



**Kirklees  
Palliative Care  
Partnership**

# **Palliative and End of Life Care in Kirklees**

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**Aims**

The aim of this paper is to provide members of the Health and Adult Social Care Scrutiny Panel with an overview of work underway within Kirklees, led by the Kirklees Palliative Care Partnership ('The Partnership'), with the vision of ensuring more people experience great care at the end of their lives. The paper also aims to underline the importance of palliative and end of life care to the priority outcomes for the population of Kirklees and for the health and social care system.

**Key messages**

The way that people are cared for at the end of their life is as important as how they are cared for at the beginning of their life. It has a lasting legacy for those who live on, and a significant impact on the use of resources across the entire health and social care system

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We should celebrate what we have in Kirklees as it compares very favourably to other areas in West Yorkshire and beyond

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People in Kirklees benefit from a more comprehensive range of hospice services than exist elsewhere in West Yorkshire, and a strong partnership of providers working to improve the quality of care available to all

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The work of The Partnership has delivered a real impact, which we seek to protect and build upon. However, the progress that we have made is at risk if capacity cannot be maintained or developed

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We have opportunities to improve and the right structure and mechanisms to do so through The Partnership and Kirklees Palliative and End of Life Care Programme (Programme)

**The committee are asked to:**

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Note the details of the current approach provided within this paper

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Consider their influence on the future areas of work

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Advocate that 'Dying well' should be a key outcome for the Kirklees Health and Wellbeing Strategy (KHWS) and that Palliative and End of Life Care remains an explicit priority within the plan

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Advocate that dying well is as important as starting well, living well and ageing well

**Why does it matter?  
The importance of  
'Dying well'**

The experience of a death is life changing for the people who are bereaved. The way that people are cared for at the end of their life has a lasting legacy for those who live on.

Care of the dying can be seen as an indicator of the quality of care provided for all sick and vulnerable people in a population. In addition, it is well documented that use of health and social care services increases significantly towards the end of someone's life, therefore good palliative and end of life care can have a positive impact on demand experienced in every part of the system.

Every year in Kirklees over 3,800 people die (KJSA). For three quarters of these people, death does not come suddenly. Instead, dying is a process that can take years, involving a progressive decline in functioning and frequent interactions with health and social care professionals.

This means that there are opportunities earlier on in people's journeys for them to plan for their future care, supported by health and social care professionals.

End of life care can encompass the entirety of a person's journey; from a diagnosis of a life limiting condition, to its progression, deterioration, care in the last year and care in the last days of life.





Through the work of The Partnership, patient stories are used to drive the work we are doing. Each partnership meeting begins with a patient story illustrating both positive and negative experiences of care, as a reminder of the purpose and impact of our joint working.

# Zuri's Story

**Zuri, who lives with her husband Bill in Dewsbury, was diagnosed with dementia seven years ago. She was referred to The Kirkwood's Admiral Nurse, Rachel last year, who supported her and Bill.**

Rachel undertook a home visit and assessment following a GP referral. The GP had referred Zuri due to concerns of her being in the advanced stages of her condition, and needing support with anticipatory care planning to ensure a focus on her goals and her families wishes.

Rachel completed a dementia palliative care assessment, which highlighted a number of unmet needs due to there being no support in place for the family and Zuri.

Zuri required input from a wide Multi-Disciplinary Team from Locala services, which Rachel co-ordinated.

The assessment and support from the Occupational Therapists and Speech and Language teams helped to maintain Zuri's quality of life. Rachel kept the GP informed throughout.

Rachel worked with Zuri and her family to undertake appropriate capacity assessments, discuss her care for the future and find out her preferred wishes.

Following another of Rachel's visits, Zuri deteriorated. As a non-medical prescriber, Rachel was able to initiate the prescription of anticipatory medications. Rachel also completed the fast track application, and a care package was put into place.

Rachel worked with District Nurses to agree palliative care support visits, with a focus on priorities of care. Bill, Zuri's husband, felt aware of the support available both in and out of hours to meet Zuri's wishes about where she wanted to be cared for, and who to contact if he had any worries or concerns. Bill was able to call The Kirkwood's 24/7 Advice Line for concerns he had – which were responded to.

When Zuri became acutely unwell with a chest infection, Bill called 111. Because of the documented care plan in place, the on-call GP was aware that Zuri's care needs were to focus on her comfort and manage her symptoms in the community. Antibiotics were prescribed and Zuri was able to remain at home.

The GP was kept updated and Zuri was discussed in the practice's Palliative Care Multi-Disciplinary Team. Rachel continued to make regular contact with Zuri and Bill for ongoing advice and psychological support.

Rachel felt this was a positive example of how working together **meant each specialist within their own field could support an agreed care plan** for someone with an advanced stage of dementia and **co-ordinate Zuri's care so she was able to meet her wishes to be cared for and die at home.**

## Why this is important now

The pandemic has brought into sharper focus the importance of end of life care and the experience of people who are bereaved and the impact of death on their health and wellbeing.

The population in Kirklees is getting older, in line with the population of the UK. If recent mortality trends continue, in 2040 there will be at least 1,200 more people that will need palliative care every year.

Over 20% of the entire NHS budget is spent on care provided to someone in the last year of their life. More than half of the complaints referred to the Parliamentary and Health Service Ombudsman in the UK concern end of life care, and over half of these are upheld.

Approximately 30% of people in the last year of life use some form of Local Authority funded social care.

Hospital costs are by far the largest cost element of end of life care, a study in 2014 found that care in the final three months of life averaged over £4,500 for every person that died, in Kirklees this would be over £17 million. The bulk of this cost is due to emergency hospital admissions where hospital costs can increase rapidly in the last few weeks of life.

## What should happen?

A partnership of national organisations with expertise in Palliative and End of Life Care have recently updated national guidance for the achievement of high standards at a local level. The 'Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026' sets out the national vision to improve end of life care through partnership and collaborative action between organisations at local level throughout England.

### The guidance details six Ambitions that should drive local action:

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**Ambition 1** – Each person is seen as an individual

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**Ambition 2** – Each person gets fair access to care

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**Ambition 3** – Maximising comfort and wellbeing

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**Ambition 4** – Care is co-ordinated

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**Ambition 5** – All staff are prepared to care

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**Ambition 6** – Each community is prepared to help

The guidance sets out what people should expect from their care and it has been incorporated into our work in Kirklees. The diagram on the next page is an extract from the Future Service Development model that has been produced by the Kirklees Palliative Care Partnership:





Fig. 1: A visual representation of elements of care included within the Ambitions for Palliative and End of Life Care guidance

### What brings about the best outcomes?

Put simply, if someone who is identified as approaching the end of their life has had a discussion about their future wishes resulting in an Advance Care Plan, and if they are known to Specialist Palliative Care services, it can make a positive difference to their outcomes.

We know that if people are identified and they have an Electronic Palliative Care Coordination System (EPaCCS) record and/or an Advance Care Plan (ACP) that they are less likely to die in hospital. An ACP improves end of life care and patient and family satisfaction, reducing hospital and care home admissions, stress, anxiety and depression in surviving relatives.

People living in Kirklees are also less likely to die in hospital if they are known to The Kirkwood's services. Typically, less than 10% of people receiving care from The Kirkwood die in hospital, this compares with over 40% for those people who are not known to The Kirkwood.

All this relies upon people having being identified as likely to be within their last 12 months of life in the first place and this initial step is crucial towards someone having a better quality experience during their final year.

This process is also essential to identify those people who are important to the person in their last year of life so they can also be supported during this difficult time.

Since 2018, The Kirkwood have been instrumental in leading the development of a system-wide partnership across health and social care. The vision for this partnership is to ensure more people in Kirklees can access great care at the end of their lives. This has been underpinned by the aims of reducing health inequalities, promoting personalised care, and improving the experience of carers.

We have achieved a great deal through The Partnership to date. As a result, more local people are benefitting from evidenced based palliative and end of life care, and Kirklees is developing a reputation for the progress that has been made.

### **The Partnership is led by The Kirkwood, with involvement from:**

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Curo GP federation

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Locala Community Partnerships CIC

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Kirklees Council

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Local Care Direct

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South West Yorkshire Partnership NHS Foundation Trust

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Marie Curie

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Mid Yorkshire Hospitals NHS Trust

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Calderdale and Huddersfield NHS Foundation Trust

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Healthwatch Kirklees

### **The Partnership has delivered a number of products that have helped influence the improvement of palliative and end of life care in Kirklees:**

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1. A Future Service Development model for integrated palliative and end of life care in Kirklees – Appendix 1

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2. The Kirklees (End of Life) Care Charter – Appendix 2

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3. An integrated approach to quality improvement

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4. A Care Home Workbook and e-learning package

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5. Handy guides to EPaCCS and Advance Care Planning

The partnership approach has been embodied in the Kirklees (End of Life) Care Charter. This was jointly created and adopted by partner organisations and is aligned to the national ‘Ambitions for Palliative and End of Life Care’. The Charter is for people with a life limiting illness living in Kirklees and explains what care people can expect, and for the partner organisations it is a pledge to improve end of life care in Kirklees. The implementation of the

standard in the Charter is ongoing and will continue to drive improvements in care to benefit the people of Kirklees.

For example, the integrated approach to quality improvement involved a review of the existing system, each organisation within The Partnership completed a self-assessment against the standards laid out in the charter identifying areas requiring improvement and developing action plans to meet the gaps.

The provider organisations within The Partnership are working well together, and this has resulted in significant improvements in the number of people with an EPaCCS record and with an Advance Care Plan.

The Partnership continues to advocate that investments in community services need to ensure that investment in palliative and end of life care features as a priority.

### **The Kirklees (End of Life) Care Charter**

The Charter sets out what people should expect from their care in Kirklees and sets out how organisations are working together to improve the quality of end of life care. All organisations within The Partnership have formally adopted the Charter and commit to it through developing and implementing their own individual action plans.

You will find an example of the Kirklees Care Charter on the next page.

# KIRKLEES CARE CHARTER

This charter was created by the Kirklees Palliative Care Partnership for people with a life limiting illness in Kirklees. We know the care system can be confusing and our aim is to ensure your care is focussed on what matters to you.

Our charter explains what you can expect from your care in Kirklees and sets out how organisations are working together to improve end of life care in Kirklees.



## I am seen as me

I am informed as early as possible that I have a condition which is life limiting and will shorten my life, although I might continue to live an active life for some time. I, and the people important to me, get the opportunity to have honest, informed and timely conversations.

## I have access to care

The people important to me are supported all the way through my journey. My care reflects my physical, social, psychological and spiritual needs.



- Physical needs
- Social needs
- Spiritual needs
- Psychological needs



## I am supported by staff who are prepared to care

All the staff I come across, wherever I am, bring empathy, skills and expertise to give me care which is compassionate.

## I am confident that my wellbeing and comfort come first

I can choose to stay where I prefer and avoid unnecessary visits to hospital. My care is regularly reviewed and my symptoms are managed as well as they can be.



## I receive co-ordinated care

My needs and plans are known by everyone involved in my care and I am helped to achieve them. I know how to reach someone who will listen and respond at any time of the day and night.

## I live in a community that is prepared to help

My community recognises that we all have a role to play in supporting each other in times of crisis and loss.



Through adoption of the Charter, each organisation will improve quality by:

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Having a process in place for early identification of people who are approaching the end of their life

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Recording wishes and preferences for future care and treatment, focusing on wellbeing and comfort

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Identifying people's physical, social, psychological, and spiritual needs

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Reviewing and updating care plans

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Signposting to other services that are available and, in particular, specialist palliative care and hospice services

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Accessing training and education for staff

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Seeking regular feedback from service users

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## What used to happen

The Partnership identified a number of gaps from work undertaken prior to the pandemic and produced a future service development plan to deliver an integrated model of care. This plan was agreed in principle within the health and social care partnership forums.

In 2021, a Quality Baseline exercise led by the Integrated Care Board required all partners to assess themselves against national Ambitions guidance, and our local Charter.

A number of key areas were identified as gaps and drivers for the Service development plan:



Fig 3: Gaps identified by The Partnership

Through the intelligence gathered by The Partnership we know that for people to be supported to remain where they want to be, all services need to be aware and have a proactive plan.

This can include all parts of The Partnership, from primary care, community services, social care, out of hours emergency care and acute trusts.

It is also worth noting the misunderstandings, myths and stigma that exist surrounding end of life care. People may have a solely medical model applied to them, despite wishing not to undergo investigations or treatments when approaching the end of their life.

Given that supporting people with a life limiting condition is a significant part of the activity across the health and social care system, we need a system wide focus on the importance of advance decisions about future treatment and not just ‘Do not attempt cardiopulmonary resuscitation’ (DNA CPR).

### The Kirklees Palliative and End of Life Care programme

The Programme brings all this work together and is described in the diagram below. There are three main working groups, made up of key members within The Partnership and this work feeds directly into The Partnership and into the ICB’s Ageing Well Programme. The structure of the programme is shown below:

Vision	More people in Kirklees experience great care at the end of their lives				
Aims	Tackle inequalities in PEOLC		More people experience great personalised care		Quality of life for carers
Measures	No. on EPaCCS	No. of ACPs	No. access SPC	Admissions	Experience
Activities	EPaCCS & ACP working group		Service Development Group		Training & Education Group
Action Plan	Improvement priorities built from self assessment against End of Life Charter				
Partner Sign Up	Baseline self assessment against ambitions of the End of Life Charter – Partner Improvement				
Partner	Broad partnership of everyone involved in providing Palliative and End of Life Care in Kirklees – bound together by formal commitment to the Kirklees End of Life Charter				

Fig 4: The Kirklees Palliative and End of Life Care Programme and component groups

## Measures of improvement

**The Partnership has developed clear measures of improvements required within the system to ensure more people receive great care at the end of their lives. These include:**

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Increasing the numbers of people identified as being in the last year of life, and increase the numbers of people with an EPaCCS record

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Increasing the proportion of people who die who have an Advance Care Plan

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Increasing the numbers of people supported to die in their own home

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Increasing the number of people cared for by The Kirkwood at the end of their life

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Reducing, where appropriate, hospital admissions in the last three months of life

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Experience of bereaved people in relation to the care the dying person has received

Working closely with the ICB we have now created a monthly data dashboard which is reviewed by The Partnership.

## What has been the impact?

The work of The Partnership has focussed on what we believe will make the biggest difference. By providing the leadership in bringing different parts of the system together, we have delivered a number of initiatives that have resulted in tangible improvements.

A clear focus on earlier identification, advance care planning and earlier referral to specialist palliative care meant we were in the best place to respond to the pandemic and deliver the best outcomes for people at that time.

**Prior to the pandemic the following improvements were delivered:**

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**60%** more people were identified as approaching the end of their life

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**180%** more people have an Advance Care Plan

**This meant that during the pandemic:**

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**43%** increase in urgent end of life activity supported by Integrated Community Care Teams

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**32%** increase in the numbers of people supported by The Kirkwood at the end of their life

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**40%** more people were supported to die in their usual place of residence

The tangible impact during the pandemic reflects the impact of our partnership and, through the programme, we are sustaining and building upon our achievements. The Kirkwood continue to be committed to building on this success to improve the experience of people.

One of the key outcomes that is of benefit to the system is the impact on hospital activity for people approaching the end of their life. The graph below is the percentage of deaths with three or more admissions in the last year of life, which is tracked by The Partnership:

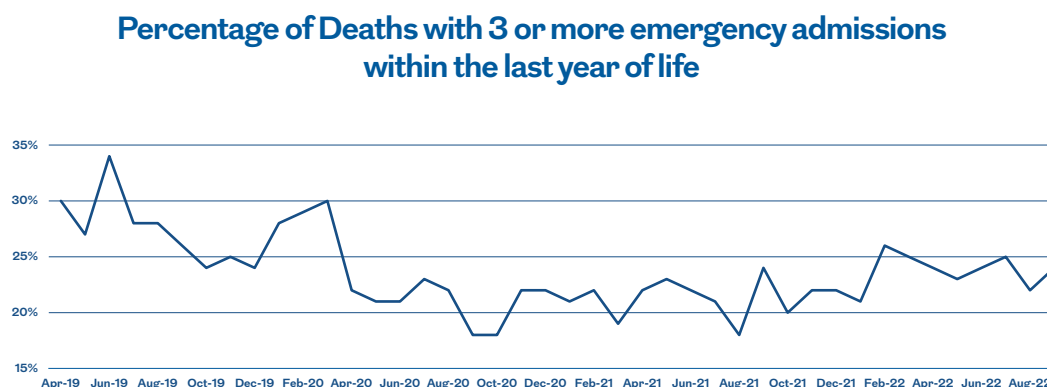


Fig 5: Percentage of deaths with 3 or more admissions in the last year of life.

There is a clear difference between the levels prior to the pandemic and what was achieved through the pandemic, which was delivered on the back of The Partnership’s improvements.

**What services currently exist to support people?**

Within Kirklees, there are a number of services currently available to support people in their preferred place of care (see Appendix 3).

The Partnership has produced a recommended Service Development Plan to create an integrated model of care (Appendix 1). This is still the desirable position. During the pandemic, more capacity was focussed on supporting people’s choice and proactively ensuring that clinically vulnerable people avoided hospital admission where necessary.

The work of The Partnership aims to build upon this to ensure we continue to support more people. This depends entirely on people being identified, having better conversations about what matters to them, providers of care sharing information and the capacity being in place within the system to deliver the care required.

**Inequalities**

Inequalities in access to end of life care have been historically identified nationally, with white, middle-class, middle-aged patients with cancer having traditionally been over-represented in hospice populations. It is also worth noting that people who die in hospital are more likely to be deprived (Appendix 5).

Hospice UK’s ‘Equality in hospice and end of life care: challenges and change’ (2021) cites a recent extensive literature search, which has demonstrated persistent inequalities in hospice care provision. This has been found to be particularly prevalent for people without cancer, the oldest old, BAME communities and those living in rural or deprived areas, who all remain under-represented among those receiving hospice care. Equally, while a substantial body of evidence now exists on inequalities linked to general health in the



late stages of life, there are still huge gaps in the evidence base, including appropriate end of life care for the LGBTQ+ community, people experiencing homelessness and those living with specific conditions.

The Kirkwood currently monitor demographic data which is regularly reviewed.

Whilst the guidance may focus on hospice care, The Partnership has identified the need to collectively review data to identify which demographic groups may not be represented in current service reach.

The integrated model developed is universal and should be applied to everyone, across all groups, through a focus on personalisation.

The Partnership is committed to learning from tactical work taking place within the wider system, which is targeting under-served communities, to reduce health inequalities.

# **Our ambitions for the future and challenges**

The voluntary sector are important partners in meeting end of life care needs, both as providers and funders of care. In Kirklees, The Kirkwood invest over £4 million of charitable funding to meet palliative care needs of local people.

Despite the challenging operating environment, The Kirkwood cared for more local people than ever before in 2021–2022. Our care was delivered in people's own homes, in care homes and out in the community. And it continued to be delivered at our hospice for all those in need of 24 hour compassionate care.

### **Our impact spans patient care, support to professionals and involvement in The Kirkwood Movement. In 2021–22:**

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**1,690 patients** were supported to maintain their quality of life by The Kirkwood

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**1,249 patients** were supported by The Kirkwood Nurses in their own homes or care homes

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**900 patients** were cared for at the very end of life

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**646 patients** in our care died in their usual place of residence and not in hospital

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**126 more people** were cared for at the end of life last year than the previous four year average

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**Just 8% of patients** who died under our care died in hospital

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**15,101 calls** were made to our 24/7 Advice Line by patients family members, carers and healthcare professionals

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**63,790 hours** were donated by our dedicated team of volunteers in our 17 shops across Kirklees

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**1,292** of the calls to our 24/7 Advice Line were made outside normal working hours and answered by our dedicated nursing team

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**27,616 individuals**, made up of patients, family members, carers, volunteers, employees, partners and supporters make up The Kirkwood Movement

Through benchmarking with the other hospices within West Yorkshire, it is clear that we have a comprehensive range of services that benefit more people in the local population compared to other places.

## What still needs to happen?

Through the work of The Partnership, we have successfully built engagement and involvement. Data is now flowing on a monthly basis for review, which is supporting the work to implement the Charter and organisational action plans. On reflecting on the successes of 2022, The Partnership identified a number of areas of focus for the future:

Where next?	Capturing impact/development of the <b>Quality of Dying</b> report
	Raising <b>awareness</b> of the work of The Partnership within the system
	Identifying <b>resource</b> from within The Partnership to support the programme
	<b>Endorsement</b> for the Charter and <b>implementation</b> within the system

The Partnership have identified the need for more capacity within community services to support people.

Ensuring that this features strategically and more explicitly within the Kirklees Health and Wellbeing Strategy and Plan will allow endorsement at the highest level.

A common theme within discussions has been the need for a deeper, more consistent understanding of how significant end of life care is in terms of the activity across the system.

## Upcoming projects in 2023

**The Partnership will be jointly progressing key areas of work in the next 12 months, including:**

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Developing a 'Quality of Dying' report, in conjunction with Public Health

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Producing a Health Needs Assessment for Palliative and End of Life Care

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Working with Healthwatch Kirklees to create a process to measure the experiences of bereaved people

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Embedding the Charter within Care Homes across Kirklees, capturing the impact on quality of care

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Reviewing key outcome measures across The Partnership in order to understand which groups or demographics may be under-served

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A training needs analysis for health and social care staff

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A review of Advance Care planning processes across organisations

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## Conclusions

The way that people are cared for at the end of their life is as important as how they are cared for at the beginning of their life. It has a lasting legacy for those who live on, and a significant impact on the use of resources across the entire health and social care system

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We should celebrate what we have in Kirklees as it compares very favourably to other areas in West Yorkshire and beyond

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People in Kirklees benefit from a more comprehensive range of hospice services than exist elsewhere in West Yorkshire, alongside a strong partnership of providers working to improve the quality of care available to all

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The work of The Partnership has delivered a real impact, which we seek to protect and build upon. However, the progress that we have made is at risk if capacity cannot be maintained or developed

## Recommendations

We have opportunities to improve and the right structure and mechanisms to do so through The Partnership and the Kirklees Palliative and End of Life Care Programme (Programme).

### **The committee are asked to:**

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Note the details of the current approach provided within this paper

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Consider their influence on the future areas of work

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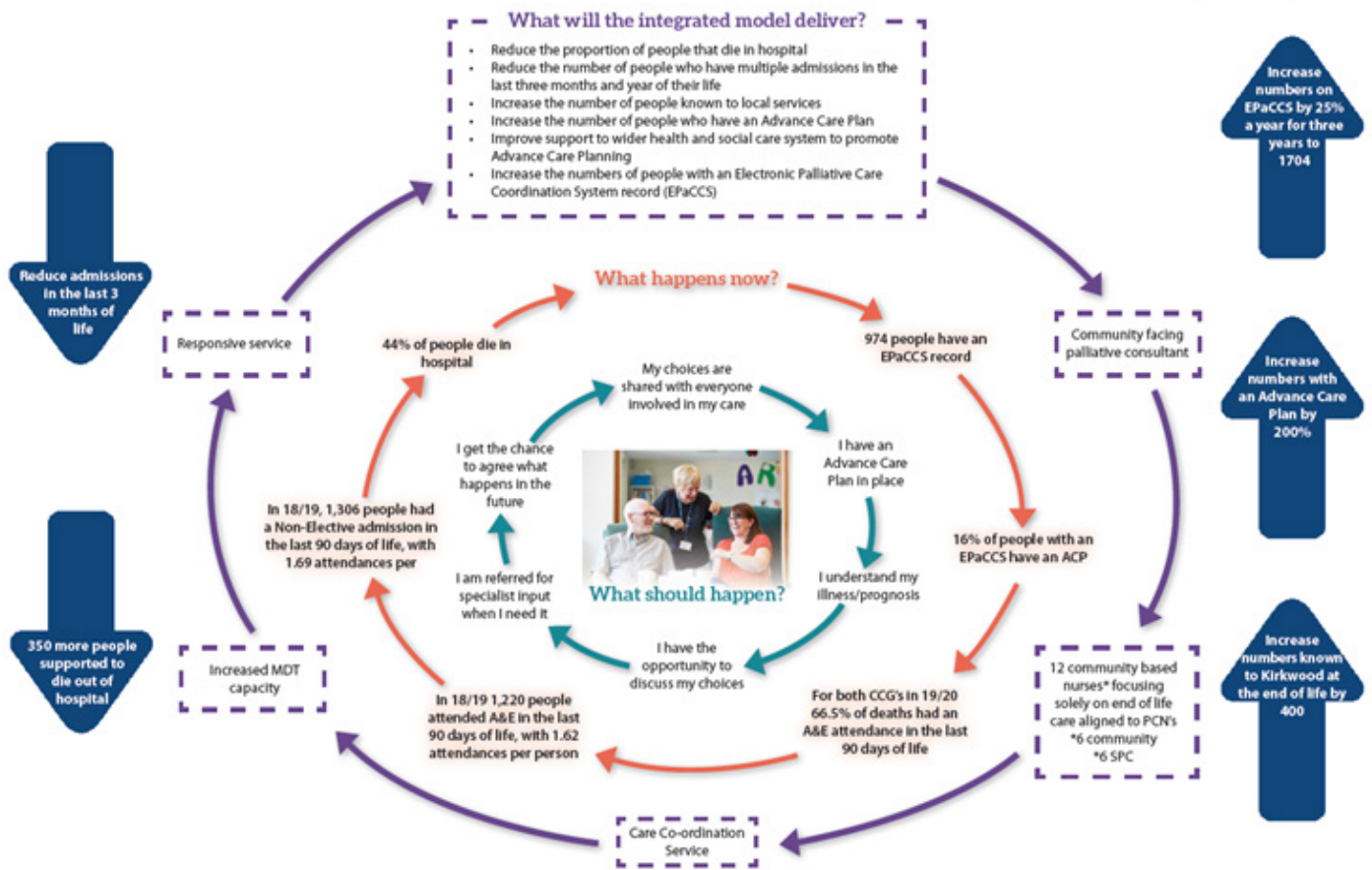
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Advocate that dying well is as important as starting well, living well and ageing well

# Appendices

Proposed Future Service Development model, developed by The Partnership



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## I live in a community that is prepared to help

My community recognises that we all have a role to play in supporting each other in times of crisis and loss.





## Appendix 3

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### Services available for people at the end of life in Kirklees

#### GP Practices

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Locala – Community Nursing and Therapies – Care Closer to Home

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Calderdale & Huddersfield NHS Foundation Trust – In-Patient Care

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Mid Yorkshire Hospitals NHS Trust – In-Patient Care

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Mid Yorkshire Hospitals NHS Trust & The Kirkwood in partnership –  
Rosewood Day Support and Therapy Services

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The Kirkwood – In-Patient Care

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The Kirkwood – Community Specialist Palliative Care inc. Dementia and Care  
Home Nurse Specialists

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The Kirkwood – Support & Therapy Services

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The Kirkwood – Counselling and Spiritual Care Services

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Kirklees Council Adult Social Care

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Continuing Health Care ‘Fast Track’ Gome Care – Delivered by Marie Curie

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Marie Curie – Planned Variable Night Sitting Service

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Kirklees Integrated Community Equipment Service – currently provided by  
Medequip

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Care Support Service – current provided by the Carer’s Trust

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Local Care Direct

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Yorkshire Ambulance Service – 111 WYUC

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Yorkshire Ambulance Service – 999

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Yorkshire Ambulance Service – Patient Transport Service

## Appendix 4

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### Key Terms

End of life care also spans organisations across health and social care as someone with a life limiting condition may come into contact with a variety of organisations across a period of time. This may create further complexity.

GP practices play a key role in identifying that their patients may be within the last year of life. GPs can then decide to add people to a **Palliative Care Register** (also known as a **QOF record**), which is a practice held list of patients. Some, but not all of patients will also have an **EPaCCS (Electronic Palliative and Care Co-ordination System)** record created.

EPaCCS is the electronic shared template which ensures people with a palliative care condition have key information recorded in one place, including their wishes for care (and whether they wish to be resuscitated)

EPaCCS also captures whether an **Advance Care Plan** is in place. Not all patients with an EPaCCS will have an Advance Care Planning discussion.

Advance care planning (ACP) is the term used to describe the conversation between people, their families and carers and those looking after them about their future wishes and priorities for care.

**ReSPECT** is a process that creates individualised recommendations for a person's clinical care in emergency situations, including cardiorespiratory arrest. It is a patient held document.

## Appendix 5

Good End of Life care has significant benefits in terms of quality of life for patients and those important to them <sup>1</sup>

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Earlier identification improves outcomes for people at the end of life <sup>2</sup>

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### Key References

Given the choice, a majority of people would prefer to die at home <sup>3</sup>

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People are less likely to experience good quality of care in hospital <sup>4</sup>

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The overall cost of care is understood to be lower outside of hospital settings <sup>5</sup>

Hospice UK (2021). Equality in hospice and end of life care: challenges and change. London: Hospice UK

Barratt H, Asaria M, Sheringham J, Stone P, Raine R, Cookson R. Dying in hospital: socioeconomic inequality trends in England. J Health Serv Res Policy. 2017

<sup>1</sup> Zimmerman et al (2008)

<sup>2</sup> Dying Matters 2015

<sup>3</sup> For example Natcen Social Research (2017)

<sup>4</sup> National Palliative and End of Life Care Partnership (2015 and Health Service Ombudsman 2015

<sup>5</sup> Public Health England - Cost-effective commissioning of end of life care 2017

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