part of legacy of the project. There is a fourth table which covers some of wider benefits of the project and what the legacy of that will be.

Work Area 1 : Clinical pathways and integration		
Achieved	Legacy and next steps	
A clinical case review of EoL respiratory	Seacroft PCN to work with Third sector and other	
patients in Seacroft was conducted from the	partners to identify the ideal process for working with	
PCN team caseload. These cases were then	people at End of Life and ensuring that they are aware	
discussed further by core group partners at a	of and engage with the range of support and	
special case review meeting in January 2024.	opportunities available in the locality. This will be done	
A number of approaches were identified that	through a larger number of case studies and the	
demonstrated how people who had	conclusions to be written up and shared (including with	
previously defaulted into unplanned care	the Leeds Palliative Care Network).	
could be maintained in their own home if the		
right care and support was in place.	Partnership MDT to be held to review a handful of	
	cases, alongside the other LCPs in the project to share	
The key learning themes that came from the	learning whilst identifying any themes that are unique	
case review are set out in <b>Appendix 2</b> below.	to Seacroft. The MDT will focus on circumstances for	
	admission, could there have been an alternative to	
Seacroft Core Group members attended and	admission, details around timely discharge or	
presented at the city-wide workshop in	associated barriers. The LCP Development Team to	
January 2024 on respiratory disease and EoL.	provide initial support this process.	
The work identified 4 key areas of focus that		
emerged from the discussions there:	Seacroft partners (via the continued Dying Well in	
1. Anxiety	Seacroft Network) to continue to work with the ICB on	



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2. Self-management

the Respiratory EoL priority and use the learning from this to inform practice across other conditions.

Care co-ordination
 Knowledge of local area

 Work Area 2 : Information offer for the Seacroft Community

 Achieved
 Legacy and next steps

 whitestion the Seacroft Core
 In May 2024, the We Are Seacroft Collective (third)

Achieveu	Legacy and next steps
In readiness for publication, the Seacroft Core	In May 2024, the We Are Seacroft Collective (third
Group has drafted a 'Dying Well in Seacroft'	sector organisations and community members) will
information sheet providing details on	produce and distribute the Dying Well in Seacroft
services and community assets that support	information as part of a new 'Living Well in Seacroft', in
people at EoL and their families and carers	leaflet form and digitally.
with planning for the future and with	
bereavement. This is to support both people	The information will form part of a wider community
working in Seacroft and living in Seacroft.	promotion on the theme of death and dying (see Work
	Area 3 below).
	The Leeds Palliative Care Network and the LCPs to
	consider how this approach could be replicated in other
	localities and also to consider how this complements
	the more generic city-wide information offer about
	P&EoL care.

Work Area 3 : Conversations about death and dying with the Seacroft community		
Achieved	Legacy and next steps	
Members of the Seacroft Core Group visited a Seacroft residents group to ask what local people thought were the priorities about	From April 2024 onwards, the Dying Well in Seacroft Network is holding monthly evening 'Life and Loss Cafes' with potential for themed sessions and	
<ul> <li>death and dying. The response included:</li> <li>There needs to be more open conversation within the community</li> </ul>	attendance by organisation who provide EoL/palliative care services.	
<ul> <li>about death and dying. It should not be taboo</li> <li>There needs to be good local and wider information about planning for the future and what to do if you/some you are close to is at EoL</li> <li>People shared very personal stories</li> </ul>	In May 2024 the We Are Seacroft collective will co- ordinate the launch of the Dying Well in Seacroft information offer (see work Area 2 above) with a wider community promotion of issues around death and dying. This will also have an on-line presence including discussion boards and videos of local people and potentially local professionals talking about death and dying and P&EoL services available.	
Following this, the Seacroft Core Group successfully bid for funding to hold two Death and Dying community events/cafes which were attended by local people and received very positive feedback.	The Dying Well in Seacroft Network will share links to these materials with the Leeds Palliative Care Network once they go live for information and so that consideration can be given to promoting similar approaches in other localities in Leeds.	



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### **Lessons Learned : Stakeholder Views**

In order to get feedback on a variety of stakeholders' views on the Project:

- 1. An on-line survey was sent out in March 2024 to all project stakeholders which provided an opportunity to comment.
- 2. A series of interviews with ten key stakeholders was conducted in April 2024 by the Local Care Partnerships Development Team.

The responses have been grouped by themes and summarised here, including some direct quotes:

#### What we did well?

- Focus on a locality rather than city wide
- Seacroft was a good pick
- Third sector/community involvement (bringing community voice)
- The work brought the opportunity to talk about death and dying across the community and has a legacy
- Learning about other projects/services happening in the area
- Getting to know colleagues and their roles in the community
- The project has positively stimulated innovation, focus and growth around palliative and end of life care in Seacroft great project legacy

#### What would we do the same?

- Providing funding to support project (even a small amount)
- Dedicated project management
- Openness of partners to learn from each other, from the process

#### What would we do more of/or do earlier?

- Core group in place earlier
- Consistency of membership across the core group
- Close working relationship of LPCN and Local Care Partnership real benefits of doing it with a breadth of partners
- Time invested to have initial conversations /engagement to ensure buy in
- Project management
- Develop a clear focus for the project earlier
- Clear aims for the project agreed which bit of end-of-life pathway we were looking at
- Clearer governance around the work where to share the learning?
- Follow the energy
- Mapping other projects that are underway, mapping local assets what is already happening in the area?
- Engagement with Adult Social Care
- Put the infrastructure in place sooner. Understand however that capacity and capability of system partners was still significantly affected by COVID impact workforce exhaustion and returning to pre COVID activity



- As a starting point when working on end of life in a new locality, it would be advisable to carry out an assessment of the locality to establish the degree to which the conditions are in place on which to build the project, i.e.
  - Pro-active case management
  - Third sector architecture
  - Care planning approaches
  - Existing cross-organisation relationships
- Trying to build on psychological safety but requires capacity and money
- Medicines access in the community and information sharing remain a challenge /problematic particularly for out of hour providers/paramedics but a local project cannot resolve these bigger system issues
- Post COVID, there was an increase in the number of people dying at home/wanting to die at home and yet there was no strategic/resource shift into community services which presents a growing challenge to cope with the increasing demand.
- The original focus on the very end of life pathway was driven by an ambition to drive greater efficiencies and collaboration and co-create and redesign a renewed and refreshed end of life pathway that would enable end of life care to be delivered equitably to meet growing demand /lower workforce challenges. This 'reimagined' pathway and new model of end of life care could have made a significant impact in the city and nationally.

#### What would we do less of?

- Being unstructured at the start of the project
- Not narrowing down the focus
- Some of the bigger workshops lacked focus

#### Other/unintended learning

- The real impact of COVID impact on people involved (energy)
- The turnover of staff lack of continuity, having to start over
- Professional connections positive consequence
- Amount that partners learnt about third sector offer and assets, spaces and places
- Not a big a problem as we originally thought
- Not as much as an issue for primary care
- Importance of care homes lack of engagement
- Adult Social Care lack of involvement
- LCH changes
- P&EoL care not a priority for some organisations
- Differences in perception of senior leaders and local partners around challenges and opportunities
- 'The LS14 trust model or equivalent should be adopted elsewhere. It seems to be the heart of Seacroft, drawing people in, developing excellent links and a great website'.
- Conceptually, we always link end of life and palliative care as one when both need different skills, competencies, decision making

Sarah Mitchell, new Associate Clinical Professor in Leeds / Primary Care Doctor, is starting a project looking at community based palliative care questions in underserved communities. The core group could be asked to consider if future innovative models of care emerge from a more academic approach.



# Systems Map for Palliative and End of Life Care in Leeds

In the early phase of the project, stakeholders produced a Dying Well in the Community Systems Map, using a Whole Systems Approach. This can be viewed on <u>the Leeds Palliative Care Network website</u> This map identifies a number of factors which would help deliver good quality care at end of life in the community. A brief analysis of which of these factors have been addressed and advanced locally in Seacroft in the course of the project and which will still require further consideration is shown below:

Covered by the project:

- number of different agencies/people visiting patient
- fully completed advanced care plan / ReSPECT form
- effective case management and understanding of roles and responsibilities
- detail of information provided at discharge / hand-over
- need for support for informal care
- knowledge/skills/confidence/experience in P&EOLC
- timely conversation about end of life care
- need to signpost to those qualified to complete advanced care plans
- effective communication / relationships between providers of P&EOLC
- cultural norm to talk about death and dying
- skills and competencies of unregistered workforce

Requires further work:

- access to / availability of medicines
- reliable sharing of information (this refers to wider IT interconnectivity issues)
- need for 24/7 access to care and support
- ability of neighbourhood teams to respond quickly



### Conclusions

#### **Conditions required**

Learning from the Project has shown that the chances of successful development work are greatly determined by a number of key characteristics and strengths that may or may not pre-exist in a given locality. These conditions provide the ideal architecture on which strong partnership development work can be built:

#### 1. Clarity on the locality(ies) and communities you are working with

From a Leeds city-wide perspective, the 'geographical subsets' of the city can be defined in a number different ways, including but not exclusively:

- Primary Care Networks (PCNs)
- Local Care Partnerships (LCPs)
- Council wards
- Neighbourhood Team patches
- Adult Social Care patches
- School clusters
- 'Natural' communities

Part of the learning from the work in Seacroft is that the population covered by the Seacroft PCN is still a fairly large one at around 40,000 people. Furthermore, and more significantly perhaps, the PCN area covers a number of different 'natural communities' and actually covers localities that reach into Gipton and Roundhay. The project focussed largely on people living and working in the Seacroft community. This was mainly because the partners who came together to drive the project forward, worked in this locality. Also, conversations were held with people living in the Seacroft community.

Future projects need to make sure they have up-to-date data on the demographics and recorded strengths and needs of the locality they are working with. The focus on deprivation in Seacroft became the equality focus for the project. Future community P&EoL projects, whether geographically restricted or not, could take the opportunity to look at needs of other communities of interest such as the experience of LGBT+ people at end of life or the experiences of people with learning disabilities.

#### 2. A structured and resourced third sector in the locality

The Project has shown that in many cases successfully maintaining a person at end of life in their own home lies in solutions that sit outside of statutory care services but within the third sector and wider community offerings. NHS teams working with people at end of life therefore need a strong working relationship with an organised and sufficiently resourced local third sector. The local third sector needs to work in such a way that it is truly embedded in the local community and has a detailed knowledge of what services, opportunities and informal offerings will help with the aims of the person at end of life. The Seacroft Project has also highlighted the importance of a robust and well-functioning 'hub and spoke' model for local third sector so that partner organisations do not have to spend valuable clinical time navigating the options within the locality.



#### 3. Capacity and drive to improve the experience of EoL

A local community EoL project such as this, needs to take account of who the local champions will be for the pathway development and wider work AND establish that local stakeholders have the time to devote to a development project.

#### 4. NHS services that have 'pro-active' case management capacity

Pressures on the Health system in terms of finance, workforce availability and complexity of Health and care needs can result in a more 're-active' service response as community-based services strive to keep the Health system moving. This can have a detrimental effect on people at end of life who require a more pro-active service in order to remain at home and avoid unnecessary unplanned care, such as a hospital admission or a care home package. People at end of life who want to die in their own home need:

- The supervisory element of pro-active care
- Continuity of health staff who know the patient and who the patient trusts and
- The ability to easily contact a member of the team on the phone

#### 5. Care planning based on what matters to the person

Whatever the presenting condition of the person at end of life may be, those planning their care need to understand what that person's subjective experience of their illness is and, within that, what the triggers are for that person to feel out of control of their condition.

In nearly all of the EoL cases reviewed in the project, people's social and psychological needs were seen to be inextricably linked with their presenting health conditions. This re-enforces the need to have a holistic assessment and understanding the person's needs, wishes and environment.

#### 6. The care home population

The population of people who live in care homes need some dedicated consideration for any future End of Life community project. This population can be overlooked but these are members of the local community whose home happens to be in a care environment and many of those living in a nursing home will be within their last weeks and months of life. Future projects should understand where this provision is in the locality and work with the care providers, primary care, Leeds Care Association and Leeds City Council/ICB commissioning to ensure that best practice EoL approaches are in place. When looking at data about people at end of life and mortality data, the impact of a large number of care homes in a particular area should be taken into account as this could skew benchmarking with other localities. Sheltered and extra care schemes could also be included in this analysis.

#### 7. Building EoL and palliative care into mainstream community Health & care developments

As important as specific developments to improve end of life care are, P&EoL care should also form part of all relevant developments within health and care, for example the development of the new home care model, promotion of pro-active case management etc..



### Resources

Leeds Palliative Care Network website Healthy Leeds Plan webpage We Are Seacroft website

# **Appendix 1 – Seacroft Core Group Members/attendees**

John Lynch Joanna Quigley Chris Jackson	Seacroft PCN Seacroft PCN LS14 Trust
Mags Grinnell	LS14 Trust
James Woodhead	Project Manager
Clare Drinkwater	LCH
Lizzy Gascoyne	St Gemmas
Jill Holmes	Seacroft PCN
Victoria Tate	LCH
Hannah McGurk	Public Health
Robina Ahmed	Public Health
Sharon Allman	LCH
Mary Windsor (MW)	LCH
Chris Bulmer (CB)	LCH

Others invited who were not able to attend: Adult Social Care (Social Work/Case Management); the Doula service



# **Appendix 2** - key learning themes from the clinical case review

Every patient/person's circumstances should be viewed with '**broader eyes**', i.e. not just their clinical conditions but their wider family, social, emotional context and their own life stories.

Every person should be looked at in the round and not approached on a 'task' basis by professionals. Professionals must be **curious** about the individuals they work with.

Every person has their own **subjective experience** of their illness so generalisations can't be made about specific health conditions.

When looking at cases we need to get underneath what the specific **triggers** were that caused an unplanned admission and which **mitigations** prevented an admission.

Services should be **commissioned** around outcomes for individuals and not to simply deliver tasks.

Sometimes **unplanned events happen** despite preventative interventions (e.g. a fall with fractures) and people need hospital care.

**Continuity of care** is crucial to support people with serious respiratory conditions (and other conditions). Patients need a trusting relationship with specific staff members if they are to fully engage with community health care. Staff need to know the patient well so that they can recognise when something isn't right (and potentially therefore avoid unplanned care/hospital admission).

People with respiratory disease need to know that they can **pick up the phone and speak to someone** who knows them and who they trust.

A **locally-focused team** (at a PCN level) is essential for holding a shared knowledge of both patients and of local services, activities, opportunities etc.

People (particularly isolated individuals) need much more than signposting to social opportunities, activities, third sector etc., if they are going to successfully engage with those opportunities.

**Pharmacists** play a crucial role within the local team and pro-active regular **medicines reviews** can prevent acute scenarios.

Weekly **Multidisciplinary Team Meetings** (MDTs) including Social Work and Community Geriatrician are needed to co-ordinate care and support.

Everyone working with people in the community should make sure the fundamental **scaffolding** is in place for all the people they work with – benefits check, Telecare, Food over Heating, Fire alarms, carers support and EoL planning (POA, will, funeral plan).