Renfrewshire Health & Social Care Partnership

NHS Greater Glasgow and Clyde

Palliative and End of Life Care Strategy: 2022 - 2025

Contents

1. Introduction to Our Strategy

1.1 Background

This three-year strategy sets out the vision and future direction for palliative and end of life care in Renfrewshire. It has been developed as the area emerges from the Covid-19 pandemic where Scotland as a whole is witnessing a growing need for palliative care alongside a rising number of people choosing to die at home. The pandemic accelerated these trends, but even as the death toll from COVID-19 recedes, the impact from it and these changes will remain for years to come.

There is a growing recognition in government and national policy organisations that palliative care, end of life care and bereavement support requires investment, a more visible infrastructure and support for local areas to grow and develop in a more sustainable way. Throughout the pandemic, many organisations in Renfrewshire stepped up to provide vital palliative and end of life support to the NHS and work collaboratively with community health and social care services to reach people in need. This model of joined-up working, with hospices and others as equal partners in the system, sets the tone in Renfrewshire for the way forward and builds on an excellent foundation of person–centred care and services.

This strategy describes how we will endeavour to improve the quality of life of patients and their families in Renfrewshire who are living and dealing with a life limiting illness, ensuring everyone receives person centred, dignified and compassionate care and individual choices are respected.

It has been developed with the national priorities in mind and is complementary to Renfrewshire Health and Social Care Partnership's Strategic Plan 2022 – 2025.

'You matter because you are you. You matter to the last moment of your life and we will do all we can, not only to help you die peacefully, but also live until you die'
Dame Cicely Saunders

1.2 Developing Our Strategy

This strategy has been developed through extensive collaborative and partnership engagement involving service users, carers, staff, providers and partners. The visual below demonstrates the breadth of involvement in determining the content for the plan.

We have also considered the evidence base locally, nationally and beyond to inform our thinking as well as considering feed-back from those people who have used services and their families.

We have considered data on need, met and unmet. We have looked at local and national research depicting future likely need and demand and have focussed our strategy to support that demand as much as possible. We continue to seek and use feedback from people and their families as a key indicator of the quality of our services and to focus areas of improvement.

We will work to agree a set of measures that allows us to demonstrate impact across the life of this strategy.

1.3 Definition of Palliative and End of Life Care

The Scottish Government adopted the World Health Organisation (WHO) definition for palliative care in its Strategic Framework for Action on Palliative and End of life Care:

> *"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."*

When we refer to palliative and end of life care within this document, we are describing the care provided to people whose health is declining and whose lives are coming to an inevitable close.

Palliative care is treatment, care and support for people with a life-limiting illness, and their family, friends and carers. Its aim is to help people in these circumstances to have the best possible quality of life. Palliative care can be provided at any stage of illness. Therefore, the length of time people receive care can vary from days and weeks to several years.

Palliative care can be provided by both generalist professionals and specialist palliative care professionals. Generalist palliative care is provided to patients / clients / service users and families by all point of care health and social care professionals in a variety of settings. Specialist palliative care is provided to people with more complex palliative care needs by specially trained teams who are generally based in a hospice, a specialist palliative care unit or as part of a hospital palliative care team.

Specialist palliative care professionals provide care and support direct to patients / clients / service users and also provide support and advice to other health professionals like GPs, hospital clinical teams, district nurses, to name a few. They provide education to general teams and often initiate research or quality improvement projects that allow the continual development and improvement of palliative care and services.

End of life care provides treatment, care and support for people who are nearing the end of their life. It aims to help people to live as comfortably as possible in the time that they have left. This care can involve managing physical symptoms and providing emotional support for everyone involved. A major part of end of life care is discussing the future, ensuring people's needs and wishes are considered and reflected in the care that they receive.

Palliative and end of life care, regardless of type, should be available to anyone in Renfrewshire with a life-limiting or chronic illness regardless of age, culture, background, belief or location. This strategy focuses on the delivery of that aim by describing specific, measurable actions that will be taken.

Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. The World Health Organisation's (WHO) definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.

- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

> *'Palliative care for children and young people is an active and total approach to care, from the point of diagnosis, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the whole family. It includes the management of distressing symptoms, provision of short breaks, and care at the end of life and bereavement support.'*
>
> *Together for Short Lives*

2. Our Vision

2.1 The national position

We support the national ambition that describes a future where all people, their families and carers, living with a life limiting illness, have the support they need to live the best possible life and to experience the best possible death.

Renfrewshire Health and Social Care Partnership's (HSCP) strategic vision reflects the intentions of the Scottish Government's Strategic Framework for Action on Palliative and End of Life Care as well as those of the Scottish Partnership for Palliative Care. The ambition being to ensure that everyone in Renfrewshire who needs palliative care will have access to it regardless of age, diagnosis or circumstance and that the care provided will be safe, effective, person-centred and person led.

Our aim was to achieve this by 2021 however the impact of the pandemic in 2020 and beyond delayed progress in some areas of agreed development. This did however allow a greater focus on other areas including palliative support in the community and in care homes where a number of new and emerging services have shown great success for people and their families. Renfrewshire has a way to go to deliver on the aim stated above but research currently underway will help us to accurately measure impact, unmet need and will support actions that reduce the gap further.

A new National Strategy and Action Plan for Palliative Care is expected to be published by Scottish Government in late 2022. The Strategy for Renfrewshire will be reviewed and adjusted, where appropriate, to ensure alignment with a national vision and supporting objectives.

2.2 Everyone's business

Renfrewshire will be a place where people live and die well.

We shall support and enable communities and individuals to help each other through declining health and ensure the best supportive care throughout their illness and end of life.

We will harness the compassion and capability in our population to support our aim.

We shall continue to care for their families and carers into bereavement.

We recognise this is a population-wide aim and will address it as such. The Compassionate Communities Programme piloted across Scotland is one example of an approach aimed at harnessing support across entire communities.

2.3 **Support for health and care staff**

Our staff and volunteers will have reliable access to appropriate palliative care education and training and to the emotional wellbeing support that they need.

Staff delivering care will be supported via learning and education opportunities to understand how best to make a significant difference to a person's wellbeing, even in the last months, weeks, days and hours of that person's life.

Maintaining staff wellbeing and providing emotional support will be a key priority.

We will work with partners across all sectors to understand needs and agree and develop the delivery mechanisms and capacity.

We recognise that this is a key area for increasing staff confidence, competence and wellbeing which will in turn support the delivery of high-quality care to those we serve.

3. Our Priorities

3.1 In Renfrewshire we will continue to build the evidence base for quality of care and service planning, commissioning, and delivery. This will involve continuing to collect, analyse and report on data that shows current activity and we will complete research that helps us to understand the access to services that people need in that last year of life. We will commission a system-wide palliative care needs assessment during the life of this strategy that will allow us to evolve and improve in response to need.

3.2 In Renfrewshire, we aim to introduce a process and tools across GP practices that will support early identification and assessment of people who would benefit from a palliative approach to care. This will ensure those identified will have the opportunity to have a holistic needs assessment with a support/care plan. Support can then be delivered in various ways depending on the needs of the individual and drawing on the wide variety of services across the Partnership.

3.3 We will work to develop, roll out and sustain an integrated community palliative care Multi-Disciplinary Team for people who would benefit from care coordination.

3.4 We will reflect on the recent pandemic and beyond to help us understand the demand and need for different types of bereavement support. We will make sure this informs service planning and commissioning. We will work in partnership with current and new providers of bereavement support to widen access and increase choice in Bereavement Care Service available for adults and children/young people in Renfrewshire. This will ensure Bereavement Services are offered on an equitable basis across the area regardless of age, faith, belief or the location of death of the loved one.

3.5 We will ensure that people and their families and carers have timely and focused conversations with appropriately skilled professionals to capture their goals and wishes, plan their care and agree the support they may need toward the end of life.
As reflected in our strategic plan priority activities, we will aim to achieve year on year increases in our use of anticipatory care plans. The National Anticipatory Care Planning tool, and local adaptations, will be used to support this process and capture people's needs and preferences, but whatever format is used it must be able to be shared across services with the permission of the person it relates too.
http://ihub.scot/anticipatory-care-planning-toolkit/

3.6 We will work to understand options that are available to improve the accessibility of patient / client / service user information tohealth and care teams, currently impeded by the barriers between sectors and organisations. This will enable care planning needs and wishes to be understood and transitions of care to be seamless for people through the palliative period and towards the end of their lives.

3.7 At the end of this strategy, we will have a clear framework for the health and social care workforce that promotes person-centred discussions with people and families, and which identifies and plans for resources to be available to support choice.

3.8 We will agree and deliver an educational and wellbeing plan that supports all staff providing palliative and end of life care in Renfrewshire.

3.9 The HSCP's Palliative Care Plan will not be used in isolation but as part of a suite of material aimed at engaging people in their care and improving quality of life and wellbeing. This includes for example:

- Scottish Government's third Dementia Strategy which is expected to be updated in 2022 (http://www.gov.scot/Publications/2017/06/7735/downloads)
- Realising Realistic Medicine (http://www.gov.scot/Resource/0051/00514513.pdf)
- The Carers Act 2016 (http://www.legislation.gov.uk/asp/2016/9/contents/enacted)

- HSCP's Carer Strategy www.renfrewshire.hscp.scot/CarersStrategy .
- NHS Recovery Plan 2021-2026 NHS recovery plan - gov.scot (www.gov.scot)

3.10 The Palliative and End of Life Care Plan will align with the aims set out in the Scottish Government's Health and Social Care Delivery Plan. In particular, with the aim that (originally planned by 2021) everyone who needs palliative end of life care will have access to care that meets their individual needs and that "all who would benefit from a Key Information Summary (KIS) will receive one". The plan also indicates that people will receive more sensitive end of life care with the aim of supporting them in the setting that they wish. These objectives remain hugely important five years on from the publication of the delivery plan.

Supporting and working with our colleagues in NHSGGC, charities and the independent sector to develop a framework for identifying and resourcing the needs of those with life shortening/limiting illness will be vital for success of the wider strategy.

3.11 Renfrewshire HSCP will aim to maximise impact on palliative and end of life care in Renfrewshire through the most effective use of our people and resources. This will support us to develop a coherent and connected approach to the provision of good palliative and end of life care by:

- Working with ACCORD and St Vincent's Hospices in the provision of care, using their specialist expertise to take forward new and innovative approaches to delivering palliative care in the community.
- Developing our relationship with charities and independent organisations in the planning and delivery of effective and sustainable service provision

By doing so, we will endeavour to meet patient preferences that may reduce the numbers of people who die in acute hospital settings and/or reduce the number of days people spend in hospital in the last 6 months of life.

4. Our Actions – "How will we do this?"

Several action areas have been identified to support delivery on our vision and aims for palliative and end of life care. The actions are detailed below and grouped into key themes:

4.1 Development of People That Support and Provide Palliative and End of Life Care

To improve outcomes for people who would benefit from a palliative approach to care we will work with our full workforce and our partners to identify learning and education needs. We will use the NHS Education Scotland National Palliative Care Educational Framework "Enriching and Improving Experience"

http://elearning.scot.nhs.uk:8080/intralibrary/open_virtual_file_path/i2564n4083939t/Palliative%20framework%20interactive_p2.pdf to achieve a consistent approach.

To do this we will:

Consider the education, training and support needs of families, carers and communities of people who need palliative care.

Aim to ensure they feel sufficiently enabled to provide the best possible support and care.

Understand the increased need for emotional support for families and carers following the pandemic.

Continue to support ACCORD Hospice and St Vincent's Hospice in delivering palliative and end of life care training to Health and Social Care staff who work in community settings. The scope of this will be widened with the utilisation of ECHO.

Consider the workforce and financial implications of meeting the increasing demand for palliative and end of life care in community settings, and work with partners to maximise resource utilisation while identifying future funding opportunities. This will need to link to the HSCP's Workforce Strategy 2022-25 and to the Scottish Government's National Health and Social Care Workforce Plan.

Consider the psychosocial and health impact on everyone who works with and supports the very ill, the dying and the bereaved on a daily basis and explore ways of supporting them, aiming to alleviate work related stress and increase their resilience. Ensure the increased emotional impact of the COVID-19 pandemic is considered and suitable support is provided through e.g.

- Clinical debrief sessions
- Clinical supervision
- Management supervision
- Utilising national and local health and wellbeing resources including the National Wellbeing Hub, NHS Inform for mental wellbeing and local support helplines and counselling services.

4.2 Establishing Our Palliative Care Planning Group Leadership and Governance

Renfrewshire HSCP has tasked us – the Palliative Care Planning Group - with implementing the Plan and ensuring implementation reflects an understanding of specific population needs in relation to palliative and end of life care.

We will:

Ensure the Renfrewshire Palliative Care Planning Group is representative of a full range of partners, including e.g. Improving the Cancer Journey (ICJ), Hospices, charities and private care providers, Health and Social Care staff across all services, and Carer services or organisations. We will bring the voice of the service user and their families into the group.

Ensure the outputs and outcomes from the group are able to influence the HSCP's Senior Management Team and Integrated Joint Board and are shared with the wider palliative care community via the HSCP's website and the NHSGGC palliative care website.

Continually review data sources and agree a suite of measures that can be used to determine the impact of the strategy over its three-year lifespan. This will include provision for ongoing monitoring and development of measures including new initiatives such as Excellence in Care.

Continue to be closely aligned with the wider Glasgow and Clyde Palliative Care Network which will provide a platform for shared communication and learning.

Continue to work with Scottish Government departments to share practice innovation and to refine reporting and feedback mechanisms to give greater clarity on the impact of good palliative care e.g.

- Emerging National Palliative Care network and new clinical lead once appointed.
- HIS frailty collaborative
- HIS collaborative testing approaches to meet Commitment 1 of the Strategic Framework for Action
- Working with NES to influence national approaches to Confirmation of Death

4.3 **Supporting Children and Young Adults**

We will:

Work in partnership with individuals and organisations to develop and implement reliable systems that allow the voices of children and young people to shape and influence care and service provision in Renfrewshire and to develop a more detailed understanding of the availability of palliative care services for them. This will complement the work undertaken for adult services. It will involve work with HSCP children's services staff, children's hospice representatives, paediatric/acute hospital services and charity and private care providers.

We will work to make clear the unmet need, if any, and will work to ensure babies, children and young people are offered in-house hospice care and CHAS at Home.

We will ensure that Family Support Teams provide emotional and practical support including during transition from children to adult services. The Activities Team offer therapeutic support to siblings pre- and post-bereavement.

4.4 Strengthening Collaborative Working to Improve People's Pathways Through Services

We will:

Outline the pathways between general and specialist palliative care and end of life care. We will ensure these are clearly communicated at a local level and understood by those requiring or delivering services.

Develop a greater understanding of the palliative care and palliative service needs of people with progressive terminal illnesses that shorten life like Motor Neurone Disease. We will then agree clearer pathways for people across Renfrewshire.

Develop our relationships with all partners in these pathways to ensure care delivery is seamless for the people we serve.

Aim to ensure effective and timely transitions between places of care with particular emphasis on the involvement of families and carers in planning care, and the provision of appropriate patient information at the point of discharge.

Improve collaborative and seamless ways of working between services by implementing more fluid means of sharing patient information, data and care plans. Aim to ensure this improves people's care pathways and helps to direct their treatment and care.

4.5 Enhancing and Embedding Anticipatory Care Planning

Anticipatory Care Planning (ACP) is a priority for all HSCPs.

We will:

Work with staff groups across all sectors to promote planning conversations that can be recorded in the most appropriate shareable format. This will support our strategic plan priority to achieve year on year increases in our use of Anticipatory Care Plans.

Work to embed Anticipatory Care approaches, using National ACP documentation where appropriate. We will ensure staff are equipped to take a holistic approach to facilitating conversations about an uncertain future, including:

- the potential benefits or side effects of various care and treatment options
- Concerns about social aspects of life i.e., isolation and loneliness
- Financial concerns
- 'Red Bag' scheme for care home residents

Work with primary care governance groups to enhance the quality of ACP and the number of people with an eKIS.

4.6 Understanding and Improving Peoples experience of Palliative and End of Life Care

We aim to ensure people's experiences inform and shape everything that we do including how we deliver, plan and shape services. We will establish, in collaboration with patients, carers and carer groups, an ongoing feedback mechanism that informs the HSCP about people's experiences and areas where further development might be required. This could include feedback on the care provided or the impact on family/carer wellbeing. Validated tools will be used where possible and direction will be sought from key national reports including 'Trees that Bend in the Wind report' by Scottish Care.

4.7 Public Health Approach to Palliative and End of Life Care

We will:

Continue to promote the wider public health messages around palliative care, with the HSCP and their partners supporting initiatives such as 'Big Conversation' and 'Palliative Care is Everyone's Business'.

Introduce the Compassionate Community model to maximise the capacity and capability of the people in Renfrewshire's communities that is available to support people to live and die well at the end of their lives.

Improve access to information for people requiring palliative care and their carers and families. This will include online and written information and will cover medical/clinical issues as well as non-medical issues such as Power of Attorney and financial advice.

Work within locality groups to ensure that service provision is equitable and consideration is given to identifying and engaging with harder to reach groups, including e.g. ethnic minorities, people with a learning disability and the homeless.

Renfrewshire aims to provide agreement on a common language used within palliative care to ensure all staff within all partner organisations, patients and their families are clear what we mean when palliative and end of life care discussions occur. This will be supported by means of written material.

4.8 Ensuring Best Practice and Quality Service Provision

We will:

Work in partnership with Equipu to monitor the provision of equipment to people with palliative care needs. This will include:

- the identification of commonly used equipment
- the planning of future provision

- the ongoing review of service response particularly to those who require items urgently.

Explore advances in telecare and telehealth for people with palliative and end of life care needs to enhance monitoring and safety within the community environment.

Continue work and development within Local Authority and private provider Care Homes with the implementation of the Supportive Palliative Action Register. This will allow Care Homes to identify residents who are deteriorating and to be supported to assess and manage their care appropriately.

Continue to roll out and engage with GP Practices to identify patients who have palliative care needs. The aim is to provide access to all to the Community Palliative and supportive care MDT to ensure all who would benefit from care coordination have access to it.

Work towards ensuring best practice around the prescribing, administering and prompting of medications used in palliative and end of life care in all care settings.

Continue to learn and build on innovative new ways of working which have been implemented in and around palliative and end of life care services during the pandemic. This includes utilising more flexible, community-based working to provide people with care in the settings most comfortable to them.

Continue to develop and utilise enhanced digital capabilities for communication and education purposes.

5. Reflecting on People's Experiences – ***to be developed as part of consultation and engagement exercise***

Appendix 1: Our Year One 2022-2023 Action Plan

This action plan identifies specific high level action areas that will support the delivery of the Palliative and End of Life Care Strategy and our vision for Renfrewshire. The Palliative Care Planning Group will be responsible for ensuring these are delivered upon. The plan will be formally reviewed and updated twice per year for the duration of the strategy. The detailed year one actions will help to inform priority actions for years two and three.

Theme	Year 1 Action	To inform years 2 and 3
Development of People that support and provide Palliative and End of Life Care	Continue to identify the education, training and support needs of our workforce, including appropriate sufficient health and wellbeing support, building on the significant work already completed.	Identified gaps from year 1 to inform workforce implications and commissioning needs.
Establishing Leadership and Governance of our Palliative Care Planning Group	Continue to review and enhance the governance structure of the Palliative Care Planning Group. Ensuring appropriate representation of partners, service users and families. Include the voices of children and young people.	Frequent review of the CPG and its impact. Evidence of service user input influencing service provision and planning.
	Implement the Palliative and End of Life Care Strategy and action plan.	Informing a longer-term year 2 and 3 workplan to be developed in 2023.
Identifying Best Practice and Learning to Improve People's Pathways Through Services	Map existing palliative care pathways in Renfrewshire to establish and understand what is currently in place, including the following: • Consider the efficiency of respite beds for patients and carers living and dealing with a life limiting illness. • Look to identify and evaluate health inequalities prevalent in Renfrewshire, and related disparities in access to our services. • Continue to roll out and engage with GP Practices to identify patients who have palliative care needs.	Develop our pathways based on the mapping exercise completed in year 1.

	Complete a needs analysis desktop exercise to ascertain existing issues and gaps in access and provision of people's needs. This will help to inform people's preferences to care and provide a shared understanding of equalities. Include current provision of Palliative Care for children in Renfrewshire.	Year 1 analysis will help to inform specific areas of work to resolve existing issues and gaps in access and provision.
Understanding and Improving People's Experience of Palliative and End of Life Care	Establish an ongoing feedback mechanism that informs the HSCP about people's experiences and areas where further development may be required.	
Public Health Approach to Palliative and End of Life Care	Introduce the Compassionate Community model to maximise the capacity and capability of the people in Renfrewshire's communities that is available to support people to live and die well at the end of their lives.	
		Utilise the year 1 work around pathways and feedback mechanisms to inform the improvement of access to information for people requiring palliative care and their carers and families. This will include online and written information and will cover medical/clinical issues as well as non-medical issues such as Power of Attorney and financial.
	Aim to provide agreement on a common language used within Palliative Care to ensure all staff within partner organisations, patients and their families are clear what we mean when palliative and end of life care discussions occur.	
Enhancing and Embedding Anticipatory Care Planning	Continue to work with staff groups to promote planning conversations that can be recorded in a shareable format, supported by staff attending training to have the competence and skills to have sensitive discussions with patients.	

	Identify and develop a mechanism for recording and measuring the quality and impact of Anticipatory Care Planning.	Improved recording and measuring to inform the quality of ACP and areas for potential improvement.
	Continue to work with Primary Care governance groups to enhance the quality of Anticipatory Care Planning and increase the number of people with an eKIS.	