How to implement the Gold Standards Framework to ensure continuity of care

All end of life services are expected to use a process such as the GSF. This article sets out how to implement the first three levels of the framework in primary care.

ELIGIBILITY FOR GSF

Determining whether patients have a life expectancy of 12 months or less can be difficult, particularly as different diseases have different trajectories.

Prognostic indicator guidance (GSF, 2008) recommends three methods to identify those for whom the framework should be initiated:

- Asking the “surprise question” – would you be surprised if the patient died within the next 12 months?
- The patient with advanced disease makes the choice to receive comfort measures only or they need supportive/palliative care.
- Using specific clinical indicators of advanced disease for cancer/organ failure/frailty and dementia.

IMPLEMENTING THE GSF

The framework comprises four levels. Level 4 focuses on sustaining, embedding and extending the use of the GSF. This article discusses levels 1-3 as they focus on implementing the seven key tasks (Fig 1).

Implementation across an organisation lends itself to a stepwise, structured and incremental approach, with each level focusing on different key tasks (Fig 1). The goals of one level should be achieved before moving on to the next.

LEVEL 1

Getting the team on board

To promote ownership, partnership and collaborative learning, engaging those involved in caring for patients in the last 12 months of life is essential. This includes GPs, practice staff, out of hours services, specialist practitioners and the community nurses, all of whom should be involved in developing implementation plans (Jones and Jenkins, 2007). Primary care trusts’ GSF facilitator/end of life care leads can be good sources of support and should be informed of the intention to implement the GSF.

PRACTICE POINTS

The following are vital to ensure effective implementation of the GSF:

- Leadership – a driving force for change and promoting the use of end of life care tools following best practice guidance;
- Workforce development – using innovative methods to support development of competence, knowledge and skills to enable preplanning, anticipatory and consistent high quality care;
- Communication – to support seamless, timely and appropriate care and teamwork within, between and across care settings;
- Resources – aligning home based services which meet patient preferences and needs;
- Evaluation and audit – to measure care quality and identify areas which need development.

- Organise an implementation meeting: all stakeholders should be invited to a meeting to discuss implementation and establish their knowledge of the GSF. The team should be given information about the framework as well as an outline implementation plan that clearly identifies the necessary changes in practice, exploring existing service inadequacies (Wagstaff, 2006).
- Identify driving forces and barriers: highlight any weaknesses or threats to facilitate open discussion and encourage the team to identify how to address these (Goppe and Galloway, 2009; Barr and Dowding, 2007). This can be done by analysing strengths, weaknesses, opportunities and threats (SWOT) or using a force field analysis (Goppe and Galloway, 2009).
- The team must own all action plans, which need to include how the existing workload is to be maintained (Hodges, 2008). This approach aims to reassure the team that the implementation framework is planned, supportive, systematic and undertaken within a realistic time scale (Barr and Dowding, 2007). Supporting development and understanding of the roles of all involved should lead to improved team dynamics.
Anticipate resistance: proposed implementation of the GSF will prompt different responses from team members and some may show resistance behaviours, such as passive resistance or active opposition. These are common reactions to change (Pearce, 2007) and can be addressed by inviting people to discuss and identify their objections and suggest realistic solutions.

Evaluate current practice
The team may need to have an explanation of why it is necessary to implement the GSF. Evidence supporting the need for change and against which their service can be benchmarked is helpful, and can be compiled by various methods, for example, by using:
- Documents published by the DH (2009; 2008a);
- Local palliative care/cancer networks in conjunction with published research.

Care can be evaluated locally using the methods in Box 1, generating data which would enable team members to determine for themselves that change is necessary and increasing the likelihood that they will accept, support and facilitate implementation (Gopee and Galloway, 2009; Hodges, 2008). These methods can also be used to evaluate care after implementing each level to determine how or whether improvements have been made and where gaps exist.

Identify a coordinator
The team should identify a GSF coordinator, defining what the role entails before deciding who would be best to undertake it.

Once the coordinator is identified it is important to work out how the role can be incorporated into their current workload, identifying capacity and workload issues and areas for appropriate delegation.

Produce a register of patients
A palliative care register (also known as supportive care register) should be produced (Thomas, 2003), listing all patients receiving palliative care and likely to be in the last 12 months of life.

This register forms the basis of multidisciplinary team (MDT) meetings and ensures all relevant patients are known to the team. The aim is to keep their condition manageable in the community through proactive management and crisis averseion. The register also ensures patients have rapid access to services to meet their needs, such as new or repeat prescriptions and prompt review visits by relevant practitioners.

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FIG 1. THE SEVEN KEY TASKS IN RELATION TO LEVELS OF IMPLEMENTATION

| Level 1 | Communication
| Coordination |
| Level 2 | Control of symptoms
| Continuity including out of hours
| Continued learning |
| Level 3 | Carer support
| Care in the dying phase |

The register must be updated to keep pace with changing situations; this requires good communication between the team who identify eligible patients and the coordinator who adds them to the register. GP practices that have a “complete register available of all patients in need of palliative care/support” (British Medical Association and NHS Employers, 2009) can claim three Quality and Outcomes Framework (QOF) points per year, worth around £600.

Identify eligible patients: the team must identify their educational needs in terms of making prognoses and determine how these needs can be met, to ensure they are able to recognise patients who they consider may be in the last 12 months of life and report these to the practice. The sooner patients are identified the sooner advance care planning can begin. Financial constraints mean education resources will inevitably be affected, so innovative and cost effective methods of addressing knowledge gaps will be needed.

Organise primary healthcare team meetings
After the initial meeting, dates for future MDT meetings should be organised, in which patients on the register are discussed. Effective communication between caregivers is vital, as best care depends on partnerships across statutory and non-statutory organisations (DH, 2008a).

MDT meetings provide an ideal opportunity to foster interprofessional partnership working and a greater understanding of each others’ roles, and a forum for sharing knowledge when discussing patient management and undertaking significant event and after-death analysis.

GP practices that undertake multidisciplinary case review meetings at least every three months in which all patients on the palliative care register are discussed can claim three QOF points per year (BMA and NHS Employers, 2009).

LEVEL 2

Identify and assess symptoms
Since a major goal of palliative care is to maximise quality of life (Peters and Sellick, 2006), early detection of symptoms or other physical, psychological, social and spiritual issues is essential.

Use recommended tools to identify and assess symptoms: the GSF team advocates using two tools: the PEPSI-COLA checklist (GSF, 2005a) and Problems and Concerns Assessment (PACA) (GSF, 2005b).

The PEPSI-COLA checklist was introduced as an aide-memoire to promote holistic assessment, addressing issues listed in Table 1 while promoting consistency between practitioners. It promotes advance care planning, personalised care and partnership working. However, it does not identify what should be assessed within each of the components, so to ensure consistency, the team must agree how each will be assessed.

The PACA tool (GSF, 2005b) can be used to measure severity of problems or concerns patients identify – they are asked to score each using the assessment key in Box 2. Using this tool, staff can identify whether the severity of the problem/concern is decreasing or increasing and refer to specialist services if a patient scores 2 or 3 for more than a week despite interventions.

Continued communication with patients and their carers/families is therefore vital to ensure they report concerns. However, patient/carer choices over visit/contact

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<tr>
<th>BOX 1. WAYS TO GATHER DATA TO INDICATE NEED FOR GSF</th>
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<tr>
<td>- Benchmark against quality markers (DH, 2009).</td>
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<td>- Discuss significant events in end of life care.</td>
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<td>- Compare preferred versus actual place of death.</td>
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<td>- Determine how many admissions are made to specialist palliative care units or acute care due to symptom management issues.</td>
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<td>- Determine the incidence and nature of out of hours emergencies.</td>
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<td>- Undertake staff satisfaction surveys.</td>
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<td>- Self assess palliative care knowledge and skills.</td>
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<td>- Collect patient and carer evaluations.</td>
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<td>- Determine the number of incident reports completed.</td>
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<td>- Determine the number of complaints received.</td>
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<td>- Obtain feedback from stakeholders about the service provided to patients at the end of life.</td>
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Consideration should be given to who initiates order in their records. However, careful arrangements need to be made to ensure an agreed “do not attempt resuscitation” flag is in place. Once implemented, use of the tools in practice could be identified during audit of deceased patients’ records and the findings acted on accordingly.

While end of life care tools are extremely valuable in any assessment, practitioners also need to use high level communication skills in sensitive areas. Training should be available to enable them to be competent and confident in difficult situations.

Establish communication methods

Patients with palliative care needs have conditions which are vulnerable to change. To ensure continuity of care, effective communication between services across all care settings is essential.

The GSF advocates clear and concise communication between out of hours and regular services to enable seamless, timely and appropriate care (Thomas, 2003). Effective communication can ensure needs and preferences are known, to support proactive planning, crisis averted and prevent unnecessary hospital admission. Reciprocal communication is also necessary between care settings where admission and/or discharge is planned or has already taken place, to ensure services are fully updated about patients’ needs and preferences.

Ensure proactive planning

Anticipatory and proactive planning is crucial to avoid crises or ensure they are managed effectively.

One controversial consideration is whether ambulance services should be informed of patients who are receiving palliative care and have an agreed “do not attempt resuscitation” order in their records. However, careful consideration should be given to who initiates such discussions with patients and carers, as well as how and where the outcomes are documented and the review process. Other considerations include ensuring anticipatory prescribing and equipment is available in patients’ homes if their clinical needs indicate treatment should start without delay or if difficulties are anticipated.

It is vital to audit out of hours incidents to enable the team to consider how they might address any issues that arise, and to improve patient experience, team effectiveness and collaborative service delivery. Audit findings may indicate that investment in rapid response services is needed to manage emergency episodes in the community.

Develop the workforce

A range of methods can be used to enable practitioners to improve their skills in symptom assessment, such as:

- Expert supervision involving shadowing or being shadowed by more experienced colleagues when assessing patients;
- Clinical supervision;
- Joint visits with specialist colleagues;
- Spending time at hospice/specialist palliative care units;
- Discussion and reflection at team meetings.

Identify strengths and weaknesses within the team. This will help highlight where knowledge and skills need to be improved and enable such issues to be addressed in personal development reviews.

Carry out significant event and after death analysis: such analysis at MDT meetings is vital to enable the team to reflect on what has gone well and what did not go so well to learn good practice (GSF, 2005c). The GSF team recommends these activities to promote shared learning (Thomas, 2003), so it is crucial to invite staff who may add value to discussions. Such analysis should be done in a place that promotes an open culture.

Measure success

Once implementation has begun, it is vital to evaluate the GSF’s impact (Gopee and Galloway, 2009; Barr and Dowding, 2007) before progressing to the next stage and to establish whether it has had any impact on patient care and service delivery.

The methods in Box 1 could be used to determine this, and data can be made available to the team, with successes recognised and a constructive approach taken to areas where improvements are still needed (Ellershaw and Wilkinson, 2003; Thomas, 2003).

The DH (2008a) also requires organisations to provide evidence of their quality, and advocates the GSF as an effective programme, in conjunction with other end of life care tools (Liverpool Care Pathway and Preferred Priorities for Care).

LEVEL 3 Support carers and provide information

Patients with advanced disease often become dependent on their families as their functional ability declines.

Family members or friends may become the main caregivers, playing a crucial role in providing palliative care and in determining whether the patient dies at home (Docherty et al, 2008). Carer breakdown is often the key factor leading to patients moving into institutionalised care, and ideally carers should be viewed as integral members of the team, taught or enabled to do as little or as much as they wish for patients, and consulted and informed at every stage (Thomas, 2003).

It is therefore vital to provide carers with appropriate information to enable them to perform aspects of care effectively and safely, as poor knowledge impacts on care standards. This can help carers to feel supported, enabled and empowered in delivering informal care, a responsibility that inevitably affects their own quality of life. Carers are also entitled to an assessment, independent of the person they care for (DH, 2008b) as their own needs are often neglected (King et al, 2003). Also, patients may be anxious about their carers’ welfare and fearful of becoming a burden (Hasson et al, 2008; Jones et al, 2004).

However, in reality, services are not wholly aligned to support carers in the community as most are deployed as visiting services and often patients at the end of life are admitted to acute care (National Confidential Enquiry into Patient Outcome and Death, 2009), with 10% dying within 24 hours of admission (NHS North West, 2008). The likelihood of this may be reduced if rapid response and
accessible services such as “Hospice at Home” services for this period are available. Carer support may need to be continued after the patient’s death, and services should not be withdrawn immediately (Rhodes and Shaw, 1999). Carers may have witnessed distress as “how people die remains in the memory of those who live on” (Dame Cicely Saunders, cited by DH, 2008a). The LCP’s final goal incorporates the need to provide signposting for carers about bereavement services (Ellershaw and Wilkinson, 2003).

**Provide optimal care in the dying phase**

The LCP (version 12) is a multiprofessional document incorporating evidence based practice and guidelines for the care of dying patients (Ellershaw and Wilkinson, 2003). It is advocated by the DH (2008a), NICE (2004) and the GSF, and is put in place following assessment and agreement by the MDT (usually the district nurse and GP) that the patient is in their final hours and days and potential reversible causes have been excluded and a second opinion is not deemed necessary (Marie Curie Palliative Care Institute Liverpool, 2009).

The pathway promotes holistic care during the dying phase and provides guidance on the different aspects of care needed. It is accompanied by prescribing guidelines for managing pain, nausea and vomiting, respiratory secretions and agitation. The DH Renal NSF Team and Marie Curie Palliative Care Institute Liverpool (2008) have also produced prescribing guidelines on managing symptoms in patients with renal failure.

If the LCP is not used for all patients in the dying phase, the reasons need to be explored and audited to determine, for example, how its use can be increased and any extra education and training needed.

**CONCLUSION**

The framework’s successful implementation can improve staff confidence and teamwork, enabling them to deliver more effective home based care, aligned with patient and carer preferences, to achieve the best quality of life, death and bereavement.

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Gold Standards Framework (2005c) Significant Event Analysis. tinyurl.com/GSFS-significant-event


