

# Scottish School of Primary Care

GP Clusters

**Briefing**

**Paper 10**



# Palliative and Anticipatory Care

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## Collaborative Quality Improvement in General Practice Clusters

This paper is the tenth in a series that relates to areas of quality and safety on which general practice clusters could usefully focus improvement activity. Each paper summarises research, guidelines and other evidence about areas of care which can be improved, and improvement methods and interventions.

### Palliative and Anticipatory Care

Research in cancer and non-malignant illnesses is increasingly showing that palliative care can prolong life as well as improve its quality. However, patients and some professionals still have a strong misconception that palliative care is only for patients who are in their last days or weeks of life rather than starting from diagnosis of any life-threatening illness as originally defined. To address this in Scotland we have made much progress with “anticipatory care planning” through use of the Key Information Summary (KIS) to help communicate a care plan with out-of-hours care. By 2017, 69% of patients with a progressive illness had a KIS in place on average 45 weeks before death.

This paper highlights how more people might access anticipatory or early palliative care, and the potential role of practice clusters to improve services and to inform patients (and the wider community) of the benefits of talking about and planning for living and then dying well.

#### The problem

Over 70% of people who die with a long-term illness can benefit from palliative care during their last year of life. [1] At present services are biased towards people with cancer; patients dying from cancer are significantly more likely to be identified for palliative care than others.[2] This presents a particular challenge in primary care because nearly all people spend most of their last 12 months living at home or in a care home under the care of their primary care team. Palliative care has been increasingly difficult to provide in primary care due to transfer of care previously delivered in secondary care and the increasingly large number of patients at home and in care homes with advanced illnesses. Lack of palliative care is associated with increased likelihood of “over treatment,” treatment of low benefit and unnecessary hospital admissions along with an increased stress and illness for family carers.

*other problems, physical, psychosocial and spiritual”.*<sup>1</sup>

Primary palliative care refers to the delivery of this approach for people living in the community by their primary care teams. To successfully deliver this approach requires:

1. early identification of people who would benefit from this approach regardless of their diagnoses, age or prognosis;
2. tools, protocols and pathways to enable high quality assessment and care planning;
3. seamless coordination of care across disciplines and settings both in and out of hours;
4. increased understanding of the nature and benefits of early palliative care among professionals, patients and the general public.

Much research and development has occurred in palliative care in the community in Scotland. Inequalities in care provision between cancer and heart failure, COPD, liver failure and people with multimorbidity have been highlighted, together with suggested improvements. Such improvements highlight the necessity for clinicians to have the ability and opportunity to systematically **identify** patients for **early** palliative care. The Supportive and Palliative Care Indicators Tool (SPICT™)<sup>2</sup> has been developed and refined to facilitate identification in a range of clinical settings including primary care[3]. Research in progress in NHS Lothian practices has used computerised searches based on the SPICT™ to identify up to 0.75% of patients on practice lists who could benefit from early palliative care[4]

A key element of early palliative care in Scotland is anticipatory care planning.[5] Scotland is also unique in developing an integrated electronic record—the Key Information Summary (KIS)—that holds both anticipatory care planning information and palliative care information in the same record and shares it routinely across NHS services.[6] A 2019 study of 16 practices across Scotland found that patients with a KIS were much more likely to die in a community setting than patients with no KIS. Crucially, the KIS allows primary care teams to start anticipatory care planning without having to overcome the “barrier” that the term “palliative care” often presents.[7]

This is particularly true for people living in care homes for whom an anticipatory care plan can be started (or updated) on admission.[8] Research has shown that it is also possible to identify proactively carers in practices by using existing opportunities, resources and computer systems.[9] Carers and family networks (where present) are an important public health “asset” in helping people live at home safely and with a high quality of life but they need support to be able to do so.

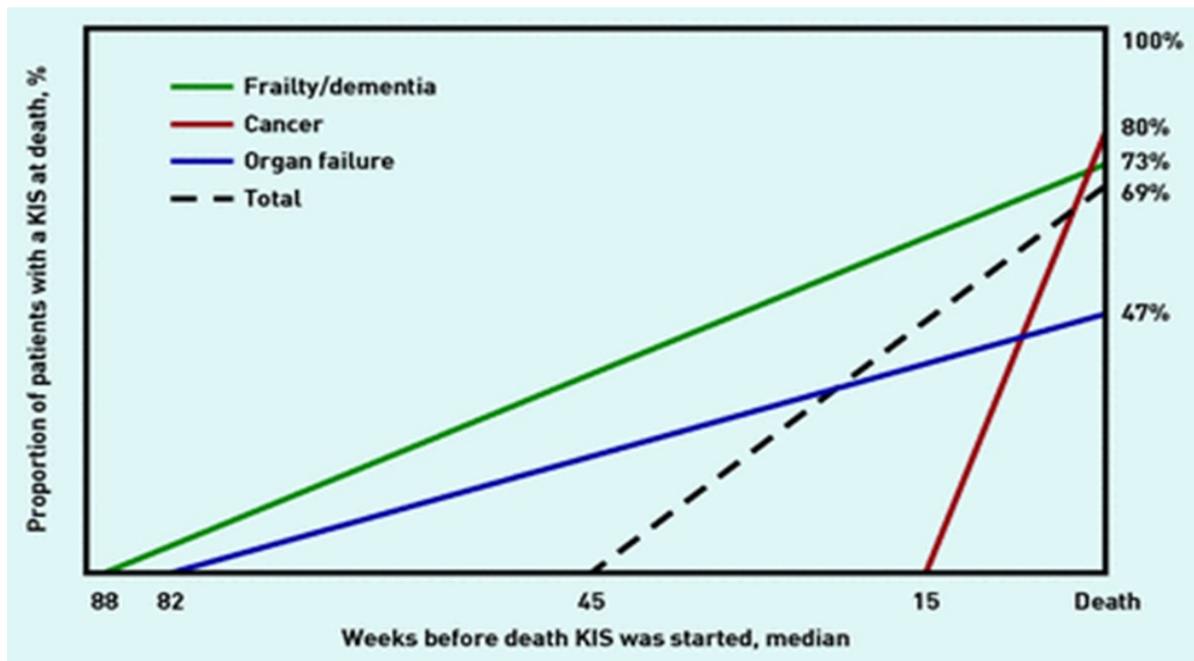
### Can access to and provision palliative care be improved?

The World Health Organisation defines palliative care as:

*...an “approach that improves the quality of life of patients and their families facing the problems 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*



Figure 1. The average number of weeks before death that Key Information summary (KIS) was documented in primary care records for patients who dies of cancer, organ failure or frailty/dementia in 2017, and the percentage in each group dying with a KIS in place. [7].



Primary palliative care needs excellent coordination of care both in-hours and out-of-hours, but this is not reliably satisfactory.[10] The 2015 Ritchie report into out-of-hours services in Scotland flagged people with palliative care needs as a group requiring enhanced access to out-of-hours services.[11] Qualitative research indicates that the decision making process about whether to call an out of hours number can be extremely complicated and is indicative of extensive unmet need.[12]

The KIS record has the potential for enhancing coordination of care via information sharing between services. Presently, people with advanced cancer receive better coordination of care than those with other advanced illnesses [13,14]. Patients with multimorbidity are particularly at risk of receiving poorly coordinated care in their last year of life. [15] Multimorbidity is now the “norm” for people towards the end of life and is thus a major challenge in providing palliative care. [16]

Education in the scope and benefits of early palliative care is needed for professionals and a public health approach is needed to raise public awareness of and engagement with anticipating decline and dying well. Doctors still associate palliative care with cancer and the last weeks of life. [7] Similarly, the general public associates it largely with death and dying. [17] A health promoting palliative care approach may address some of these issues, and promotes the involvement of local organisations or communities in providing practical support. [18] National campaigns such as *Good Life, Good Death, Good Grief*<sup>3</sup> and information resources can lead to better public awareness and engagement, and lead to dissemination of best practice nationally.

### Implementation in real-life NHS practice

In 2016 the Strategic Framework for Action on Palliative and End-of-life Care set out the Scottish Government's vision: that by 2021 everyone in Scotland who needs palliative care will have access to it.[19] Its commitment to this is evidenced by continued funding for palliative care and anticipatory care planning, which brings an early palliative care approach, a holistic and planning approach to chronic disease management. [20] It also instigated a Scottish Research Forum for palliative care to focus on how people might be identified more effectively and consistently, how professionals might manage and communicate uncertainty better and how a greater public awareness and discourse might be achieved.

Ongoing developments of the KIS, enabling wider access and, possibly, greater numbers of professionals being able to input data are improving information sharing and facilitate coordination of care. The KIS is facilitating earlier and broader identification of people for anticipatory care.[5] Developments in out-of-hours services for people with palliative care needs will also be of benefit for the increased number of patients identified in-hours. The primary care team—GPs and district nurses—is centrally placed to coordinate such care due to their holistic understanding of the patients involved but expansion of numbers of people on palliative care or anticipatory care lists risks creating additional work that PCTs may struggle to manage. Additional tools, resources and training to efficiently manage expanded lists is vital if this improvement is to be delivered. The Scottish Government has developed courses at HIS and NES to facilitate training and



service developments in primary care [21], and integrated health and social care boards are now responsible for delivery of early specialist and general palliative care according to the needs of people dying in their catchment areas.

With respect to improving clinical care, the Scottish Palliative Care Guidelines were updated in 2016, and are an excellent resource about pain and symptom control, palliative emergencies, last days of life information, and prescribing. It is available in a pocket handbook, web version, and a smartphone app.<sup>4</sup>

### Implication for collaborative quality improvement in general practice clusters

General practice clusters offer potential economies of scale and the ability to share their processes and innovations in anticipatory care and early palliative care. The new Scottish GP contract allows greater flexibility for cluster groups to work together in carrying out anticipatory care planning, and to consider how the care of older patients with multimorbidity could be improved. Multidisciplinary working, including with social care in an IJB should reduce the number of people who fall “through the gaps.” Social care staff are often the professionals who have the most interactions with patients and families towards the end of life, and are greatly appreciated especially if continuity of care and adequate time are available.

Clusters may have around 40,000 patients registered at the practices, with around 400 deaths annually, with patients mostly on lengthy unpredictable trajectories of physical decline through organ failure and dementia/frailty.

Co-ordination of identifying patients at cluster level by pooling resources and sharing expertise and knowledge of local resources in the community can assist in their management and in updating and supporting the skills and knowledge of GPs and community nurses. Named local hospice staff could be encouraged to support the practices at MDTs, and the care homes within each cluster. Likewise, district nurses will be able to share information and best practice between different practices in a cluster as they work with them. Practices within a cluster can also share expertise with identification tools and the use of routine data. For example, the SPICT™ can be used reactively in consultations or proactively at MDTs to identify patients for palliative care or for anticipatory care. Guidance for so doing is available online and there is an app which can be downloaded on desktops and smartphones. The use of SPARRA data, computerised searches and the potential for accessing new types of routine data through the SPIRE project<sup>6</sup> offer great potential for aiding identification that could be realised at a cluster level through sharing expertise.

Collaborative working can help with a new model of palliative care that integrates active, anticipatory care throughout a patient's illness trajectory. Figure 1 above shows Scottish data available from 2017 that indicates when on average, for each of the main illness trajectories leading to death (cancer, organ failure, dementia/frailty) anticipatory care started for people who died and the percentage of patients who died with a KIS in place. This is great progress compared to 2011 and

2014 in Scotland, and compared with other countries. GP clusters can work to improve the total number of patients provided with anticipatory and/or palliative care and to start anticipatory care earlier. Anticipatory care is basically early palliative care, and many GPs are providing this person-centred care without calling it palliative care with patients.

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**The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.**

**Look for any general indicators of poor or deteriorating health.**

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

**Look for clinical indicators of one or multiple life-limiting conditions.**

## Cancer

Functional ability deteriorating due to progressive cancer.

Too frail for cancer treatment or treatment is for symptom control.

## Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Urinary and faecal incontinence.

Not able to communicate by speaking; little social interaction.

Frequent falls; fractured femur.

Recurrent febrile episodes or infections; aspiration pneumonia.

## Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Persistent paralysis after stroke with significant loss of function and ongoing disability.

## Heart/ vascular disease

Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.

Severe, inoperable peripheral vascular disease.

## Respiratory disease

Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.

Persistent hypoxia needing long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

## Other conditions

Deteriorating and at risk of dying with other conditions or complications that are not reversible; any treatment available will have a poor outcome.

## Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping or not starting dialysis.

## Liver disease

Cirrhosis with one or more complications in the past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is not possible.

**Review current care and care planning.**

- Review current treatment and medication to ensure the person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family. Support family carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, communicate and coordinate the care plan.