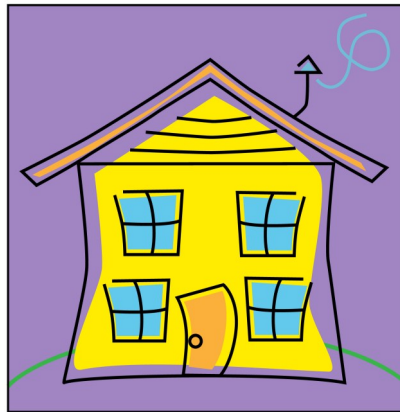


The Gold Standards Framework in Domiciliary Care Training Programme



Good Practice Guide

Guidance and resources to accompany the distance learning
GSF Domiciliary Care Training Programme and DVD
Phase 3

The right people, right care, right place, right time, every time

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For further details please see information governance section of the GSF Website or contact the National GSF Centre.

The GSF Centre is a training centre focused on enabling generalist frontline staff to deliver a 'gold standard' of care for all people nearing the end of life. We do this through delivering training and accreditation based on adapted frameworks for each setting, providing resources, tools, evaluations and measures, with local support for best implementation.

GSF is a best practice model in end of life care recommended by all major UK NHS and social care policy guidance. With a longstanding national reputation for practical evidence-based training and support, GSF has helped deliver effective grass-roots improvements, which has helped many thousands of people nearing the end of life. GSF was one of the original 'best practice tools' endorsed by the Department of Health EOLC Programme and National Strategy 2008. GSF includes care for all people considered to be approaching the final year or so of life, in any setting, with any condition, particularly those with frailty, dementia and other disadvantaged groups. By improving the proactive coordination and systematic processes of care, GSF complements specialist care and enables generalist frontline staff in many settings to provide optimal end of life care for all.

The GSF Centre is a voluntary sector not-for-profit Social Enterprise company (CIC) that emerged from the NHS in 2011, bringing together all aspects of GSF services under one roof. It grew from 12 years of work within the NHS (and a Department of Health End of Life Care (EOLC) grant (05-11)). We provide training and support for a large number of NHS and social care organisations on a commissioned basis, working with local areas and partners such as the University of Birmingham, St Christopher's Hospice and other GSF Regional Centres in England and internationally.

The National GSF Centre for End of Life Care

GSFDC Training Programme

www.goldstandardsframework.org.uk domiciliarycare@gsfcentre.co.uk
01743 291 891

Prof Keri Thomas, National Clinical Lead for the GSF Centre, Hon Professor End of Life Care, University of Birmingham, Royal College General Practitioners End of Life Care Clinical Champion
Maggie Stobbart - Rowlands GSF Centre Lead Nurse, Lucy Giles Clinical Nurse Advisor
Supported by the GSF Centre administration team

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Section A—Good Practice Guide for the GSF Domiciliary Care Training Programme

- **Welcome, Introduction and Overview of GSF in Domiciliary Care**
- **Overview of the work of the GSF Centre**

Session 1 – Why is end of life care important and what is the role of the domiciliary care worker?

Learning Outcome: To understand the context of end of life care and the role of the domiciliary care worker

- Action Points after Session 1
- **Resources**

Session 2 – Do we identify people in the last year of life?

- **Learning Outcome:** To understand the use of needs based coding in identifying people near the end of their life
- Action Points after Session 2
- **Resources**

Session 3 – Are we providing the right care for people nearing the end of life?

- **Learning Outcome:** To explore the use of assessment tools, and carer support and assessment, what to do and when to refer
- Action Points after Session 3
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Session 4 – Do we know about peoples' personal preferences?

- **Learning Outcome:** To learn about communication skills in Advance Care Planning, the role of listening. Reducing hospitalisation
- Action Points after Session 4
- **Resources**

Session 5 – Are we supporting the dying and their families?

- **Learning Outcome:** To learn about care in the final days, care pathways and anticipatory care - just in case thinking'
- Action points after session 5
- **Resources**

Session 6—Are we working together as a team?

- **Learning outcome:** To understand the importance of good team working and cross boundary care and communication
- Action points after session 6

Additional Resources

National Endorsement and Support for the Gold Standards Framework Programmes

"The GSF is one of the most significant developments in the improvement in end of life care since

Dame Cicely Saunders founded the hospice movement. At St Christopher's Hospice we are committed to working with care homes to implement the GSFCH as we believe this is an outstanding tool for bringing the standards of hospice care out into the care home setting"

"Every organisation involved in providing end of life care will be expected to adopt a coordination process, such as the GSF"

Department of Health End of Life Care Strategy England 2008

"GSF is the bedrock of generalist palliative care"

DN Norfolk

"The quality markers do not necessarily require new work or new thinking. Where organisations are already implementing ...end of life tools (Gold Standards Framework, etc), for example they will already be compliant with many of these markers"

DH Quality Markers for end of life care, 2009

"GSF hits all the buttons of quality, choice, equity and value for money, in the crucial area of end of life care that affects every one of us, as people and as professionals"

SHA Senior Manager

"GSF has transformed End of Life Care here in Greater Manchester and Cheshire and I urge all clinicians to adopt this framework and improve the quality of care for dying patients in their area. There is only one opportunity to get it right"

Hilary Compston, Associate Clinical Director Greater Manchester Cancer Network



replace with quote from skills academy

"The College is pleased to support GSF, as a major component of the new RCGP End of Life Care Strategy. It is clear that end of life care should be part of the core business of general practice, and GSF provides a standard against which we can measure our practice and a means to further improve it."

Prof Nigel Mathers, Chair CIRC, RCGP

"Primary care teams should institute mechanisms to ensure that the needs of patients with Advance cancer are assessed, and that the information is communicated within the team and with other professionals as appropriate."

The Gold Standards Framework provides one mechanism for achieving this"

NICE 2005 Recommendation 13. Improving Supportive and Palliative Care for Adults with Cancer

"The 'Gold Standards Framework' (GSF), a widely implemented programme of care for palliative care patients, is now associated with a considerable degree of research and evaluation and is key to thinking through and implementing high quality patient centred care at the end of life for patients with both cancer and non cancer diagnoses"

British Medical Association (BMA). Quality and outcomes framework guidance. London (UK): 2006.132

"In my experience of working to improve end of life care in East London, the GSF has been key. I believe it is one of the single greatest aids to this work, drawing together generalists and specialists to address the needs of patients and their families."

Heather Richardson Clinical Director of St Joseph's hospice London



"The RCN fully supports this renewed effort and determination to ensure that the GSF is implemented across the country. Nurses play a significant part in the care of people who are at the end of their life – regardless of the setting in which care is being provided – and we welcome the opportunity to contribute towards achieving a universal gold standard for all."

Lynn Young, Primary Health Care Adviser, Royal College of Nursing

Welcome and thank you for joining the GSF Domiciliary Care Training Programme

A big welcome to you !

Firstly *thank you* for taking part in this training programme, to help you care even better for people who are seriously ill and nearing the end of life. We very much hope you will enjoy doing this programme, that it will boost your confidence and job satisfaction and enhance your enjoyment of your day-to-day work with those you care for. We are sure that, once fully implemented, GSF will be a real help to you and your team, to enable you to give the best possible care to every one of your service users nearing the end of life.

What about you? What would gold standard care mean for you?

If you stopped for a second and thought what kind of care you would wish for if your mother, father, wife, husband, child or even yourself were nearing the end of life? What words come to mind? What are your priorities?

People often say they want the best medical care and support, delivered in a human and compassionate way by people with whom they can develop trusting relationships. They want to have some control in their care, be involved in decision making, to be comfortable and minimise suffering with no scary emergencies and for things to be as normal as possible, so they can enjoy life to the full whilst they still have it. Its about quality not just quantity - 'living well to the end of life'. Many are worried they might become a burden to their families or carers, they might fear being alone, or in pain or other serious concerns. Some have unfinished business to sort out, both practical but often emotional and spiritual, and want time to say important things to those closest to them. Most say they would prefer to be at home, feeling safe knowing what to do if they did need help but surrounded by people they love and life-affirming familiar things that remind them of their well lived life.

The aims of GSF - enabling a 'gold standard of care. This is what we aim to do - to enable people nearing the end of life to remain at home and to live out their final days as well as possible in accordance with their wishes. This is not an unreasonable request you might think - but somehow it can still be quite a challenge to get this right every time and it does take some backstage planning - hence GSF!

The aim is to build on the good work and loving care that you provide, by giving you more knowledge and skills to care better for people approaching the end of life and feel more confident in working with others in the team. By looking ahead, providing earlier support for these people, better predicting, planning and anticipation of their likely needs, then this wish is more likely to be fulfilled for more people.

This is what GSF aims to do - to improve the organisation or 'hands' of care, to help the 'head' knowledge and 'heart' care so that they all work together to improve the person's experience of care. We have broken this programme down into key messages, learning outcomes and take-home messages, with illustrations to make it real for you. But it is up to you to make it come alive in your daily work and make a real difference for those you care for - as in many things, you get out what you put in!

We very much look forward to meeting you and to hearing of the great work you are doing. Do contact us with your thoughts, suggestions and feedback - we are keen to hear from you and are always here to support you if we can. We know this makes a real difference in peoples' lives - so give it your best!

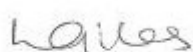
With all good wishes from the GSF Team

Lucy

Maggie

Keri

and the rest of the GSF team





Development of GSF Domiciliary Care Training Programme

We asked groups of domiciliary care workers, at workshops and events, what were the main challenges that they experienced in their work while delivering end of life care to people in their own homes. We also reviewed national policy documents, such as the National end of Life Care Programme, Route to Success.

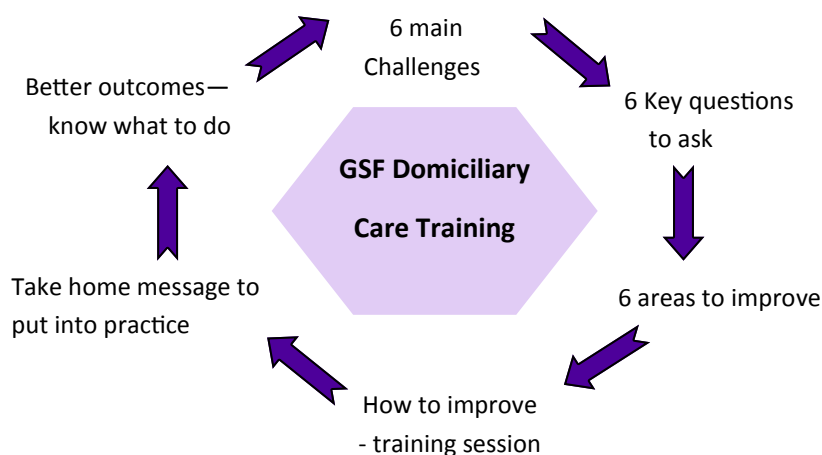
The six main challenges, which were a recurrent theme, are:

1. **Confidence.** Low confidence and Isolation, poor collaboration, feeling unvalued. Inconsistency of care, not fulfilling our role, could do more
2. **Thinking ahead,** Lack of anticipatory planning & consistency, crisis management.
Communication difficulties
3. **Giving good care.** Not understanding what can be done and who to ask. Lack of knowledge , information and best clinical care.
4. **Living well.** Helping people live how they would like. Relationships, deeper conversations, Communication issues & time pressures
5. **Dying well.** People who were dying admitted to hospital in a crisis rather than being able to keep them in the home
6. **Working together** within the teams. Working with GPs, DNs and others

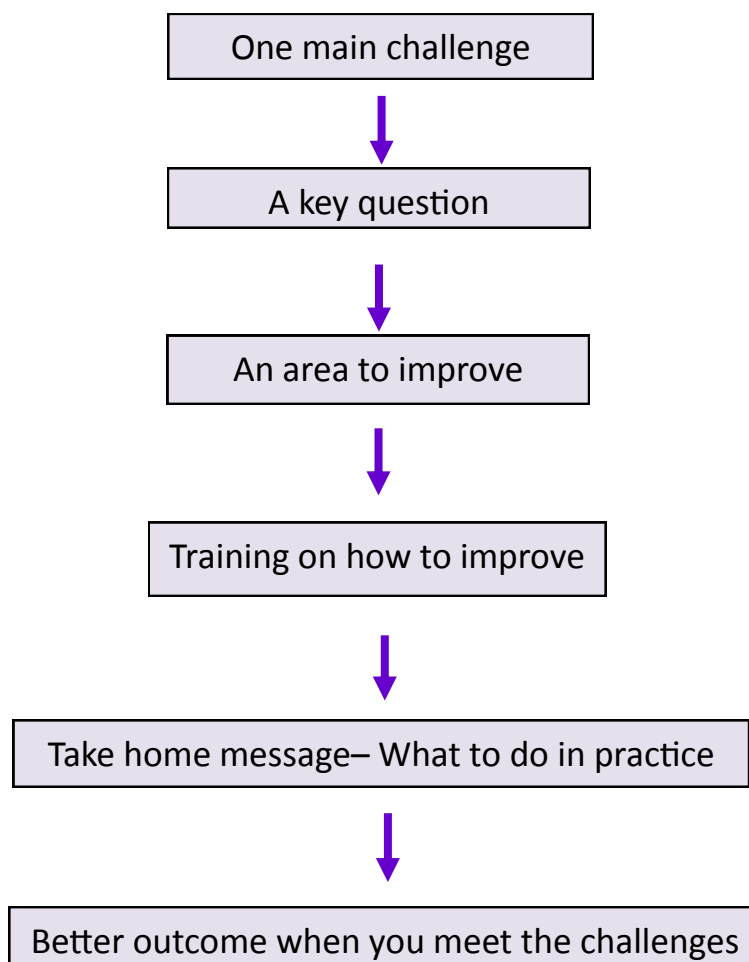
With these challenges we developed **six key questions** to help us focus on each training session:

1. a) Why is it important to provide good end of life care with dignity and respect?
b) What is the role of the domiciliary care worker?
2. Are we identifying people in the last year of life and recognising decline?
3. Are we recognising decline? Are we giving good care ?
4. Are we providing the right care for people in the last year of life?
5. How can we best support people who are dying and their carers?
6. Are we working well enough to provide coordinated care?

Following these key questions, learning outcomes and take home messages were developed for each training session, details of which can be found at the beginning of each individual session



So for the GSF Domiciliary care programme we cover in each of the 6 sessions:-



As an overview and guide to the programme we include the plan of the whole GSF Domiciliary care programme but suggest you take this one step at a time as we go through the training programme.

Remember, its not about what you know but what you do and how you do it



Development of training based on key challenges in domiciliary care

Key Challenges For Domiciliary providers

Isolation, poor collaboration. Low confidence & feel undervalued. Inconsistency of care, not fulfilling our role, could do more.

Lack of anticipatory planning & consistency, crisis management. Communication difficulties.

Understanding best clinical care and what can be done and who to ask. Lack of knowledge and information.

Relationships, deeper conversations, helping people live as they would like to. Communication issues & time pressures.

People admitted to hospital to die in a crises care rather than dying at home.

Working together within the teams. Working with GPs DNs and others.

Key Question

1. Why is it important to provide good end of life care with dignity and respect?
2. What is the role of the domiciliary care worker?

Are we identifying people in the last year of life and recognising decline?

Are we providing the right care for people in the last year of life?

How are we listening to people and understanding their needs and wishes?

How can we best support people who are dying and their carers?

Are we working well enough to provide coordinated care?

Take home message

We understand the importance of providing good end of life care with dignity and respect, and we know we have an important role to play

We can recognise change in the people we care for and we know what to do.

We can safely care for people who are seriously ill and we know when to seek help.

We can listen to people and we can help their voice be heard.

We can support people when they are dying at home.

We can give well coordinated care as a team, working well with others.

GSF Domiciliary Care Training Schedule & Overview of workshops and sessions

GSFDC over-view	Key question	Learning outcomes	Activities	Take Home Message	Action plan
Session 1 Overview	Why is it important to provide good end of life care with dignity and respect? What is the role of the domiciliary care worker?	To understand the context of End of Life Care and the role of the domiciliary care worker	Case study SEA Target Bill Challenges	We understand the importance of providing good end of life care with dignity and respect, and we know we have an important role to play	What are you going to do differently now? What else do you need to do? What else do you need to know- what are your learning needs? Other areas
Session 2 Identify	Are we identifying people in the last year of life and recognising decline?	To understand the use of needs based coding in identifying people nearing the end of life	Indicators Needs based coding Needs support matrix	We can recognise change in the people that we care for and we know what to do.	How do we identify people near the end of life and code them? Who do we need to discuss this with? How are you going to use the Needs support matrices? Documentation – how can you best integrate?
Session 3 Assess- clinical	Are we providing the right care for people in the last year of life?	To understand the use of assessment tools for service users and carers, what to do and when to refer	Assessment tools Molly assessment tools Supporting carers	We can safely care for people with a serious illness and we know when to seek help	What assessment tools do you find useful? Who might you communicate your findings with? What other areas do you need to focus on? Other areas
Session 4 Assess- personal	How are we listening to people and understanding their needs and wishes?	To learn about communication skills in advance care planning, the role of listening and reducing hospitalisation	Your ACP Stanley –ACP ACP in groups	We can listen better to people and help their voice be heard	How can we listen better to people? Advance care planning - how do we communicate this to others? Do we need to do this differently Other queries
Session 5 Plan- Dying?	How can we best support people who are dying and their carers?	To learn care in the final days and anticipatory care – 'just in case' thinking	CPR + photo Identifying dying and symptoms of dying? Stanley- minimum protocol Dignity in dying	We can support people when they are dying at home	Being aware of Res and DNACPR discussions Care in the final days and LCP – what can you do? How can you support carers and families in bereavement? Other areas
Session 6 Plan- Coordination	Are we working well enough to provide well-coordinated care?	To understand the importance of good team working and cross boundary care and communication	coordinated care SEA Supporting carers Target	We can give well-coordinated care as a team, working well with others	How can you provide well-coordinated across boundary care? How can you provide spiritual care? How can you support carers? What are your next steps to sustain the work

Grass roots development of GSF

GSF was first developed in 2000 from within primary care - it developed *from the bedside not the board room, from clinicians not committees!* It grew from a strong belief that we are doing well, and we care very much ...but we could do even better. Sometimes, despite our best intentions, things aren't as good as we would like, often due to a lack of planning that could have been addressed with a bit of forethought.

As well as this one, there are now GSF Training Programmes for:-

- Primary Care – basic Foundations Level and Going for Gold
- Care Homes – nursing and residential homes
- Acute Hospitals
- Community Hospitals
- Others e.g. dementia and bereavement
- Plus a toolkit of GSF tools, resources and measures

GSF focuses on improving 'organisational learning' – the way that teams work together and collaborate with their usual day-to-day processes and systems of care.

With the increasing challenge of the aging population and the rising death rate (predicted to rise by 17% from 2012), it is vital that we act now to improve the provision of care for the increasing numbers of people nearing the end of life with ever more complex conditions – caring for people at home, who are nearing the end of life is becoming increasingly important.

Key Messages in End of Life Care

- End of Life Care is important and affects us all
- Most die of non-cancer, co-morbidity in old age
- Too few people die at home/ in their place of choice
- Hospital deaths are expensive, usually not where patients choose to be and often avoidable
- Everyone has a part to play
- GSF helps improve quality and coordination of generalist care

Domiciliary care workers are at the frontline of providing this care. You have a very special role to play!

Head, hands and heart— building step by step to fulfil your potential.

- We talk of improving the 'head, hands and heart' of care – knowledge skills and attitudes. To help people receive the best care possible, it takes all three elements working well together. In GSF we focus mainly on the 'hands' systems, but support also 'head knowledge' and 'heart' elements of care.
- This training programme builds on your current work, but helps towards improved communication, collaboration and co-ordination, especially in cross-boundary areas of working.
- It will give you skills and knowledge, help you know more and organise things more proactively, but

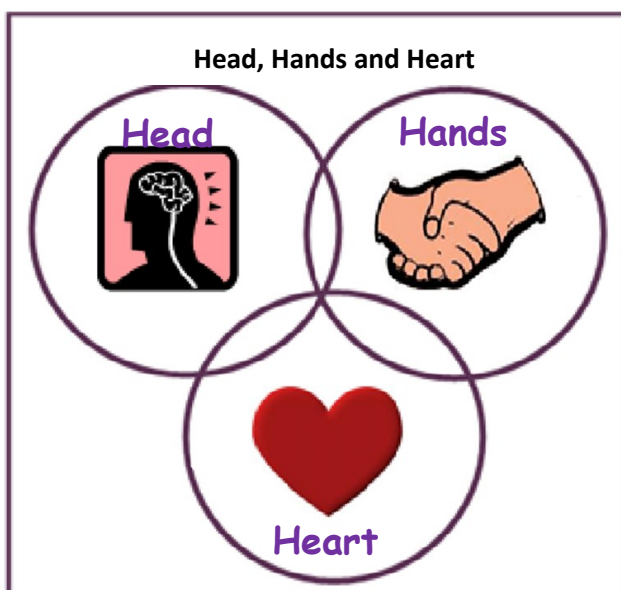
mainly it will help you gain confidence in your ability to give good care for the most vulnerable people

- We aspire to the best care we can provide — the 'gold standard' of care, knowing that in real life this can be tough, but is always worth aiming for.

'We only have one chance to get this right!'

- This is based on adult learning — self motivated and self directed learning, helping you work as a well functioning team (TEAM = Together Everyone Achieves More). It improves organisational systems — the right thing, at the right time and the right person — everyone is involved.

- We can always improve — we learn most when things go wrong. How can we improve care further? Action planning is a key part of this — a practical way of developing your own ideas for best practice.



The Domiciliary Care Training Programme

This interactive course in improving care for people nearing the end of life, is based on the learning of over 12 years of the Gold Standards Framework (GSF) Training Programmes and a strong base of evidence of its use in primary care, care homes and hospitals.

By introducing this programme to Domiciliary Care Workers, it can help to improve the care at home for many people who wish to remain in their own homes, collaborating with primary care teams and others using GSF.

This covers the Skills for Care and Skills for Health Common Core Competencies in End of Life Care

- Care Planning
- Symptom control
- Advance Care Planning
- Communication Skills

What difference does GSF make?

1. **Quality** - Attitude awareness and approach
 - Better quality patient experience of care perceived
 - Greater confidence, awareness, focus and job satisfaction
2. **Coordination/Collaboration** - structure, processes and patterns
 - Better organisation, coordination, documentation & consistency of standards
 - Better communication between teams, co-working and cross boundary care
3. **Patient Outcomes** - hospitalisations, ACP alignment
 - Reduced crises, hospital admissions, length of stay e.g. halve hospital deaths - more patients dying in preferred place
 - Care delivered in alignment with patient and family preferences

The learning will be based on these principles to help you build on your own current experience and stretch yourself as you learn. It will be delivered via 6 interactive workshops delivered by your trainer. You will be working as a group using DVDs, individual workbooks and locally facilitated support.



There are assessments at the start and end of the programme. On successful completion of the programme you will be awarded a certificate of completion. The trainers are also assessed and awarded certificates

Resources, Support and Assessments

Resources - you will receive:

1. **Good Practice Guide and Workbook** to include:
Preparation Guidance
Activities to accompany DVD
2. **DVD/Access to Virtual Learning Zone-** GSF Domiciliary Care to cover all 6 sessions of the programme
3. **Access** to protected domiciliary care area of GSF Web site
4. **On-going support** from your local trainer/ facilitator

Assessment—baseline and follow up measurements of:

- Confidence of staff in End of Life Care—self assessment before and after
- Outcomes – sample of 2 peoples' Supportive Care Analysis before and after (SCA - an adaptation of the GSF After Death Analysis Audit tool)
- Workbook - assessment of knowledge and skills in End of Life Care through case histories

Evaluation of the programme:

- Analysis of learner assessments
- Analysis of SCA audit
- Feedback Survey questionnaire of service users and their families/carers
- Evaluation of training programme – Final feedback at the end
- Evaluation after each workshop

What you will receive at the end:

- Certificate of completion of the training programme once all assessments completed
- Guidance on next steps and sustainability
- Your Domiciliary Care service will be able to confirm how many staff have completed GSF Domiciliary Care Training



Session One

Key Question



- Why is it important to provide good end of life care with dignity and respect?
- What is the role of the domiciliary care worker?

Learning Outcome

To understand the context of End of Life Care and the role of the domiciliary care worker

Activities

1. Case Study SEA
2. Target Practice
3. Case study - Bill
4. Challenges

This session helps meet the following national policy standards:

National Occupation Standards (NOS):
HSC385

National Institute for Clinical Excellence (NICE) Quality Standards in End of Life Care (see appendix):
8, 15, 16

Department of Health End of Life Care Strategy Quality Markers:

8. Be aware of end of life care training opportunities and enable relevant workers to access or attend appropriate programmes dependent on their needs.

Take Home Message

We understand the importance of providing good end of life care with dignity and respect, and we know we have an important role to play.

1. Introduction

2. Identify

3. Assess
Clinical

4. Assess
Personal Care -
ACP

5. Plan Care of
Dying

6. Plan
Coordinated
Care

As a domiciliary carer you will have cared for many different types of service users in the community. Some will be elderly frail, others will be seriously ill and approaching the end of their lives. For those at this important stage of their lives, we want to ensure that the right thing happens at the right time. The term **end of life care** is used in many different ways. In this context we take it to mean the period for which a person is cared for at home for the last period of their life. It is the care that we would like to receive ourselves, or would like to see our parents, brothers, sisters or children receiving when they reach that period of their lives

Key Messages in End of Life Care

End of Life Care is important and affects us all
Most die of non-cancer/co-morbidity in old age
Too few people die at home/in their place of choice
Hospital deaths are expensive and often avoidable
Everyone has a part to play
GSF helps improve quality and coordination of generalist care

The skills which are required to ensure that a person enjoys the best quality of life during his or her time at home are the very same skills that will be required to look after him or her when they are actually dying. This will present you with many challenges.

The introduction invites you to consider whether the care you provide for your service users nearing the end of their life could be improved, particularly in the care of non-cancer patients.

This helps teams to be prepared and to focus on their key areas needing further work in future.

Many consider there are three bottlenecks in community care delivery of End of Life Care.

Three key bottlenecks that GSF can help with



- **Identification of all patients**
particularly those with non cancer
- **Difficult conversations with patients and families,**
advance care planning discussions
- **Effective coordination and proactive planning**
predicting needs and delivering care through
good team working , in alignment with wishes



What is the Gold Standards Framework?

1 Aim – GSF is a framework to deliver a 'gold standard of care' for all people nearing the end of life

"It's about living well until you die"

GSF is a systematic common-sense approach to formalising best practice, so that quality end of life care becomes standard for every person. It helps to identify people in the last year of life, assess their needs, symptoms and preferences and plan care on that basis, enabling them to live and die where they choose. GSF embodies an approach that centres on the needs of service users and their families and encourages inter-professional teams to work together.

"It's less about what you know and more about what you do."

Benefits of GSF

- ↑ Improve quality of care
- ↑ Improve coordination and collaboration
- ↑ Improve home care and cost effectiveness

Quality Improvement

Quality Assurance

Quality Recognition

Essentials of GSF—3 simple steps

Identify

Service users who may be in the last year of life and identify their stage?

Assess

Current and future clinical needs and personal needs

Plan

Coordinated cross boundary care and care of the dying

GSF is about ...

- Enabling Generalists - improving confidence of staff
- Organisational system change
- Patient led - focus on meeting patient and carer needs
- Care for all people regardless of diagnoses - non-cancer, frail
- Pre-planning care in the final year of life - proactive care
- Care closer to home - decrease hospitalisation
- Cross boundary care - home, care home,

GSF Toolkit



Prognostic Indicator Guidance – PIG + Surprise Questions



Use of templates in Locality Registers

Advance Care Planning – Thinking Ahead



Passport Information



After Death Analysis (ADA)

	Pt needs	Support from hospital/SPC	Support from GP
Years			
Months			
Weeks			
Days			

Needs Support Matrix

1. Introduction

2. Identify

3. Assess Clinical

4. Assess Personal Care - ACP

5. Plan Care of Dying

6. Plan Coordinated Care

GSF in practice - what this means for service users and their families

Care of Bill

Reactive care before using GSF, 2000

GP Practice responding to disease symptoms. Worsening of Mr Barker's condition prompts action.



Less choice or control

End of life never discussed, Mr Barker just worried about it but couldn't ask the questions he needed to.

No one asked what was important to him.

Care felt haphazard

Ad hoc visits - no future plan discussed
Duplication e.g. Nurse and GP visit same day
Advice only given if Mr Barker asked. He didn't always know what to ask for.

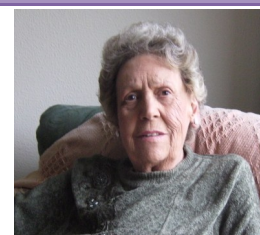
Wife struggling to cope unsupported

When Mr Barker became unwell at a weekend, everyone was upset and panicked. A 999 call led to A&E — 8 hour wait on trolley, no notes available. He died on the ward. His wife didn't realise he was so ill and dying so was not there.

Care of Mrs Jones

Proactive care

Earlier identification of stage of life Mrs Jones was at by the team. Identified as needing priority care. Early Assessment.



More choice and control

Mrs Jones felt in control with an Advance Care Plan. End of life discussions offered sensitively so she felt able to ask the awkward questions and felt reassured.

Planning- regular review and support

The primary care team all seemed to know that Mrs Jones needed priority care, receptionists, nurses and doctors, domiciliary care workers all working together.

All aspects of care considered regularly.

Family and Carers are supported with fewer crises

Home care needs anticipated. The right drugs and equipment in the home. Mrs Jones had 'Passport information' for hospital when needed. The out of hours doctor already had this information when they were called. Admission was avoided. Mrs Jones died at home as she had wanted, with her family around her.

Better outcomes for everyone and most cost effective use of NHS funds

Definition of End of Life Care

General Medical Council, NICE

People are 'approaching the end of life' when they are

likely to die within the next 12 months.

This includes people whose death is imminent (expected within a few hours or days) and those with:

- **advanced, progressive, incurable conditions**
- **general frailty and co-existing conditions that mean they are expected to die within 12 months**
- **existing conditions if they are at risk of dying from a sudden acute crisis in their condition**
- **life-threatening acute conditions caused by sudden catastrophic events.**

GMC definition — (www.gmc-uk.org/static/documents/content/End_of_life.pdf)

Domiciliary Challenges & Solutions

What do you think are the main challenges for you in the care you provide for your service users?

These are some of the answers that others came up with;

Listening to domiciliary care workers, they have identified certain challenges that can affect the seamless care that everyone strives for when delivering end of life care in the community. This training programme is designed to address these challenges and offer solutions that will be beneficial to everyone involved in a person's care.

	Challenges	Solutions
Workforce	Isolation – not considered as members of wider team Lone workers GP's and DN's don't come to meetings Clients admitted to hospital – nursing assessment – not to be returned home Age – young carers – limited life experiences High staff turnover Understanding of role Valued as a care worker	Cascade plan – core team Clinical supervision Information letter Information to hospital on services that domiciliary carers can provide with support from GP and DN for EOLC also CQC issues. Written information on GSF and EOLC (small booklet or Filofax) Job Description – supportive information on career opportunities. Roles and responsibilities of role Factsheet explaining role to fit with PHCT's – raise profile of role
Continuity	Different people visiting Difficult to get information, information not shared - different sources When someone reaches the end of life, care package changes	Allocate staff to specific people – build up teams - for continuity Key worker in team identified Note who does what and how to communicate – ACP, Resuscitation status etc. Give the carers the skills to continue, giving the higher level of care required for end of life care
Communication	People won't communicate with care support workers	Means of communication – inclusion in discussions of care management Check confidentiality clause in contracts Form links with other services (NH support team, community matrons etc.) Identify templates to assist with communication with health care professionals

Home Work

Following on from Session 1 of the domiciliary care training programme we are asking you to complete the following tasks:

- ⇒ Complete your action plan
- ⇒ You should complete the target exercise as a team to review what you do currently for your service users
- ⇒ Complete the self assessment confidence exercise
- ⇒ Consider as a team the current practice and care that you provide to service users who are dying using the supportive care analysis

Take home message 1



We understand the importance of providing good end of life care, with dignity and respect and we know we have an important role to play.

1. Introduction

2. Identify

3. Assess
Clinical

4. Assess
Personal Care -
ACP

5. Plan Care of
Dying

6. Plan
Coordinated
Care

Action Plan – Session 1



	To do		By when
1	What will you do differently now?		
2	What else do you need to do?		
3	What else do you need to know? – what are your learning needs		
4	Other areas		



Resources for session 1

Activities

Activity 1—Significant Event Analysis

Activity 2 —Target exercise

Activity 3—Bill

Activity 4—Challenges



Evaluations—Pre training

Self assessment of confidence

Supportive care analysis

Detailed evaluation form to be completed after each session





It is good practice to complete an SEA as a team and or individually following the death of a service user

What went well?
What didn't go so well?
What could be improved?
Action Plan





Activity 2—Target Exercise

Self-Reflection Target Exercise

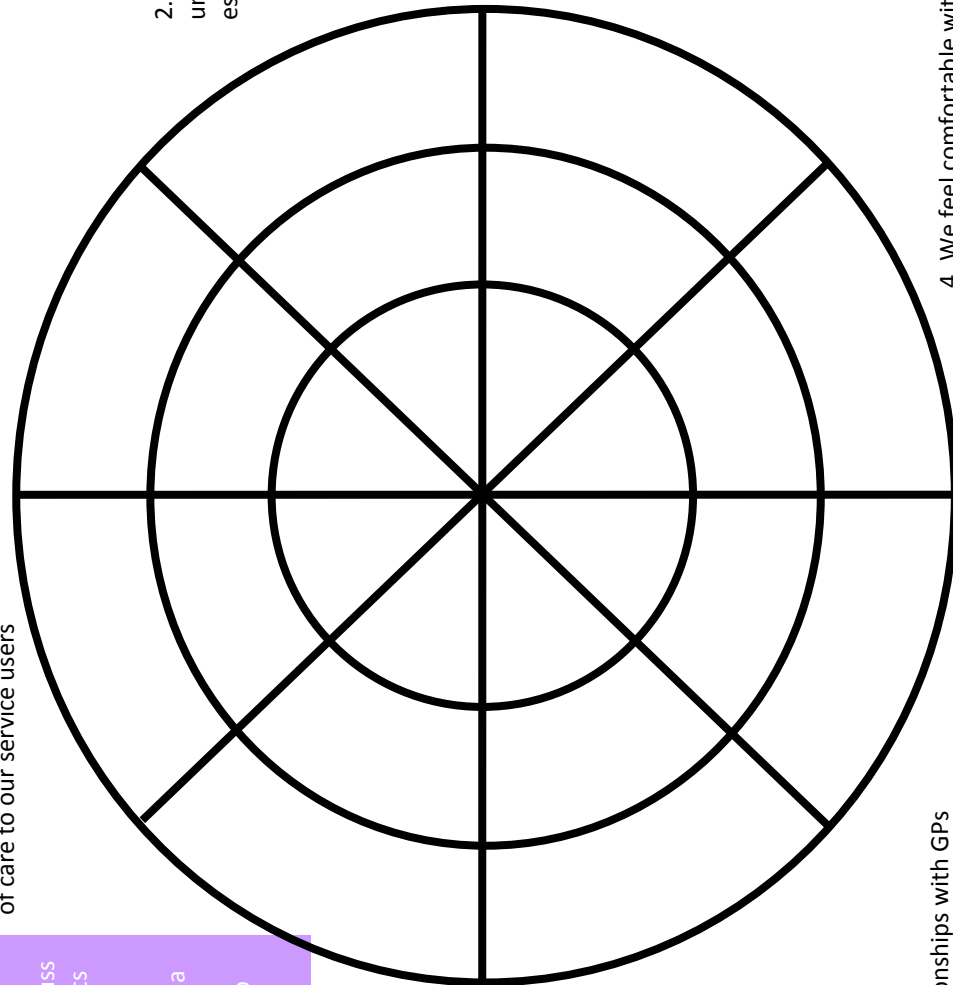
On the target there are eight statements. As a domiciliary care agency, go round every statement and get each person to make a dot on the target with the marker pen to 'score' how much you agree with each statement. If you strongly agree you should put a dot in the middle circle. If you disagree your mark goes in the outer circle. It's a snapshot. Go with your initial feelings and do not reflect at huge length. Do not discuss anything or challenge each other while dots are being placed on the target. When you have all marked all the segments of the target, discuss the results. Where you are a high achieving provider of care services – identify your top 3 priorities **1 2 3** next to those statements

8. We provide good continuity of care to our service users

1. If a close family member was dying and was a service user of this domiciliary care agency, you would feel happy with the care

2. We do everything we can to avoid unnecessary hospital admissions, especially in the last stages

3. We feel confident in assessing people's clinical conditions and knowing when to seek help



7. We have protocols in place which allow us to administer drugs to service users

6. We use a care of the dying pathway, in conjunction with district nurses,

5. We have very good working relationships with GPs and other health and social care professionals and good means of team working e.g. via the coordinator

4. We feel comfortable with advance care planning discussions with our service users. These are discussions to find out the service user's choices for their care when they approach the end of life phase. not care packages but discussions asking how and where they would like to be cared for





Activity 4 Domiciliary Care – Challenges and Solutions

Challenge	Problem	Solution
Workforce		
Continuity		
Communication		
Other		



Baseline Pre training evaluations

The accompanying exercises will also help you to identify your learning needs, and give a baseline measurement prior to undertaking this programme.

The key tasks you will need to complete at this point are:

- Self Assessment of Confidence in End of Life Care
- Complete data for 1 of your service users using the Supportive Care Analysis

These should be completed on the VLZ at the end of session 1

- Detailed evaluation to be completed after **each** session and handed to your trainer at the end of the programme

1. Self assessment confidence
2. Supportive care analysis
3. Detailed evaluation form



Staff Baseline Confidence Assessment Survey Questionnaire –before training

Care Agency:		To be completed online then click Enter Username & Password or manually and pass completed survey to your trainer
Name:		
Date completed:		
Job Title:		
Qualifications eg NVQ		

1. I feel I need to know more about the following areas in end of life care?

a) Communication skills	Strongly disagree	0 1 2 3 4 5 6 7 8 9 10	Strongly agree
b) Holistic assessment	Strongly disagree	0 1 2 3 4 5 6 7 8 9 10	Strongly agree
c) Symptom management	Strongly disagree	0 1 2 3 4 5 6 7 8 9 10	Strongly agree
d) Advance care planning	Strongly disagree	0 1 2 3 4 5 6 7 8 9 10	Strongly agree
e) Care planning	Strongly disagree	0 1 2 3 4 5 6 7 8 9 10	Strongly agree
f) Care of carers	Strongly disagree	0 1 2 3 4 5 6 7 8 9 10	Strongly agree
g) Care of the dying	Strongly disagree	0 1 2 3 4 5 6 7 8 9 10	Strongly agree

h) Comments: _____

2. Do you have any experience of the National End of Life Care Tools?

Gold Standard Framework	Yes (aware of) ☐	Yes (have used) ☐	No ☐
Preferred Priorities for Care	Yes (aware of) ☐	Yes (have used) ☐	No ☐
Liverpool Care of The Dying Pathway	Yes (aware of) ☐	Yes (have used) ☐	No ☐
Advance Care Planning	Yes (aware of) ☐	Yes (have used) ☐	No ☐

Comments: _____

3. I feel confident in caring for people nearing the end of life?

Strongly disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree

4. I feel confident in recognising service users who may be in the last year of life?

Strongly disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree

5. Do you use any specific tools as a trigger to identify service users in the last year of life? Yes ☐ No ☐

Please state: _____



6. I feel confident in having open communication with service users and relatives about a person's deteriorating condition?

Strongly disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree

7. I feel confident in having discussions with service users about their personal wishes, preferences and concerns (Advance Care Planning)?

Strongly disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree

8. I feel confident in having discussions with relatives or carers of service users about their concerns, needs and preferences (Advance Care Planning)?

Strongly disagree 1 2 3 4 5 6 7 8 9 10 Strongly agree

9. Do you develop a plan for future care in the light of such discussions? Yes ☐ No ☐

Comments: _____

10. Do you routinely discuss service users nearing the end of life care at regular Multi Disciplinary Team meetings? Yes ☐ No ☐

Comments: _____

11. Do you routinely transfer information regarding end of life care and patient's wishes (including Advance Care Planning discussions of needs and preferences) to?

GP Practice Yes ☐ No ☐

District Nursing Team Yes ☐ No ☐

Other, please specify Yes ☐ No ☐ _____

12. I need to know more about the following areas of care? Please state:

Any other comments or suggestions?



Name of Organisation

Names of main carers involved in care

Date of Completion.....

Service User detail	Service User
Main conditions of Service User	
Age of Service User	
Are they on their GP palliative care register?	Yes No
Do they have a needs based code?	blue greenamber red none
Have you been involved in any planning discussions about key issues or concerns about the service user with other care providers eg GP, District Nurse, Community Matron, Specialist Nurse, Out of Hours service, Hospice at Home etc?	Yes No Who? _____
How do you communicate with others involved in providing ongoing care—GP, District Nurse, Community Matron, Specialist Nurse, Out of Hours service, Hospice at Home etc?	Written Telephone/Verbal Face to Face
Are you aware if there has been a recorded advance care plan discussion?	Yes No verbal only not recorded
Are their wishes/preferences being listened to and respected/acted upon at present?	Yes No Not known
Are you aware of the service users preferred place of care?	Yes No Not known
Main place of care	Home Care Home Hospice Hospital Other
For the family/carers of the service user, were their needs assessed?	Yes No Not known
Number of crisis admissions to hospital in past 6 months of this service user, if this is known	----- / not known
Length of stay in hospital in past 6 months if this is known	----- / not known
If the service user died, did they die in their preferred place of care?	Yes No Not known
Was the care they received in accordance with their wishes?	Yes No Not known
Over the course of their care	
Positives - What went well?	
Negatives - What didn't go so well?	
Ideas - What could be improved upon? Eg: better communication Earlier identification of deterioration	



Detailed Evaluation Form – GSF Domiciliary Care Training Programme

— to be completed by learner after each workshop

Care Agency Name

Date

Delivery and Presentation of DVD sessions:		☹						☺
	Content	1	2	3	4	5	6	
	Overall Value to me	1	2	3	4	5	6	
Personal Benefit (How much did you personally gain from the course?):		☹						☺
	Content	1	2	3	4	5	6	
	Overall Value to me	1	2	3	4	5	6	
Usefulness to your work:		☹						☺
	Content	1	2	3	4	5	6	
	Overall Value to me	1	2	3	4	5	6	
Session One – Overview :		☹						☺
Date:	Content	1	2	3	4	5	6	
	Overall Value to me	1	2	3	4	5	6	
Session Two - Assessing Service Users:		☹						☺
Date:	Content	1	2	3	4	5	6	
	Overall Value to me	1	2	3	4	5	6	
Session Three – Assessing Clinical Needs:		☹						☺
Date:	Content	1	2	3	4	5	6	
	Overall Value to me	1	2	3	4	5	6	
Session Four – Assessing Personal Needs:		☹						☺
Date:	Content	1	2	3	4	5	6	
	Overall Value to me	1	2	3	4	5	6	
Session Five – Planning Care Across Boundaries:		☹						☺
Date:	Content	1	2	3	4	5	6	
	Overall Value to me	1	2	3	4	5	6	
Session Six - Planning Care In The Final Days :		☹						☺
Date:	Usefulness	1	2	3	4	5	6	
	Interest to me	1	2	3	4	5	6	

PTO



Things that went well...



Things that could be improved...

What are the key things that you have learnt

General Comments:

State 3 key changes in your work as a result of this training:

1

2

3