

Corporate communications

nhsfife.org  facebook.com/nhsfife  twitter.com/nhsfife

 instagram.com/nhsfife  linkedin.com/company/nhsfife



Special Update | 19 May 2023

Special Elected Members Update for local MPs, MSPs and Councillors

This update is part of our ongoing commitment to keep elected members informed of the latest developments at NHS Fife that may be of interest to you and your constituents. We would also encourage you to regularly visit and refer your constituents for the latest news and updates from NHS Fife on our [website](#): or follow us on our social media channels.

ENGAGEMENT ACTIVITY - PALLIATIVE CARE IN FIFE

NHS Fife and the Fife Health and Social Care Partnership have re-designed the way that specialist palliative care services are delivered, with a focus on providing more specialist, multidisciplinary care in the community. This means moving away from the inpatient-focused model employed for more than 20 years and increasing community support, enabling greater patient and family choice and supporting many more people to receive end of life care at home, or close to home.

There have been no cuts or changes to the service's resources, with all changes being undertaken to extend and enhance palliative and end-of-life care for the people of Fife.

The proposed model for the future has been developed alongside a comprehensive and extensive programme of engagement carried out prior to, during and after the COVID-19 pandemic with patients, family members and the members of the Fife local public participation networks. The proposals, which have been developed by our specialist palliative care clinicians, have been rigorously tested for more than three years.

This briefing has been produced in response to feedback from our elected members and councillors to outline the extensive programme and reach of our engagement activity that has been integral in shaping our proposals.

This document follows an [earlier briefing](#) provided to elected members on 05 May 2023 on the proposed new model of specialist palliative care in Fife.

1. BACKGROUND

- The [Future of Hospice Care in Scotland](#) document describes hospice care as an ethos, rather than something that takes place in a specific building.
- *The intelligence garnered through our engagement, coupled with wide-ranging feedback from patients, families, and professional partner colleagues, has helped shape the way that palliative and end-of-life care has been delivered in Fife over the last three years.*
- *This work to extend access was accelerated by the pandemic and has been tested over the course of the last three years. Within the new model, many more patients and families can receive hands-on specialist palliative care than was possible previously.*

Prior to the start of the pandemic, it was acknowledged across Scotland that it was necessary to extend palliative care access to greater numbers of those living with life-limiting conditions.

Published in 2015, the Scottish Government's [Strategic Framework for Action on Palliative and End of Life Care](#) stated that everyone in Scotland who required palliative care should have access to it. The [Future of Hospice Care in Scotland](#) document (Hospice UK 2021) describes hospice care as an ethos, rather than something that takes place in a specific building. It further states that the majority (81%) of hospice care is delivered to people at home or in the community.

In response to the [Strategic Framework for Action on Palliative and End of Life Care](#), the Fife Specialist Palliative Care Service commissioned an independently funded service review, which took place throughout 2018 and 2019 by Macmillan Cancer Support.

The commissioning of this independent review demonstrates our commitment to engagement from the outset of our improvement programme; ensuring that we incorporated extensive engagement with patients, families, clinical staff and delivery partners as we evolved and developed our plans. The independent review was concluded in 2019, with engagement activities continuing to date and playing an integral role in informing ongoing service development and delivery.

As the COVID-19 pandemic hit in March 2020, the intelligence garnered from the review coupled with wide-ranging feedback from patients, families, and professional partner colleagues, played a vital part in helping shape changes to the way that specialist and generalist palliative and end-of-life care was delivered in Fife. The work to extend access to specialist palliative care in Fife in all care and residential settings was accelerated by the pandemic and the need to keep vulnerable people safe.

These changes have been tested over the course of the last three years and have enabled the service to care for more than three times the numbers of patients and families than was possible previously. The Fife Specialist Palliative Care Service is now far better able to meet the needs of the population, and better placed to respond to the growing numbers of people likely to require specialist palliative care in the coming years.

2. PLANNING PLAN WITH PEOPLE

NHS Boards and Integration Joint Boards have a statutory duty to involve people and communities in the planning and development of care services, and in decisions that will significantly affect how services are run. - Scottish Government – Planning with People, February 2023

Engaging with, and involving people is an integral part in the design and delivery of our services. People are routinely asked for their views, via a range of established networks and forums about their experience of services, that help to contribute to and inform staff training and service development.

The key national policy drivers make it clear that we must embed engagement as good practice in all that we do. By inviting the views and opinions of patients, service users, carers, stakeholders and local people, organisational decision making is then better informed.

Our Community Engagement Commitment

Effective services must be designed with and for people and communities – not delivered, top down for administrative convenience. In order to be effective, community engagement must be relevant, meaningful and have a clearly defined focus. NHS Fife and the Fife Integration Joint Board follow the principles set out in the [National Standards for Community Engagement](#).

Our sustained and comprehensive programme of community engagement in relation to the specialist palliative care service has followed a purposeful process that over the past three years has developed a strong working relationship between patients, their families, community groups, clinicians, and stakeholders to help us identify and act on community needs and ambitions for specialist palliative care.

This comprehensive programme has included qualitative as well as quantitative research and ensuring a respectful dialogue between everyone involved, aimed at improving understanding between them, and taking joint action to achieve positive change based on user need, expectations, and clinical best practice.

3. PROGRAMME OF ENGAGEMENT

- **A variety of methods have been used to help us capture what matters most to patients and their families in the final months, weeks, and days of life; and what kind of care and support benefits them the most.**
- **At the same time, we have taken learning from the experience of clinical staff and partners delivering hands-on generalist palliative and end-of-life care to people across Fife 365 days a year.**

The proposals for the future delivery of specialist palliative care have been shaped by an extensive programme of engagement with a range of individuals and groups. This process began formally in 2018 and continues to the present.

A wide range of methods have been employed with the aim of capturing the key themes and developments that matter most to patients and their families, whilst at the same time taking the views of clinical staff and partners to help us deliver on these.

The methods of engagement have included:

- Face-to-face interviews with patients, families, and carers with lived experience of receiving palliative and end-of-life care
- Surveys with clinicians involved in the day-to-day delivery of palliative and end-of-life care, such as GPs and district nurses.
- Presentations by our senior clinicians with follow-up discussion sessions to evaluate the ways in which care is delivered. The audiences have included our public engagement network, the Integration Joint Board and NHS Fife's Executive Directors Group.
- Stakeholder Engagement Sessions with clinicians in the acute hospital, local GP groups, district nurses, care, and nursing home managers, IJB and EDG as well as with specialist palliative care staff.
- Group discussions using through Fife's local public engagement networks.
- Academic research – Fife's Specialist Palliative Care Service has led a research study looking at the reality of being cared for at home at the end of life, and of caring for a family member. This has involved in-depth interviews with people nearing the end of life, their families, and carers, including those who have experienced a bereavement. The themes which have emerged from this academic work are helping inform the model of care for palliative care patients in Fife and their families.
- Online meetings with Scottish Care, Scottish Ambulance Service and Macmillan Cancer Support.

4. TIMELINE

The timeline below summarises our engagement programme that has directly contributed to our proposed model. This engagement has involved patients, carers, public engagement networks, health and social care staff using a range of channels to gather feedback and based on national guidance and clinical best practice.

2015/16

- **Publication of the Scottish Government's *Strategic Framework for Action on Palliative and End of Life Care*** – with the national ambition that everyone in Scotland who require palliative care should have access to it by 2021.
- **Publication of the NHS Fife's Clinical Strategy** – this echoed the above aim with a clear goal of providing 24/7 accessible generalist and specialist palliative care for the entire Fife population.
- **Programme of qualitative interviews** – a series of in-depth interviews with patients and families with experience of palliative care to look at the future priorities and inform service developments.

2018/19

- **Macmillan Service Review** – Macmillan Cancer Support carry out an independent review of Fife’s Specialist Palliative Care Service, with a view to expanding provision to make it available to all of those in Fife who need it. The review incorporated engagement with in excess of 500 individuals. The findings suggested that specialist palliative care in Fife needed to be more responsive to the needs of patients and families, available 7 days a week and with services more joined up across the specialist, community, and acute services. Importantly, the report reinforced that the needs of families and other unpaid carers were critical.

2020/ 21

- **Fife’s Palliative Care Collaborative established** - the collaborative brought together professionals from health, social care and third sector organisations to ensure a co-ordinated approach to palliative care delivery, designed to meet the evolving needs of people in Fife.
- **Fife-wide survey of GPs and district nurses** – GP’s and district nurses co-ordinate and deliver the majority of generalist palliative care provision in Fife and these surveys sought their views on how changes to palliative care delivery were impacting their patients and families. Feedback was overwhelmingly positive. Suggestions for further improvements, such as better informing patients and families about the District Nurse Palliative Care Helpline, have been actioned.
- **Engagement with Care Homes** – a series of engagement sessions were held with care home managers to look the care of palliative and end-of-life residents and explore how staff could be better supported by the specialist service. This included education, access to clinical advice and in-reach into homes to provide hands-on care. Multiple education sessions have been provided for staff working in care homes supporting people near the end of life. Fife Specialist Palliative Care is now contacted regularly by care home staff and their residents are able to receive clinical assessments and support from the specialist service’s outreach team, seven days a week.
- **Academic research** – funding was secured from the Fife Health Charity in 2020 to lead a research study exploring the reality of being cared for at the end of life at home, and the reality of being a caregiver for someone nearing the end of life at home. Alongside this, work with Public Health Scotland analysts demonstrated a shift of care at the end of life to the community, with many more people spending more time in their last months of life at home, and dying at home. This work was presented at a national NHS Scotland event in 2021.

2022/23

- **In-depth interviews conducted with people at the end of life and their families, in their own homes.** Interviews explored people’s experience of palliative care, what kind of care and support was most meaningful and where gaps in care were felt. The results of this study are being developed into recommendations for policy and practice; so that they can lead to real improvements to palliative care for people in Fife and beyond.
- **IJB Development Session** – three separate engagement sessions were held with members of Fife’s Integration Joint Board to provide a deep dive into the proposed model of specialist palliative care delivery, incorporating evaluation data which allowed comparisons to be

drawn between the historical model of care and the current model. IJB members were invited to critique the proposed model of care.

- **Hospice Garden Committee** – the Hospice Garden at Queen Margaret Hospital is renowned for its beauty and provides a calming outdoor space for patients and families alike. The garden is maintained by a hugely dedicated group of volunteers. Engagement was undertaken with the committee to discuss the proposed changed model of specialist palliative care delivery and the commitment to offer specialist care to all those who need it; also to ensure that the beautiful garden can continue to be enjoyed by patients and visitors at Queen Margaret Hospital.
- **Public Engagement Networks sessions** – a series of engagement sessions have been held with representatives of Fife’s many public engagement networks. This has allowed members of the public from across Fife to consider the proposed new extended model of specialist palliative care provision and the implications for patients, carers, and families.
- **Engagement with elected members**
MPs and MSPs – all MPs and MSPs in Fife were invited to take part in a deep-dive engagement session with NHS Fife’s Chief Executive, the Director of the Fife Health and Social Care Partnership and a senior consultant in Palliative Medicine. This session involved a detailed presentation and testimony from staff and a family member with lived experience of caring for their loved one at home. All attending elected members were invited to ask any questions about the proposed model and a briefing document was provided to all elected members in Fife following the session.
- **Engagement with key partners**
Engagements sessions also took place with a number of other key partners in the delivery of palliative care in Fife. This included the Scottish Ambulance Service, Scottish Care, Macmillan Cancer Support and Marie Curie.

5. ENGAGEMENT INFORMING THE CLINICAL MODEL

The extensive engagement carried out with patients, families, local clinicians, and other stakeholders prior, during and after the COVID-19 pandemic has shaped the current delivery model of specialist palliative care in Fife, and the proposed model of care for the future.

Engagement with patients, carers and the wider public

The lived experience of those who have received palliative and end-of-life care, along with their families and other loved ones, has been crucial in developing a model of care that is truly person-centred and responsive to the changing preferences and needs of patients.

In-depth interviews with patients and families have ensured that their lived experiences are heard, and that they are informing recommendations for policy and practice. These interviews have encompassed all aspects of the care and support and have specifically sought to identify those areas where care and support could be improved. Through this research, people in Fife have told us that what matters to them in relation to their palliative care is:

- **Person-centered care** – a personal experience of care where the care that is offered matches each person’s own goals and priorities.

- Access to care – to be cared for, and enabled to die, in the place of their choice, often in their own homes or close to home and family, but also in hospice where this is needed
- Equal access to palliative care for people with non-cancer conditions
- Their families and carers will receive support during their illness and when they die and following a bereavement.
- Holistic care – optimal symptom control with psychological, social, and spiritual support
- To be treated as individuals, with dignity and respect, and to have their voices heard in decisions about their treatment and care
- Sensitive face-to-face communication
- High quality and well-coordinated care, which is responsive to their changing needs, including in the out of hours period, seven days a week.

The themes outlined above have become the cornerstones around which the proposed future model of specialist palliative care delivery in Fife has been built upon.

Local Participation and Engagement Networks

Fife has a well-established network of public engagement groups made up of local people across Fife committed to helping feedback and improve public services in the Kingdom.

Earlier this year, members of Fife’s public engagement networks were invited to take part in a series of engagement events to learn more about the proposed model of specialist palliative care delivery in Fife, consider the impact of the new model for patients and carers and provide comment and critique on the proposals.

Through Fife’s public engagement networks, around 5,000 people in Fife were invited to take part in the sessions. The intention was to capture feedback from all parts of Fife, including via our seven localities and across all age ranges and demographics, as well as the views of minorities and other hard-for-us to reach groups.

The following organisations and groups were invited to participate:

- | | |
|------------------------------|---------------------------|
| ▪ Fife Council Peoples Panel | ▪ Fife Carers’ Centre |
| ▪ NHS Fife Virtual Panel | ▪ Fife Voluntary Action |
| ▪ Fife Centre for Equalities | ▪ Fife Independent Sector |
| ▪ Fife International Forum | |

In order to adhere to Covid restrictions and to help make the engagement sessions as accessible as possible, these were held online and took place on a variety of dates and times of date. A further face-to-face session was held for those unable to take part in or access the online sessions.

Stakeholder Engagement Activity

The vast majority of palliative care in Fife is not delivered in a hospice setting by our Specialist Palliative Care Service and is provided by generalist clinicians like our GPs and district nurses, along with those working to care for patients in our community hospitals and care homes.

The feedback received from palliative care generalists delivering hands-on palliative care on a daily basis through their lived and clinical experience has been vital in helping to design a model of care; which not only places the patients and their wishes at the centre of service planning, but also enables the service to better meet the current and future palliative care needs of people in Fife, whilst adhering to best clinical practice

Through this extensive engagement with our stakeholders, this feedback and critical peer appraisal has helped us better capture and understand the wishes of patients and carers, who are in constant dialogue and providing real time feedback to those delivering the majority palliative and end-of-life care in Fife. In addition to their clinical roles, crucial stakeholders like our GPs and district nurses have acted very much as patient advocates, relaying the themes they hear from palliative care patients and family members each and every day.

The table below outlines the key formal stakeholder engagement work carried out to date:

	2018	2019	2020	2021	2022	2023
Macmillan Service Review						
Stakeholder Engagement Sessions						
Acute Team Engagement Session						
Palliative Care Collaborative						
GP Cluster Group Meetings						
GP and District Nurse Survey						
Community Care Roadshows						
Mixed Method Research						
Palliative Care Helpline Feedback						
Palliative Care Conference						
Presentation - Governance Lead and Care Home Managers						
HSCP Byte Size Session						
GP Lunchtime education session						
Out of Hours GP session						
District Nurses lunchtime session						
NHS Fife Grand Round						
Care Home Education Sessions						
Nursing Home Education Sessions						
IJB Development Session						
Acute Senior Leadership Team						
Executive Directors Group						
Quality & Communities Committee						
Finance, Performance & Scrutiny						
FSPCS Staff Engagement Session						
Meeting - Scottish Care						
Meetings – Scottish Ambulance Service and Macmillan						
QMH Hospice Garden Committee						
Urgent Care/Flow & Navigation						
Patient Experience re Volunteers						
Spiritual Care						
Carers Representative Meeting						

MP/MSP Briefing						
On-line public engagement						
Face to Face Public Engagement						
IJB Drop-In sessions						
H&SC Forum, Fife Voluntary Action						
Engagement with local and national media						

Establishment of the Palliative Care Collaborative

Engagement has been at the forefront of the developments around specialist palliative care delivery, and indeed palliative care more widely. These developments have been overseen by the Palliative Care Collaborative – an integrated forum leading and informing the revised service planning, education delivery and the rapid production of new clinical guidelines and pathways.

The Palliative Care Collaborative brings together professionals from a range of areas to help ensure a co-ordinated approach to palliative care delivery, designed to meet the evolving needs of people in Fife. There are representations within the group from the following specialities and agencies: -

- Specialist Palliative Care Service
- General Practice
- Hospital@Home
- Urgent Care Services
- Community Nursing
- Local care homes
- Marie Curie
- Spiritual Care
- Pharmacy
- Acute Services

The Collaborative helps to support and assure safe, effective, patient-centred, and sustainable palliative care services for the population of Fife.

6. CRITICAL AND CONSTRUCTIVE FEEDBACK

The Fife Specialist Palliative Care Service, and the wider Palliative Care Collaborative, has consistently been open to hearing diverse opinions, concerns and indeed criticism. Throughout this sustained period of engagement, we have been committed to learning from feedback and to addressing it in a timely manner.

Feedback from patients, families and our colleagues has helped us to make meaningful refinements to palliative care delivery across Fife. Throughout this intensive programme of engagement, we have been able to respond to and address a range of concerns. Some recent examples have included:-

- **Query regarding additional travel for families visiting loved ones in Kirkcaldy** – the primary focus of the proposed model is to ensure the specialist palliative and end-of-life care is centred on the needs and preferences of patients and their loved ones. There has been a significant drive to take specialist care to where patients are, rather than take patients away from their home to where the specialist care happens to be. Crucially, the vast majority of patients receiving inpatient palliative care are not in the hospice, and are in general wards within our acute and community hospitals. The development of our

outreach model enables a greater number of patients to be cared for at home rather than in hospital (a reduction of >3,000 hospital bed days in the last three months of life for people who died during 2021), making visits from loved ones much easier and reducing the amount of travel necessary.

- **Query about choice and whether patients and families in Fife have to commit to palliative care either at home or in an inpatient setting** – a core part of palliative care is having discussions with patients and families about their preferences for care, including care location. It is understood that people’s preferences commonly change over time and also that patients and their families may have different preferences and needs. Fife Specialist Palliative Care is now better able than ever before to flex their care offer as people’s preferences change. Often this happens at short notice, requiring an ‘on the day’ shift from home to hospice or hospital, or inpatient setting to home. With a specialist team that now works across all care and residential settings, 7 days a week, people in Fife now have more choices about where they receive their palliative care than ever before.
- **Query regarding what would happen if the hospice was full** – there are times when the inpatient hospice beds are full, as there was previously under the old model. Encouragingly though, under the current setup means that hospice bed availability in Fife is better than it ever has been, with our waiting list time more than halved (from mean of 3.4 days to 1.4 days). We continue to work with our acute and community colleagues to admit to non-acute beds in community hospitals for those who do not have acute clinical needs but who cannot be safely cared for at home. The development of the outreach model means the service can now provide essential care and clinical assessments for patients at home until a hospice bed becomes available, which was not the case previously.
- **Query about the possibility of making outreach available as a 24 hour service** – the establishment of the Fife District Nursing Palliative Care Helpline means that expert clinical advice is available 24 hours a day, 7 days a week, bypassing the need to call NHS 24. The helpline has received in excess of 12,000 calls since April 2020, with 85% of people registered with the line supported to die at home. With our current model of care, we can now offer clinical assessments in the community from specialist clinicians 7 days a week (previously just on weekdays) and we can provide support with essential care in the community 7 days a week (a service that did not previously exist) 8am to 8pm. We also work very closely with Marie Curie and the out-of-hours district nursing service to ensure there is cover in the community 24 hours a day, 7 days a week to rapidly respond to any changes in a patient’s condition. Fife Specialist Palliative Care offers specialist advice overnight via their on-call medical rota.
- **Query about capacity to provide personal care for patients near the end of life** – through the development of the new model, an Essential Care Service was established which did not exist under the previous ways of working. Staff within the Essential Care Service work closely with District Nurses and with the social work End of Life Care Team and can sometimes supplement their visits and flex around what is available to optimise support. Capacity to provide personal care is also discussed daily basis as part of the multi-professional huddles.

- **Query around access to specialist input for patients and families to be optimally set up for care (and often death) at home** – The Fife Specialist Palliative Care Service now has a Specialist Occupational Therapist and Specialist Physiotherapist embedded within the community team. These new posts have been transformational and have enabled patients with deteriorating health and debility to remain in their own homes with the appropriate care and equipment. In addition to being able to assist patients with rehabilitation and non-pharmacological symptom management, they are also available to carers and other healthcare professionals in safe techniques for manual handling.

7. SUMMARY

Since September 2018, Fife Specialist Palliative Care has been on an improvement journey involving significant alterations to its delivery model, with a clear commitment to ensuring better palliative care for everyone in Fife with palliative care needs. The new direction of travel is aligned with national and local strategic ambitions, has been informed by a Macmillan-funded Service Review and the resultant changes in needs and preferences of the population. Patients and families in Fife are at the heart of all that the specialist service offers.

The Fife Specialist Palliative Care Service has listened closely to people in Fife, who have consistently told us why home is where they wanted to be, and what care needs to look like in order that they and their families are well supported. They have also told us that choice is vital throughout the entire duration of their care, and that their preferences may change over time.

The new model has been tested now for more than three years. Inpatient hospice care in Fife has never been more accessible, with waiting list times now less than half what they were before the COVID-19 pandemic. Far greater numbers of people, including those with more complex needs, can now have a genuine choice about where they receive specialist palliative care, with the choice to die at home now being a new reality for many.

The Fife Specialist Palliative Care Services is now offering specialist care and support to more people, more accessibly and more reliably than ever before. Engagement has been, and will continue to be, critical as the service continues to evolve to best meet the needs of people in Fife.

All Information correct at time of publishing. Issued by NHS Fife Corporate Communications.