

Palliative care in Fife – Future proposals

Following on from last week's Elected Members TEAM briefing, NHS Fife and Fife Health and Social Care Partnership made a commitment to provide a dedicated briefing on the proposals outlining the future direction and expanded reach of the specialist palliative care service in Fife as part of our comprehensive programme of engagement.

The formal proposal will be presented to the Integration Joint Board (IJB) on 26 May 2023.

The paper will seek to agree and issue a direction to formally adopt the extended model of palliative care delivery for the whole of Fife, which has been embedded over the course of the last three years and has been shown to better meet the needs of the population.

1. More information on specialist palliative care in Fife can be found [here](#).
2. A news release on the proposed changes can be found [here](#).

Palliative care in Fife

The quality of care that patients receive in the last months, weeks, and days of their lives, and the support offered to their family and loved ones, is incredibly important and it is crucial that we do all we possibly can to get that care right.

Palliative care is delivered across Fife, 24 hours a day by a range of generalist and specialist clinicians. Most of the palliative care in the community in Fife, like elsewhere in the country, is co-ordinated and delivered by GPs and district nurses. Families and other unpaid carers are very often also heavily involved in the care of their loved ones.

For people with more complex palliative care needs, Fife's specialist palliative care service can provide hands-on care in a range of settings, including the hospice, care homes, hospitals and at home, as well as providing expert advice and guidance to non-specialist clinicians around the management of any patient's needs.

Background to the upcoming proposals

- *Prior to 2020, many people in Fife were unable to access the responsive palliative care at home that they needed. This is no longer the case.*

In 2018, a specialist palliative care service review was undertaken. As part of this review, people in Fife were asked what mattered to them in relation to local palliative care. They responded by outlining four main priorities:

- holistic care (caring for the whole person, not just their physical needs);
- access to quality care seven days a week;
- co-ordinated care; and
- support for families.

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 by 2021

Prior to the start of the COVID-19 pandemic, it was acknowledged across Scotland that not all of those who required palliative care had access to it and so it was necessary to explore ways to extend palliative care to greater numbers of those with life-limiting conditions.

Work to extend access to specialist palliative care in Fife was accelerated by the pandemic and the necessity to keep vulnerable people safe, which in very many cases meant providing care away from hospitals where COVID-19 patients were being treated. This very quickly led to two under-occupied hospices with excess clinical staff, and so as part of a response to the COVID pandemic a decision was made to move to a single hospice and establish a new community-based specialist outreach team, staffed by experienced palliative care clinicians.

Since its inception in 2020, this model has remained across Fife whilst continuing to evolve to meet the needs of the local population. Importantly, the evolved model has enabled three-times as many patients to access specialist multidisciplinary palliative care than was possible under the previous way of working.

The proposed model being considered later this month by the IJB has been devised by specialist palliative care clinicians who are caring for patients and their families each day across Fife and follows extensive engagement with public groups over a number of months.

Data and demand

- *Waiting times for a hospice bed have reduced from around 3.4 days to 1.4 days.*
- *More than three times as many patients can be cared for by the specialist multidisciplinary team than under the previous model.*
- *Many patients are being admitted to the hospice on the day of referral.*

The demand for inpatient palliative care reduced significantly at the start of the pandemic, with vulnerable patients anxious about the perceived risk of catching the Covid-19 virus in a healthcare setting. Throughout the pandemic, this demand continued to be far lower and remains so in the post-COVID recovery period. One of the major drivers for this reduced demand is the enhanced, community palliative care provision available and greater patient choice.

Throughout the last three years, Fife has operated a single hospice combined with the community-based specialist palliative care outreach team, who provide multidisciplinary care in patients own homes, as well as community hospitals and in local care homes, and an acute hospital team within the Victoria Hospital, Kirkcaldy

Under the previous model of care a maximum of 19 patients could be cared for at any time across two hospice units - the purpose-built Victoria Hospice within the grounds of the Victoria Hospital in Kirkcaldy and a hospice ward within Queen Margaret Hospital, with both serving patients and families from all over Fife. The establishment of the community outreach team enables as many as 60 patients at any time, from all areas of Fife to access specialist, multidisciplinary care, and support 7 days a week. The strength of this clinical service model is that the resources are agile and prioritise patients with the most clinically complex conditions. Such patients are discussed on the various huddles which take place throughout the day in collaboration with District Nursing Service, Marie Curie and the social care End of Life team.

This care is able to flex as patient and family needs change, with urgent on the day visits typically readily available. This responsive community care has led to a sustained reduction in the waiting time for a hospice bed from an average of 3.4 days under the previous model to 1.4 days currently. Very often, patients can now be admitted to the hospice on the day of referral with no waiting time at all. For anyone who is waiting, specialist palliative care support is readily accessible, in all care and residential settings. Hospice is now required for far fewer people, but is more accessible than ever.

Comprehensive programme of engagement

- ***Engagement with patients, families, unpaid carers, and local public participation networks.***

A programme of comprehensive and extensive engagement has been carried out on the future delivery of palliative care provision in Fife, the results of which, along with the data, have helped shape the proposals.

The process of engagement began under the previous care model in 2019 with an independent study, supported by *Macmillan Cancer Support*, and continued throughout the pandemic and after. Engagement by the Specialist Service has been undertaken through a number of stakeholder events, group discussions and face-to-face interviews. In-depth qualitative interviews with people living with advanced illness and their families and unpaid carers (including in bereavement) have provided meaningful insights into the lived experiences of care and have helped the service to better understand what matters most to patients and those close to them. This included:-

- Acute team engagement sessions
- Stakeholder engagement sessions
- Palliative Care Collaborative meetings
- GP Cluster Group meetings
- GP and District Nursing survey
- Community Care Roadshows
- Palliative Care Helpline Feedback
- Meetings with Governance Lead and Care Home Managers
- Care Home and Nursing Home education sessions
- GP lunchtime education sessions
- Staff engagement sessions
- Compliments and complaints
- Care Opinion
- Research

Our most recent programme of engagement included three online engagement sessions via the MS Teams video conferencing platform with representation from the following groups who shared their views and feedback on the proposals: -

- Fife Council People Panel
- NHS Fife Virtual Panel
- Fife Centre for Equalities
- Fife International Forum
- Fife Carers Centre
- Fife Voluntary Action
- Fife Independent Sector

After registration, participants were asked to submit their comments and questions in advance of the engagement events; and post event evaluations were sent out. Overall feedback has been positive, and events were well received.

A further face to face event is scheduled for mid-May for those who expressed an interest in attending but were unable to join online.

Below is a summary of some feedback shared with the service at these events: -

“After listening to the presentation, I can see that there has been huge advances from 20 years ago when my wife and I were caring for parents. It’s a great thing to take care of carers as this seemed to go unnoticed at that time and it almost broke my wife”

“It was a really positive presentation, I haven’t experienced palliative care services personally but from what’s described, this is what we would want”

“I was going to talk about all the failings, but I think you have sorted that out. When I needed end of life care for my husband, we suffered from all the things you seem to have changed, so that’s good”

"I was glad to see an acknowledgement and mention in the details that the family and unpaid carers are as important as the patient within the palliative care journey"

"I am very much a "generalist" at heart and think the changes in Fife sound excellent."

Providing greater choice

"As clinicians, we want to be able to provide patients with personalised care, in a place of their choosing, whether that is at home or in a hospital. In the past, we couldn't offer that choice, with many people unable to be cared for at home with their loved ones around them.

Post-pandemic we are now able to offer patients a real choice in terms of where they wish to be cared for, whether that is at home, in a care home, in hospital or hospice."

Dr Jo Bowden, Consultant in Palliative Medicine

A strong theme running through the engagement work was the need for patient choice. The proposed service model ensures that there is an increase in the options available to patients, with some requesting or requiring inpatient care, and the overwhelming majority choosing to be cared for at home. It is common for people's needs and preferences to change over time and the specialist palliative care service is now better placed than ever to respond to these changes. Where inpatient care is needed, a setting close to home is often possible in a local community hospital (of which there are five, across Fife), or a care home. Many patients requiring acute hospital care in the Victoria Hospital Kirkcaldy receive regular specialist palliative care input, including supported discharge back to the community

The establishment of the specialist palliative care outreach team, coupled with better integration between specialist palliative care and local health and social teams, mean that we can now provide patients with a genuine choice over whether to be cared for at home or in healthcare setting – a choice which was rarely available previously.

Making best of our resources to improve care for all

- *Approximately 4,000 people in Fife die each year, most of whom require palliative care.*
- *Prior to 2020, around 4% of deaths in Fife occurred in an inpatient hospice yet our hospices accounted for around 80% of the total palliative care resources*

There was recognition prior to the pandemic of the need to expand palliative care provision with the aim of making palliative care available to all of those who would benefit from it.

The proposed model of palliative care in Fife has been driven solely by the desire to provide patients and their families with the best possible care and support, wherever they are, seven days a week during the most difficult and emotional time for everyone involved. The changes are not driven in any way by resource and the service's budget has not been affected.

The numbers of staff in Fife's Specialist Palliative Care Team have remained broadly unchanged both pre and post COVID.

Members of the clinical team were deployed to create the specialist community out-reach service as well as sustain specialist inpatient hospice provision. Over time the skill mix within this team has been enhanced to introduce a specialist occupational therapist and physiotherapist to better meet the needs of the patients and their families.

The clinical roles include:

- Consultants in Palliative Medicine
- Clinical Nurse Specialists
- Registered Nurses and Healthcare Support Workers
- Specialist Occupational Therapists
- Advanced Nurse Practitioners
- Physiotherapists
- Counsellors
- Dietitian

The specialist palliative care medical team offer multiple home visits each day across the whole of Fife, seven days a week. Patients with the greatest need have had daily consultant-led care over their last days or several weeks of life. The team have been able to support a breadth of clinical complexity, encompassing people with complete bowel obstruction, intractable seizures, airway obstruction, haemorrhage and severe terminal agitation.

By shifting a greater balance of palliative care into Fife's communities, this extended model of care is now better able to meet the needs of our local population, with the specialist service is more able than ever to respond to the growing demands for home based palliative care in addition to providing hands-on care; the new model also enables specialist clinicians to better support local GPs and district nurses, who themselves co-ordinate and deliver palliative care across Fife. This has been achieved through the establishment of a seven-day, single point of access helpline where local healthcare teams can seek expert advice from the duty senior nurse or consultant, who can also initiate a home visit whenever this is required.

Through adapting to the new model, this has allowed us to achieve the following:-

- Waiting time for hospice admission has reduced from 3.4 to 1.4 days, with those awaiting admission receiving support from the multi-disciplinary community out-reach team.
- Hospice can admit patients 7 days a week.
- 3,297 fewer days in hospital for those in the last 100 days of life (35% reduction) and 1,293 fewer days in their last 30 days (30% reduction).
- The service is not only supporting more patients overall. They are also able to care for an increased number of people with a non-cancer diagnoses – increased from 9% to 30% of their active case load;

- The Single Point of Access (SPOA) Professional to Professional Helpline is available 7 days per week and receives calls for between 150 and 200 new patients per month.
- High level of satisfaction from GPs and District Nurses who contact SPOA for advice and planning.
- A 42% increase in “own home” deaths for patients supported by the Fife Specialist Palliative Care service.
- Reduced admissions to acute hospital for patients in the last weeks of life.
- A reduction in emergency ambulance use for people in their last weeks of life.

Specialist care, closer to home

- *Easier for loved ones to be there for patients, in a place that is meaningful to them.*
- *Where palliative and end of life care at home is not an option, inpatient palliative care is available across Fife in five community hospitals.*

Our aim is to provide patients and their families with the best possible care and support, close to home wherever possible, which is centred around the individual and their wants and needs.

Support is available 24/7 to patients and families through a dedicated phone line, without having to go through NHS24, with staff available to visit the patient in their own home regardless of the time of day or night.

Understandably, most palliative care patients wish to be cared for at home wherever possible, in order that they can be around those who matter most to them. By taking the specialist care to wherever the patient is, rather than bringing the patient to the care, we can achieve that in a patient’s own community and make it far easier for their loved ones to be around them.

There will always be instances where an individual may need or choose to be cared for in hospital. Where this is the case, patients can often be cared for in their nearest community hospital, with skilled clinical teams leading their care and specialist palliative care service support wherever needed. For those with especially complex care needs who cannot appropriately be cared for at home or in a community hospital, the Victoria Hospice in Kirkcaldy remains available.

Importantly, the sustained reduction in demand for specialist inpatient palliative care means that bed availability in the hospice is better than ever before.

Equity of access for all Fifers

The priority for almost all our palliative and end-of-life care patients is to spend as much time with friends and loved ones as possible. However, there will always be some patients who cannot be cared for at home, either because their personal circumstances don’t allow it or because they have complex clinical needs which can only be provided in an inpatient setting.

Our inpatient hospice is essentially an Intensive Palliative Care Unit for all of Fife. The vast majority of people do not require intensive palliative care. As a result of the change in model, palliative and end of life care that is responsive to the needs of individuals and families is more accessible.

Palliative and end of life care is delivered in Queen Margaret Hospital, Cameron Hospital, Glenrothes Hospital, Adamson Hospital, Victoria Hospital and St Andrews Community Hospital. The nursing and medical teams are trained to provide this care and if specialist input is required then this can be co-ordinated via a telephone call to the professional-to-professional helpline. Advice can be provided for in-person clinical assessment, as indicated.

Where travel for families to see their relatives in the hospice is at all difficult, support is also available.

Summary

Throughout this briefing the clear evidence-based and experience-informed case for change has been made. The current specialist palliative care delivery model has the needs and preferences of the people of Fife at its heart. Indeed, specialist palliative care has never been more accessible.

The development and the delivery of the model has been and continues to be both clinically-led and informed by patient and family experience. The consensus amongst the clinical team delivering specialist palliative care and their generalist palliative care colleagues, is that the current model of care offers significantly enhanced care, 7 days week, to many more people in Fife.

Useful Links

More information on specialist palliative care in Fife can be found [here](#).

A news release on the proposed changes can be found [here](#).

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