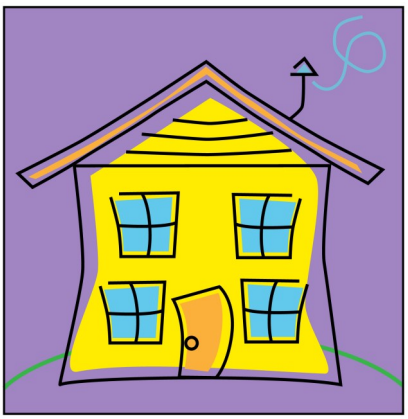
The Gold Standards Framework in Domiciliary Care Training Programme



Good Practice Guide

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

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

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, support and accreditation 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 291 898

Prof Keri Thomas, Founder and 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, Deputy Lead Nurse
Supported by the GSF Centre administration team.

Contents

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 programme as we believe this is an outstanding tool for bringing the standards of hospice care out into the care home setting"

Penny Hansford, Director of Nursing, St Christopher's Hospice London

"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

RCGP Royal College of General Practitioners

"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

Royal College of Nursing

"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 about the 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. It's 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 have other serious concerns. Some have unfinished business to sort out, practical but often emotional and spiritual too, 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 aim 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, 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 Giles | Maggie Stobbart-Rowlands | Keri Thomas | and the rest of the GSF Team

This page is intentionally left blank.

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 and 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 and 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?
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:-

One main challenge

↓

A key question

↓

An area to improve

↓

Training on how to improve

↓

Take home message – what to do in practice

↓

Better outcome when you meet the challenges

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	Key Question	Take Home Message
Isolation, poor collaboration. Low confidence & feel unvalued. Inconsistency of care, not fulfilling our role, could do more.	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?	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
Lack of anticipatory planning & consistency, crisis management. Communication difficulties.	Are we identifying people in the last year of life and recognising decline?	We can recognise change in the people we care for and we know what to do.
Understanding best clinical care and what can be done and who to ask. Lack of knowledge and information.	Are we providing the right care for people in the last year of life?	We can safely care for people who are seriously ill and we know when to seek help.
Relationships, deeper conversations, helping people live as they would like to. Communication issues & time pressures.	How are we listening to people and understanding their needs and wishes?	We can listen to people and we can help their voice be heard.
People admitted to hospital to die in crisis care rather than dying at home.	How can we best support people who are dying and their carers?	We can support people when they are dying at home.
Working together within the teams. Working with GPs DNs and others.	Are we working well enough to provide coordinated care?	We can give well coordinated care as a team, working well with others.

GSF Domiciliary Care Training Schedule & Overview of Workshops and Sessions

GSFDC Overview	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
Session5 Plan - Dying?	How can we best support people who are dying and their carers?	To learn about 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 – 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
- 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.

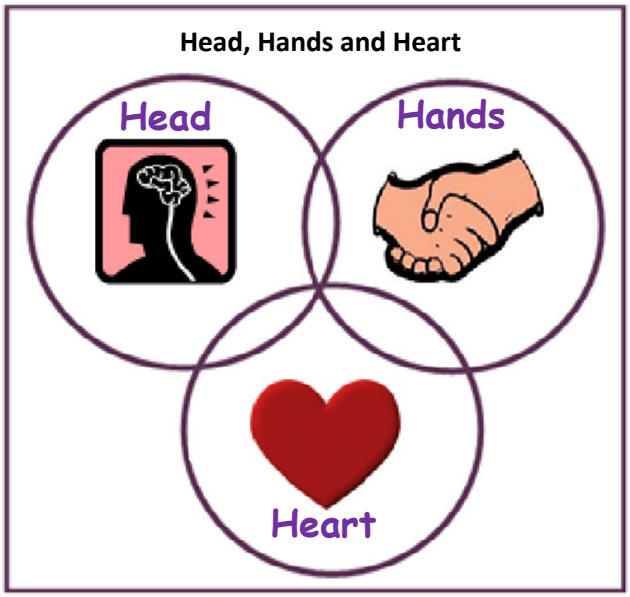
Key Messages in End of Life Care

- **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 the Virtual Learning Zone, 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 the Virtual Learning Zone

2. **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 Website
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

This page is intentionally left blank.

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.

As a Domiciliary Care worker 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 them 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

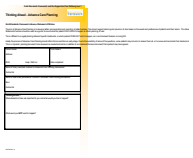
Coordinated cross boundary care and care of the dying

GSF is about…

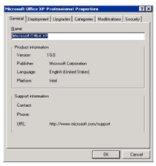
- Enabling generalists - improving confidence of staff
- Organisational system change
- Being patient led - focus on meeting patient and carer needs
- Care for all people regardless of diagnosis - non-cancer, frail
- Pre-planning care in the final year of life - proactive care
- Care closer to home -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

GSF Toolkit

Prognostic Indicator Guidance – PIG + Surprise Questions

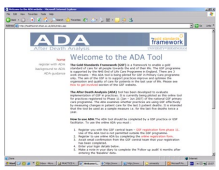


Advance Care Planning – Thinking Ahead



Use of templates in Locality Registers

Passport Information



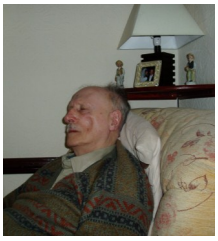
After Death Analysis (ADA)

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

Needs Support Matrix

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

Care of Mr Barker



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 the 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 GPs and DNs 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 PHCTs - 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 (NHS 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 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

⇒ Complete your action plan

⇒ You should complete the target exercise as a team to review what you do currently for your service users

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.

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		

This page is intentionally left blank.

Resources for Session 1

Evaluations - Pre Training

Self-assessment of confidence

Supportive care analysis

Detailed evaluation form to be completed after each session

Activities

Activity 1 - Significant Event Analysis

Activity 2 - Target exercise

Activity 3 - Bill

Activity 4 - Challenges

This page is intentionally left blank.

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 start 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 of confidence
2. Supportive Care Analysis
3. Detailed evaluation form

This page is intentionally left blank.

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 e.g. NVQ		

I feel I need to know more about the following areas in End of Life Care?

1. **Communication skills**	Strongly disagree	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Strongly agree
2. **Holistic assessment**	Strongly disagree	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Strongly agree
3. **Symptom management**	Strongly disagree	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Strongly agree
4. **Advance care planning**	Strongly disagree	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Strongly agree
5. **Care planning**	Strongly disagree	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Strongly agree
6. **Care of carers**	Strongly disagree	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Strongly agree
7. **Care of the dying**	Strongly disagree	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Strongly agree

Comments: _____

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

8. **Gold Standard Framework** **Yes (aware of)** ☐ **Yes (have used)** ☐ **No** ☐
9. **Individual Plan of Care for End of Life** **Yes (aware of)** ☐ **Yes (have used)** ☐ **No** ☐
10. **Preferred Priorities for Care** **Yes (aware of)** ☐ **Yes (have used)** ☐ **No** ☐
11. **Advance Care Planning** **Yes (aware of)** ☐ **Yes (have used)** ☐ **No** ☐

Comments:_____

12. 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**

13. 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**

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

Please state:_____

15. 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

16. 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

17. 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

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

Comments:_____

19. Do you routinely discuss service users nearing the End of Life Care at regular Multi Disciplinary Team meetings? Yes ☐ No ☐

Comments:_____

Do you routinely transfer information regarding End of Life Care and patient's wishes (including Advance Care Planning discussions of needs and preferences) to?

20. GP Practice Yes ☐ No ☐

21. District Nursing Team Yes ☐ No ☐

22. Other, please specify Yes ☐ No ☐ _____

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

_____

_____

Any other comments or suggestions?

_____

Supportive Care Analysis - Before

Name of Organisation .....

Names of main carers involved in care Date of Completion.....

Service User Detail	Service User
Main conditions of Service User (main illness/disability)	
Age of Service User	
Are they on their GP palliative care register?	Yes No
Do they have a needs based code?	Blue Green Amber Red None
Have you been involved in any planning discussions about key issues or concerns about the service user with other care providers e.g. 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 on-going 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? E.g.: Better communication Earlier identification of deterioration	

This page is intentionally left blank.

Detailed Evaluation Form - GSF Domiciliary Care Training Programme

To be completed by learner after each Workshop

Care Agency Name **Date**

		☹					☺
Delivery and Presentation of VLZ 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

Activity 1 - SEA (Significant Event Analysis)

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

This page is intentionally left blank.

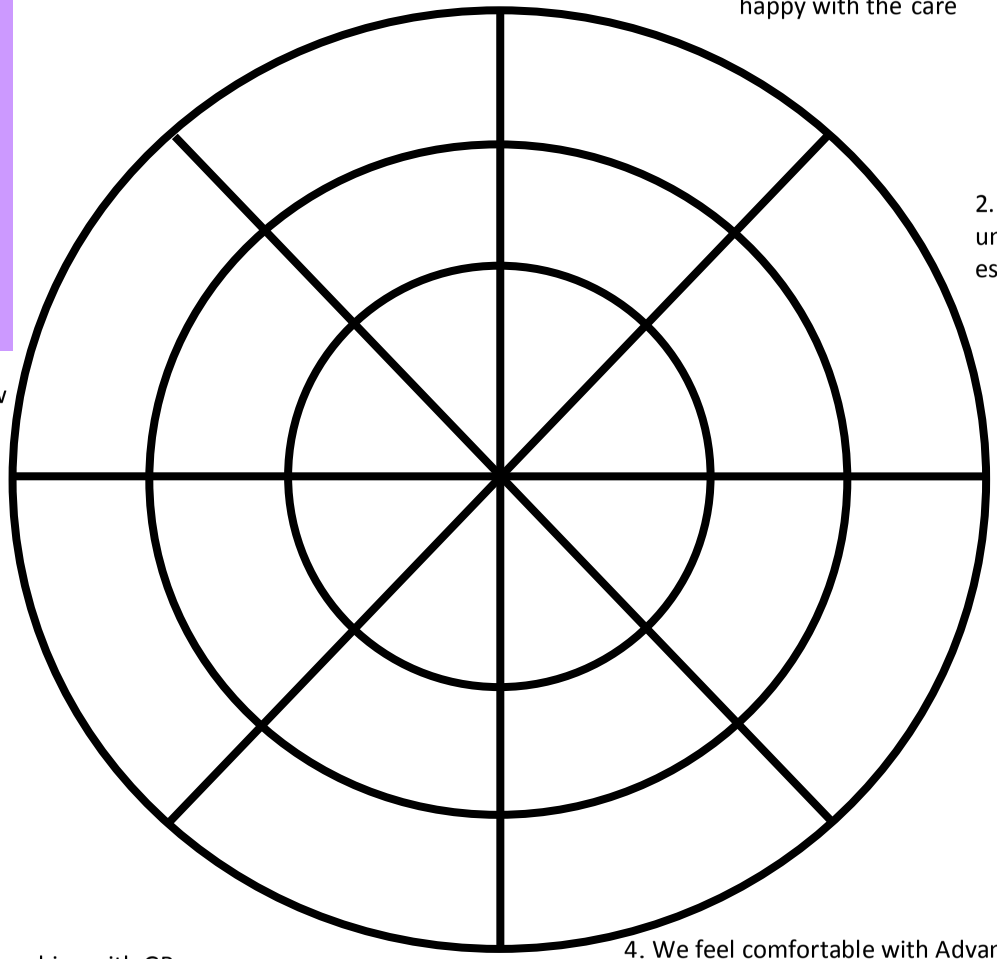
Self-Reflection Target Exercise

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

Activity 2-Target Exercise

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

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

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

6. We use an individual person centred plan of care for end of life 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 users 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.

the gold standards framework Domiciliary Care

This page is intentionally left blank.

Activity 3 Bill

Consider the following questions and use the template to record your answers.

How has Bill been treated?
How would you want to be treated?
What safeguarding issues might you wish to consider?

This page is intentionally left blank.

Activity 4 Domiciliary Care - Challenges and Solutions

Challenge	Problem	Solution
Workforce		
Continuity		
Communication		
Other		

This page is intentionally left blank.

Session Two

Key Question

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

Learning Outcome

To understand the use of Needs Based Coding in identifying people nearing the end of their life

Activities

1. Indicators
2. Needs Based Coding
3. Needs Support Matrix

This session helps meet the following national policy standards:

National Occupation Standards (NOS):
HSC385
HSC387
HSC3100

National Institute for Clinical Excellence (NICE) Quality Standards in End of Life Care (see appendix):
1, 9, 15

Department of Health End of Life Care Strategy Quality Markers:
1. Have an action plan for the delivery of high quality End of Life Care, which encompasses patients with all diagnoses, and is reviewed for impact and progress.
2. Institute effective mechanisms to identify those who are approaching the end of life
10. Monitor the quality and outputs of End of Life Care and submit relevant information for local and national audits.

Take Home Message

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

Identifying Which Service Users May Be In The Final Years Or Months Of Life

Why we do it - benefits

For many people this is the hardest area to get right. Once identified and included on the GP palliative care/GSF register, then the coordinating process is found to be considerably easier. We all find this difficult and we could all improve!

You may decide to keep a register of your service users that are in the last year of life, however we strongly recommend that this needs to be linked with the service user's GP Practice register.

The aim is that you are aware of the GP's register and that you communicate with the GP regarding those service users that you have identified.

The GSF National Primary Care Audit Snapshot in 2009, involved the records of over 4500 patients in 502 GP practices using ADA for all patients who had died in February and March 2009. (see http://www.goldstandardsframework.org.uk/NewsandUpdates)

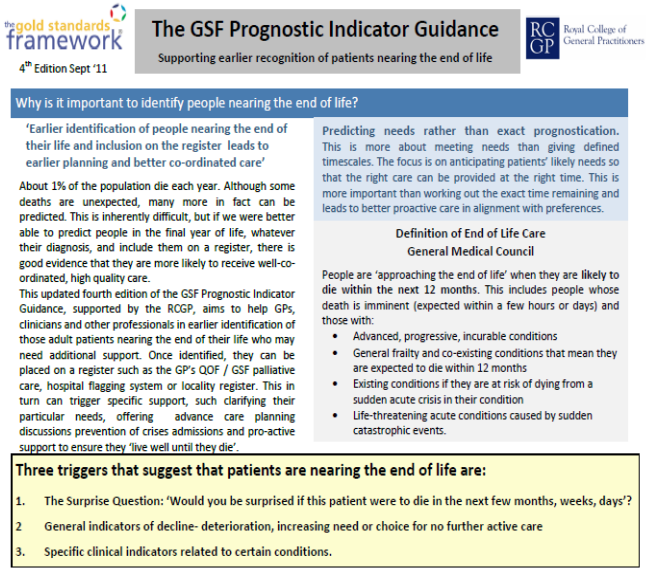
Identification was found to be one of the key bottlenecks and weak areas. This showed that we need to:

Identify more people

- Only **27%** of all deaths were on the palliative care register
- Practices said half of deaths were unpredictable but the National Audit Office says less than **10%** are unpredictable
- **15%** more missed out on care but could have been predicted

Identify more people with diagnoses other than cancer

- **26%** who died had cancer, yet **69%** of the people on the register had cancer



the gold standards framework
4th Edition Sept '11

The GSF Prognostic Indicator Guidance

Supporting earlier recognition of patients nearing the end of life

RCGP Royal College of General Practitioners

Why is it important to identify people nearing the end of life?

'Earlier identification of people nearing the end of their life and inclusion on the register leads to earlier planning and better co-ordinated care'

About 1% of the population die each year. Although some deaths are unexpected, many more in fact can be predicted. This is inherently difficult, but if we were better able to predict people in the final year of life, whatever their diagnosis, and include them on a register, there is good evidence that they are more likely to receive well-co-ordinated, high quality care.

This updated fourth edition of the GSF Prognostic Indicator Guidance, supported by the RCGP, aims to help GPs, clinicians and other professionals in earlier identification of those adult patients nearing the end of their life who may need additional support. Once identified, they can be placed on a register such as the GP's QOF / GSF palliative care, hospital flagging system or locality register. This in turn can trigger specific support, such clarifying their particular needs, offering advance care planning discussions prevention of crises admissions and pro-active support to ensure they 'live well until they die'.

Predicting needs rather than exact prognostication. This is more about meeting needs than giving defined timescales. The focus is on anticipating patients' likely needs so that the right care can be provided at the right time. This is more important than working out the exact time remaining and leads to better proactive care in alignment with preferences.

Definition of End of Life Care
General Medical Council

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.

Three triggers that suggest that patients are nearing the end of life are:

1. The Surprise Question: 'Would you be surprised if this patient were to die in the next few months, weeks, days'?
2. General indicators of decline- deterioration, increasing need or choice for no further active care
3. Specific clinical indicators related to certain conditions.

GSF Prognostic Indicator Guidance

Identifying patients with advanced disease in need of palliative/supportive care for register.

Three triggers:

1. Surprise question: 'Would you be surprised if this person was to die within the next year?'
2. Patient preference for comfort care / need - General indicators of decline
3. Clinical Indicators - Suggested that all patients on register are offered an ACP discussion

GSF - How Domiciliary Care Agencies Can Use GSF Supportive/Palliative Care Register

C1 Communication	GSF resources/templates available on the website
• Agencies maintain a GSF Supportive Care Register (palliative care register). • This can be paper or electronic. The register is used to plan and monitor patient care. • The register should include patients identified as being in the last 6-12 months of life and should include people with cancer and non cancer diagnosis. • You may want to keep a register of your service users that is linked with their GP practice.	GSF Supportive Care Register templates: SCR1 and SCR2
The register can be colour coded so that proactive care can be planned according to patient need/prognosis. This can support the larger agencies that could have more than 20 patients identified for the Supportive Care Register. A colour coding system is included in the Prognostic Indicator Guidance: ✦ **Blue** – year ✦ **Green** – year/months ✦ **Amber** – months/weeks ✦ **Red** – weeks/days	GSF Prognostic Indicator Guidance to support identification of patients in the last 6-12 months of life
The register is used to support proactive planning of patient care at regular primary care team meetings. The meetings should ideally be monthly.	
The aim of the meeting should be to: Support flow of information and communication within the care agency team ✦ Promoting proactive care and ensuring appropriate care is being coordinated to meet the needs of identified patients ✦ Promoting Advance Care Planning ✦ Reflective practice and evaluation of care, to clarify areas for future improvement at service user level.	

Identify - Needs Based Coding

Surprise Question
Use of Needs Based Coding
Use of Needs Support Matrices

A All - stable from diagnosis	year
B Unstable, advanced disease	months
C Deteriorating, exacerbation	weeks
D Last days of life pathway	days

Use of Needs Based Coding

Communicating to others

- Records/notes can be colour coded or tagged, card filed or white board used in private staff area
- The coding can be shared with others e.g. GPs, District Nurses, out of hours etc.
- Care workers can specifically direct the GPs to those thought to be most unwell e.g. Cs and Ds / Amber/Reds

In some areas this can lead to active support e.g. coding amber leads to additional DN support

Predicting and meeting needs

- The Needs Based Coding leads to use of the Needs Support Matrices as a checklist to ensure proactive care
- These Matrices are of varying types - some general and some for specific disease groups
- They are not an exhaustive list and can be added to with individual people or circumstances
- Others are available from the National GSF Centre
- They have been successfully used in care homes and increasingly in hospitals to ensure that nothing has been forgotten at the varying stages and that good proactive management is made routine practice
- Some laminate the sheets and include them next to notes

This can help focus on provision of different support e.g. the role of GPs, specialists etc.

Note:- People can 'move' up and down the coding (as in example in the DVD film)

The introduction of the stable, unstable, deteriorating and dying categories has been a useful and simple method for care support staff to help identify patients/residents of care homes on their illness journey."

Care Home Nurse GSFCH Phase 4

Example of Modified GSFDC Needs Support Matrix (can be amended as needed)

Name:..... DOB:.....

A	B	C	D	After Care
Assessment of needs, level of dependency and level of care ☐	Regular team monthly review at meeting and needs assessed ☐	Regular team review at least weekly and needs assessed ☐	Recognition of dying by the team ☐	Support for relatives and early bereavement care ☐ Support and debriefing for other staff ☐ Removal of equipment ☐ Significant event analysis ☐ Audit – after death analysis ☐
Advance care plan or leaflet to help planning discussion ☐	Support from district nurses if not involved ☐ Plan of action developed with GP/ DN ☐	Support from district nurses if not involved ☐ Plan of action reviewed with GP/DN ☐	Support from district nurses if not involved ☐	
Assessment of spiritual and social needs – 'what is important to you?' ☐	Assessment of needs of relatives and support provided ☐ Communication with GP practice team and others ☐	Assessment of needs of relatives and support provided – increased contact ☐ Communication with GP practice team and others ☐ Discuss anticipatory drugs with GP/ DN ☐	Increased contact— with relatives and support provided— discussed deterioration and given other relevant information ☐ Increased communication with GP practice team and others e.g. DNs, specialists ☐ Check anticipatory drugs in place ☐	
Assessment of financial need – involvement of social worker ☐	Advance care plan reviewed or leaflet to help planning discussion ☐ DNAR/AND/ADRT status reviewed ☐	Advance care plan reviewed care provided as requested ☐ DNAR/AND/ADRT status reviewed ☐ Spiritual or religious care according to wishes considered ☐	Advance care plan reviewed and care provided in alignment with wishes ☐ DNAR/AND/ADRT status reviewed ☐ Spiritual or religious care according to wishes considered ☐	
	Check if DS1500/continuing care funding or other benefits are required ☐	Check if DS1500/continuing care funding or other benefits are required ☐ Increase care package ☐ Specialist equipment - beds/mattress etc. ☐	Increase care package ☐ Specialist equipment - beds/mattress etc. ☐ Marie curie/hospice at home/night sitting service ☐	
		Contact numbers for all Out Of Hours teams ☐	Contact numbers for all Out Of Hours teams ☐	
	Reduce chance of avoidable hospital admission ☐	Reduce chance of avoidable hospital admission ☐	Reduce chance of avoidable hospital admission ☐	

Sample sheet for each service user

Name:..... DOB:.....

Diagnosis:.....

DATE	A	B	C	D	After Care	COMMENTS	Signed

GSF Needs-Support Matrices *for End of Life Care in the home - used with the needs based prognostic coding to predict and achieve the right care at the right time every time.*

1. Elderly Care Needs-Support Matrix

	Needs	Support
Underpinning Plans	Planned framework of care e.g. -Attitude -Patterns of working -Outcomes e.g. dying at home	▪ Agreed ethos/ 'culture of care agency and priority for end of life care ▪ Systems in place e.g. GSF, accessing equipment, working with GP, district nurses and specialists etc ▪ Ongoing education for staff and at induction ▪ Ongoing addressing of spiritual needs ▪ Other.....
A Years	Adjustment to living well in a new home, with regular review of care	▪ Introduction and preparation for GSF ▪ Assessment of needs , level of dependency and level of care ▪ Advance Care plan including preferred place of care and DNACPR discussion ▪ Spiritual and social needs assessed -'what is important to you?' ▪ Other.....
B Months	Regular proactive review of patient needs and care.	▪ Communication with GP, district nurses, primary care team, CNS ▪ Advance care plan reviewed ▪ Assessment of family needs, level of care involvement etc ▪ Assessment and/or Continuing Care Funding review of care. ▪ Other.....
C Weeks	Preparing for final stage - seeing family	▪ Regular Assessment of needs and symptoms at each stage and agreed management ▪ Regular discussion within team and increased proactive review by GP, DNs, CNS etc ▪ Increased contact with family ▪ Advance care plan rechecked and preference for place of care reassessed and enabled ▪ Continuing Care Funding review if needed ▪ Sending of OOH Handover Form if not already sent by GP/district nurse ▪ Anticipatory prescribing - just in case drugs in the home ▪ Other.....
D Days	Preparation for death in preferred place - resisting transfers	▪ Diagnosing Dying by MDT ▪ Use of Care Pathway for Final days e.g. minimum protocol ▪ Close contact with GP and district nurses (+OOH Handover form sent DNAR status) ▪ Contact with family increased, discuss prognosis and provide some pre-bereavement care. ▪ Follow symptom control guidance ▪ Spiritual and/or religious care according to needs ▪ Other.....
Aftercare		▪ Verification of death procedure clarified - who to contact ▪ Staff protocol for after death care ▪ Bereavement care for family ▪ Bereavement care for other residents e.g. remembrance service ▪ Staff support, debriefing ▪ Audit of care provision e.g. After death analysis ▪ Other.....

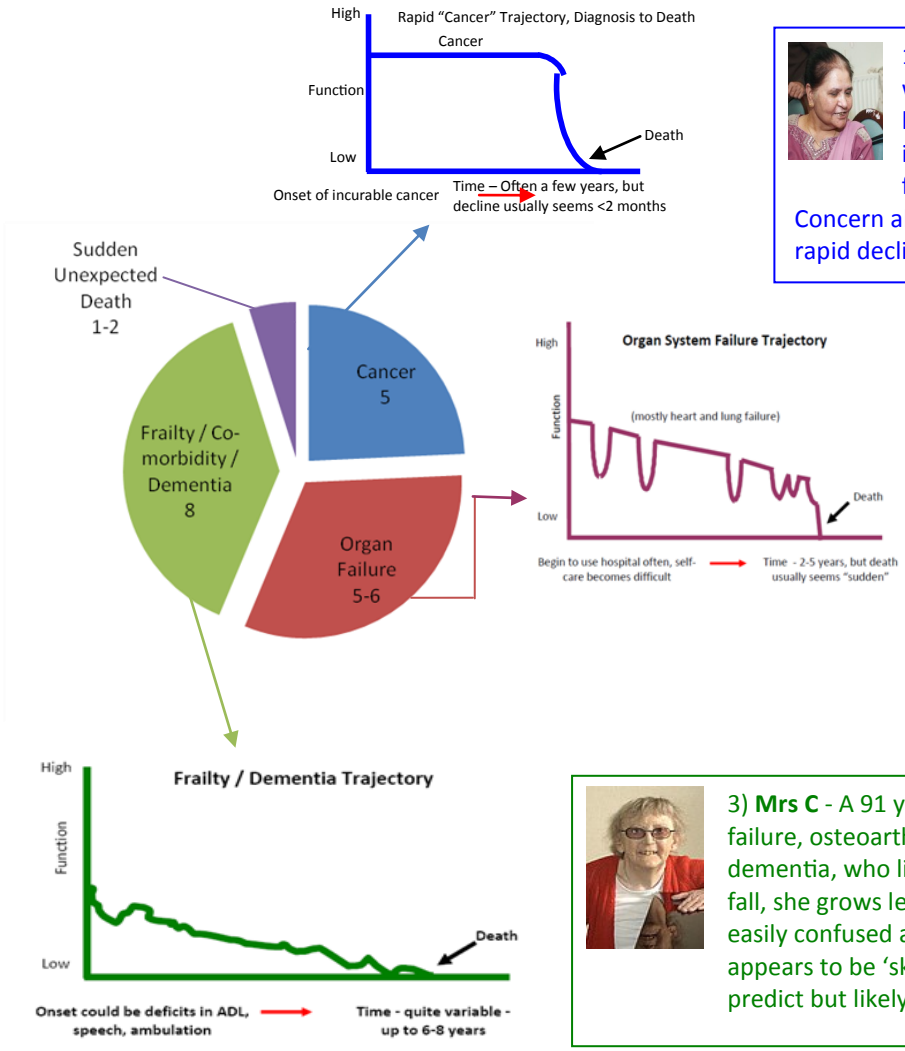
Guidance on Coding and Identification of Likely Prognostic Stage of Service Users

We are aware that there are different illness trajectories in the final years and months of life. People have differing needs at different times during the course of their illness and yet some of these follow a similar pattern that becomes apparent to healthcare providers. It is inherently difficult to accurately predict the exact stage that someone has reached in their illness trajectory, yet if this were possible, then there would be more likelihood that the right thing would happen at the right time for every person and that their needs would be anticipated and met.

In our experience, using the GSF Needs Based Coding extensively in care homes and in primary care, this simple tool has helped ensure that staff begin to anticipate and predict patient's needs earlier and can meet these needs more proactively. It is not about prognostication but about estimating likely needs at different times, leading to better care.

Three Ways of Dying: Rapid, Erratic and Slow Dying Trajectories – After Lynn

Average GP's workload - average 20 deaths/GP/year approximate proportions



Typical Case Histories

1) **Mrs A** - A 69 year old woman with cancer of the lung and known liver secondaries, with increasing breathlessness, fatigue and decreasing mobility. Concern about other metastases. Likely rapid decline.

2) Mr B - An 84 year old man with heart failure and increasing breathlessness who finds activity increasingly difficult. He had 2 recent crisis hospital admissions and is worried about further admissions and coping alone in future. Decreasing recovery and likely erratic decline exacerbation.

3) **Mrs C** - A 91 year old lady with COPD, heart failure, osteoarthritis, and increasing signs of dementia, who lives in a care home. Following a fall, she grows less active, eats less, becomes easily confused and has repeated infections. She appears to be 'skating on thin ice'. Difficult to predict but likely slow decline.

Definitions of 'Phase of Illness'

Start of phase	End of phase	For example
Stable: • Patient problems and symptoms are adequately controlled by established plan of care and • Further interventions planned to maintain symptom control and quality of life **and** • Family/carer situation is relatively stable and no new issues are apparent	**Stable:** • The needs of the patient and or family/carer increase, requiring changes to the existing care plan (ie the patient is now unstable, deteriorating or terminal)	Symptoms and other concerns are well controlled and stable. Family carers are aware of how to access support in the event of change.
Unstable: An urgent change in the plan of care or emergency treatment is required **because** • Patient experiences a new problem that was not anticipated in the existing plan of care, **and/or** • Patient experiences a rapid increase in the severity of a current problem; **and/or** • Family/ carers' experience changes which impact on patient care	**Unstable:** • The new care plan is in place, it has been reviewed and no further changes to the care plan are required (ie the patient is now reverting to the stable or deteriorating phase) **and/or** • Death is likely within days (ie patient is now terminal)	Symptoms and overall condition need regular review because they are unpredictable and at risk of worsening quickly. Informal carers need additional support as condition is unpredictable.
Deteriorating: The care plan is addressing anticipated needs but requires periodic review **because** • Patient experiences an anticipated and gradual worsening of existing problem **and/or** • Patient experiences a new but anticipated problem **and/or** • Family/carers experience gradual worsening distress that is anticipated but impacts on the patient care	**Deteriorating:** • Patient condition plateaus (ie patient is now stable) **or** • An urgent change in the care plan or emergency treatment is required **and/or** family/ carers experience a sudden change in their situation that impacts on patient care, and requires urgent intervention (ie patient is now unstable) **or** • Death is likely within days (ie patient is now terminal)	Symptoms and overall condition are gradually worsening, but in an anticipated way. Informal carers may need pre-emptive support to facilitate on-going care
Terminal: Death is likely within days	**Terminal:** Patient dies **or** Patient condition changes and death is no longer likely within days (ie patient is now stable, unstable or deteriorating)	Prognosis is assessed to be hours or days Review and re-assessment is frequent (daily or more than daily contact)

Note 1: The key distinction between 'Unstable' and 'Deteriorating' is whether the phase is ***unpredictable (and so in the 'unstable' phase)*** or ***anticipated (and so in the 'deteriorating' phase).***

Note 2: If the patient is 'stable' but family needs are unpredictable or family distress is worsening, then categorise according to family needs.

Are there general indicators of decline and increasing needs?

- Decreasing activity - functional performance status declining (e.g. Barthel score) limited self-care, in bed or chair 50% of day and increasing dependence in most activities of daily living
- Co-morbidity is regarded as the biggest predictive indicator of mortality and morbidity
- General physical decline and increasing need for support
- Advanced disease - unstable, deteriorating complex symptom burden
- Decreasing response to treatments, decreasing reversibility
- Choice of no further active treatment
- Progressive weight loss (>10%) in past six months
- Repeated unplanned/crisis admissions
- Sentinel Event e.g. serious fall, bereavement, transfer to a nursing home
- Serum albumen <25g/l
- Considered eligible for DS1500 payment i.e. prognosis under 6 months

Functional Assessments

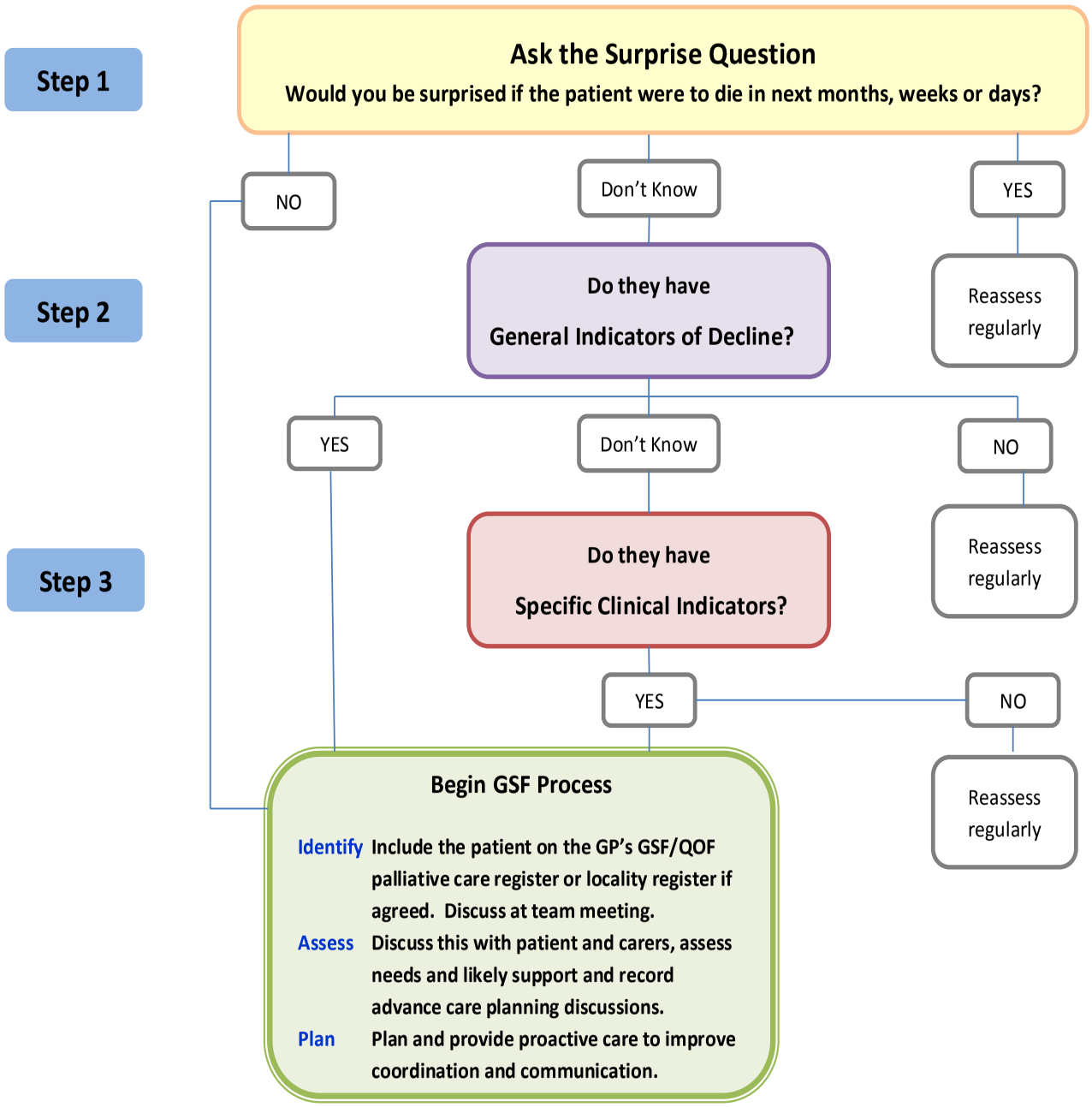
Barthel Index describes basic Activities of Daily Living (ADL) as 'core' to the functional assessment E.g. feeding, bathing, grooming, dressing, continence, toileting, transfers, mobility, coping with stairs etc.

PULSE 'screening' assessment -
P (physical condition); U (upper limb function);
L (lower limb function); S (sensory);
E (environment).

Karnofksy Performance Status Score
0-100 ADL scale

WHO/ECOG Performance Status
0-5 scale of activity

Summary of suggested three steps for earlier identification



The GP practices that you work with may be GSF practices and therefore follow a similar system of coding for their patients.

Coordination in GP Practices

Each GP practice has a nominated coordinator for palliative care (ideally this should be the practice manager, senior admin) to ensure good organisation and coordination of GSF in the practice.

You may consider nominating a co-ordinator within your team who can liaise with the GP Practices, District Nurses and attend multidisciplinary meetings.

The Coordinator's role

- Ensuring the Supportive Care Register is maintained and updated appropriately by the team and associated community nurses
- Alerting Primary Health Care Team/Practice re: changes in the person, proactive planning of care, audit, reflection and evaluation of care
- Ensuring the team have access to appropriate GSF tools and templates such as: Supportive Care Register templates, assessment tools, minimum protocol
- It is advisable to have a nominated deputy as GSF coordinator, to ensure on-going support and sustainability within the team

Frailty

Individuals who present with multiple co morbidities with significant impairment in day to day living and deteriorating functional score e.g. performance status - Barthel/ECOG/Karnofksy

Combination of at least three of the following symptoms:

⇒ Weakness
⇒ Slow walking speed
⇒ Significant weight loss
⇒ Exhaustion
⇒ Low physical activity
⇒ Depression

Home Work

Following on from Session 2 of the Domiciliary Care Training Programme we are asking you to complete the following tasks:

⇒ Begin to use the coding and needs support matrices for your service users

⇒ Consider how you are going to record the codings, look at the supportive care register and consider incorporating them into your existing paperwork

⇒ Consider how you are going to communicate the codings to the team members and the wider team e.g. district nurses/GPs

Take Home Message 2

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

Action Plan - Session 2

	To do		By when
1	How do you identify people near the end of life and code them?		
2	Who do you need to discuss this with?		
3	How are you going to use the needs support matrices?		
4	Documentation - how can you best integrate it into your work?		

This page is intentionally left blank.

Resources for Session 2

Activities

Activity 1 - Indicators

Activity 2 - Needs Based Coding sheet and Needs Support Matrix

Documents

SCR 1 Supportive summary of service users care register

SCR 2 Supportive Care Register service user summary sheet

This page is intentionally left blank.

Activity 1 - What would indicate to you that someone is A,B,C or D or Blue, Green, Amber and Red?

	Indicators
A **Years** **Stable**	
B **Months** **Unstable**	
C **Weeks** **Deteriorating**	
D **Days** **Dying**	

This page is intentionally left blank.

Activity 2 - Using the GSF Needs Based Coding & Needs Support Matrices

	B. Months	Weeks	Days	After Care
Triggers How might you identify these residents?				
Support				
GP/Primary Care Key Tasks				

This page is intentionally left blank.

SCR1 TO BE INSERTED HERE

This page is intentionally left blank.

Name DOB Address	NHS Number Key GP Key Worker
Tel No	Current Code A-D Date A=Years A B=Months B C= Weeks C D=Days D
Main Diagnosis Other Conditions	Family/carer contacts + Tel No Contact at night Y/N Comments
Personnel involved Health/Social Professionals Domiciliary Care Agency Hospital Specialists District Nurse team Others (OT, Physio, Priest) Macmillan/Nurse/SPC Hospice Social Services	Advance Care Plan Discussion (Thinking Ahead) Y/N Special Requests (wishes documented) – Review DNAR template Y/N Date DNAR status

Past Treatment & Current Medication
Priorities (Problems and concerns – physical, psychological, social spiritual) Other issues (incl. care plan, out of hours information, anticipatory drugs left in home, before considering admission try etc.)

Preferred place of care: Date:	Date of death:	Place of Death:	Comments:

Supportive Care Register Service User Summary Sheet

/cont. over.....

Date	Initials	Notes/Important Events	Needs Based Code (Refer to Matrix for Action)

Session Three

Key Question

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

Learning Outcome

To understand the use of assessment tools for service users and carers, what to do and when to refer

Activities

1. Assessment tools
2. Molly Assessment tools
3. Supporting carers

This programme helps meet the following national policy standards:

National Occupation Standards (NOS):

HSC385
HSC387
HSC45
HSC416
HSC427
HSC434

National Institute for Clinical Excellence (NICE) Quality Standards in End of Life Care (see appendix): 4, 7, 9, 10, 11, 15

Department of Health End of Life Care Strategy Quality Markers:

3. Ensure that people approaching the end of life are offered a care plan

5. Ensure that the needs of carers are appropriately assessed and recorded through a carer's assessment

Action Plan

- 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

Take Home Message

We can safely care for people with serious illnesses and we know when to seek help.

Assessment Tools

Assessing symptoms and the needs of your service users is a normal part of your regular care, you may have used some assessment tools for manual handling and worked with District Nurses who use pain assessment tools. There are others available that address different areas such as depression.

The assessments fall into two groups - specific and holistic. The tools and templates suggested in the workbook or on the GSF website are all optional suggestions, to be used if wanted.

- **Holistic**

The PACA assesses patient's problems and concerns. The PEPSICOLA checklist is a holistic guide to considering all areas, not just physical. It has been found to be of use in many areas and we include one adapted example from Brisbane, Australia.

The Distress Thermometer has been adapted for use with the elderly in care homes and has been found to be useful to many staff in assessing areas that otherwise might not come to light and developing a therapeutic plan to help resolve them. It is used often by psychologists for care of cancer patients. It is self explanatory and can examine the impact of certain issues and conditions on patients - there are other forms available for other conditions.

- **Specific**

These include the pain charts, body charts, etc. Patients with dementia may become agitated by pain so full assessment using the Doloplus or Abbey Scale can help determine whether pain is the cause of agitated behaviour.

Best practice recommends that :

C3 Control of Symptoms	GSF resources / templates available on the website
Each service user has their symptoms, problems and concerns (physical, psychological, social and spiritual) assessed, recorded, discussed and acted upon according to an agreed process.	Examples of palliative assessment tools
This could include: ✦ Service users having holistic assessment and care/treatment plan	
✦ Agency knowledge and understanding of contact details for local specialist palliative care providers, referral criteria to specialist palliative care, access to advice and support with symptom control in palliative care	

Support For Relatives And Staff

Supporting families as their loved one approaches the end of their life is an important part of our role. The practical help they can be given and the information that is both shared verbally and in written format is helpful and supportive. This aspect of the programme looks at ways we can do to offer this support. There has been good evidence where families have been supported both physically and emotionally to enable them to help care for their loved one, provided with helpful written information on what they should expect and practical advice regarding the dying stage. Some resources utilised are from national literature, others have found their own relevant words in the provision of a leaflet or booklet explaining many aspects of the care and process of dying.

Feedback from relatives, and the 'thank you' letters and cards that staff receive following the death of a loved one at home, are important for staff to evaluate the care they give. If a death does go badly this can cloud all the good care that someone has previously received and affect the normal bereavement process. We have one chance to get it right, families will never 'forget us' if we do; if we get it wrong they will never 'forgive us'.

Following the death of a service user the follow up care is as important as the care their loved one received at the time of death. How relatives are supported at this time can impact on the way people are able to come to terms with their loss and what aspects of the episode they remember in the future. Choices and practical arrangements will have been discussed and recorded prior to the event, but checking with the relatives is advised.

Staff support is also important at this stage, allowing and encouraging staff to attend funerals of service users is an important opportunity for staff to say their own individual 'goodbye' and go through the grieving process.

Some organisations have counselling sessions available to staff.

Carer's assessment and support is a crucial area and one that will often require further specific efforts by Primary Care teams.

This is one of the most important aspects of the care provided by primary health care teams. Carer breakdown is THE key factor in prompting institutionalised care for dying people. This is the experience of most health care professionals and is reflected loudly and clearly in the literature.

There is strong evidence that without support from family and friends it would be impossible for many patients to remain at home. Those without carers are less likely to be able to remain at home to die - they present particular difficulties.

Carer's anxiety is rated alongside service user symptoms as the most severe problems by both service users and families. Despite their natural feelings of trepidation beforehand, there can be a great sense of satisfaction in bereavement for the carer in fulfilling the wishes of their loved one who expressed a preference to stay at home during their final days. However this places a great strain on carers, both emotionally and physically.

The family will usually be registered as patients of the GP practice as well, and often a special relationship remains after the person has died, which may be therapeutic in the grieving process.

Main needs of the carers

- **Recognition** - of their value and importance
- **Being involved -** in devising care plans (one in three carers felt their comments and concerns were not taken into account)
- **Information** - sources of support, decision making about medical care, relevance of symptoms, what to do in an emergency etc.
- **Support** - practical, emotional, social, financial, spiritual
- **Training -** e.g. in lifting, giving medication etc.
- **Confiding in and being listened to -** needs expressed and supported often outside the home
- **Coping strategies -** both internal (faith, positive attitude etc.) and external (social networks)
- **Personal health -** time out to sleep, socialise eat well etc.

C6 Carer support	GSF resources/templates available on the
Carer's details are recorded in the GSF Supportive Care register. The agency recognises the needs of the informal carers involved in the care of identified End of Life Care service users. This includes:	Patient and carer section on the website
✦ Written information is given to carers including: agency information and contact details for in and out of hours services	GSF patient and carer information leaflet
✦ Carer's details are recorded in the GSF Supportive Care Register	GSF Supportive Care Register templates SCR1 and SCR2
✦ Carer's needs are assessed and acted upon	
✦ Bereavement support for carers: agencies plan support, for example agency bereavement protocol, visits, notes tagged	

There are many different ways and organisations that we can turn to that can help us to support families and their carers - both formally and informally.

Family care:

- Written information regarding what symptoms can happen as someone comes to the end of their life (session 5)
- Who else can help (Home Care pack session 3)
- Charities
- Benefits advice
- Developing partnership working
- Referral to others - e.g. GP

Staff care and support:

- Individually or as a team
- Debriefing sessions
- Reflection of practice at case meetings (Significant Event Analysis session 1)
- Opportunities for clinical supervision
- Staff support and encouragement
- Access to other training/support

Home Work

Following on from Session 3 of the Domiciliary Care Training Programme we are asking you to complete the following tasks:

⇒ Consider the use of assessment tools

⇒ Research what tools are available and what other professionals are using locally

⇒ What might be the most appropriate for your service users

Take Home Message 3

We can safely care for people with a serious illness and we know when to seek help.

This page is intentionally left blank.

Action Plan - Session 3

	To do		By when
1	What assessment tools do you find useful?		
2	Who might you communicate your findings with?		
3	What other areas do you need to focus on?		
4	Other areas		

This page is intentionally left blank.

Resources for Session 3

Activity

Activity 1 - Assessment Tools

Activity 3 - Stanley case study (part 1)

Documents

PACA

PEPSICOLA

SCR5 - Pain Assessment

Abbey Pain Scale

Doloplus Pain Scale

Distress Thermometer

Geriatric Depression Score

Ten Top Tips in End of Life Care and Dementia

This page is intentionally left blank.

Activity 1 - Assessment Tools

Consider a time when a resident had issues with symptom control and how you used assessment tools.

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

This page is intentionally left blank.

Case study for Stanley

Part 1

Setting the Scene

Stanley is 92 years old and lives in his own bungalow with his 88 year old wife, Ada.

They have a son and daughter. The daughter, Jane, lives an hour away and sees them every weekend and their son visits twice a year.

Stanley has a long history of Osteoarthritis. He had 2 knee replacements many years ago. During the last one he had an 'incident' while on the operating table and has now been left with some heart problems.

His arthritis causes him quite a lot of discomfort and he takes regular pain killers. He has had several hospital admissions because of 'funny turns' which were diagnosed as transient ischaemic attacks (TIA - mini strokes). Each time he has had a TIA, he has been left a bit more confused and has now been diagnosed as having vascular dementia. He is considered to be in the last year of life by his GP.

Stanley has recently returned home from hospital following another TIA. He was in for a few days and had a lot of investigations. He was taken off his anti-inflammatory drugs for his arthritis because of side effects and he now cannot mobilise as easily as before. He feels that his stay was a waste of time as nothing has changed to improve his condition and he is worse off than before because of his mobility.

While he was in hospital it was discussed that he should have some help with personal care when he went home but he was reluctant to agree to this as he said that Ada can help him.

His GP has visited and has noticed a change in Stanley's physical and mental status. He is quite low because of his reduced mobility and now being unable to do all the things he used to be able to do.

Due to the number of TIAs he has had, and that there is little that can be done to reverse the deterioration, the GP changed Stanley's coding to C (deteriorating with weeks to live) and asked the District Nurse to visit for a full assessment.

Session 3 Activity 3 - Carer Support

When the District Nurse visits she quickly realises that Stanley's wife is struggling to cope with the change in circumstances. Ada has now become his carer in a change of role - Stanley had cared for her for many years through long standing mental health problems. Ada finds it difficult to cope with Stanley's poor mobility and confusion and can be very intolerant of his increasing need for help. She will not help with his personal care and she will not always prepare meals for him. Stanley is becoming agitated and has become aggressive, hitting out at people when disturbed. His sleep pattern has altered and he is not sleeping at night.

The District Nurse speaks to Stanley and Ada about help with personal care and they agree to be assessed for home care. She also refers him to Occupational Therapy for a full assessment of aids that could make things easier for him around the home.

Your manager visits and assesses that visits twice a day would be appropriate for Stanley and she negotiates with him suitable times.

The visits for Stanley begin, but Ada is finding it very difficult to cope with the number of different people coming into the house and the disruption it is causing.

This page is intentionally left blank.

SCR 3: PACA Score

PROBLEMS/CONCERNS OVERVIEW	Patient Name

An up to date summary of patient and carer's problems/concerns, regularly assessed and scored with suggested referral criteria. Please ensure you cover physical, social, psychological and spiritual issues, including those listed.

Diagnosis

	DATE							
PROBLEMS/CONCERNS of PATIENT								**COMMENTS**
Pain								
Nausea/Vomiting								
Constipation								
Insomnia								
PROBLEMS/CONCERNS of CARERS								
Signature								

Assessment key for previous 24 hours

0 - Absent

1 - Present, not affecting daily life.

2 - Present, moderate effect on daily life

3 - Present, daily life dominated by symptom

(Add so the score Patient (P) or Observer (O) if patient unable to communicate)

Suggested referral criteria

If a patient scores 2 or 3 for more than a week despite interventions, suggest referral to specialist palliative care service.

This page is intentionally left blank.

	Date	Date	Date	Date
P - Physical **Symptom control** **Medication - regular & as required** **Compliance/stopping non-essentials** **Complementary therapies**				
E - Emotional **Understanding expectations** **Depression and adjustment** **Fears/Security** **Relationships**				
P - Personal **Spiritual/religious needs** **Inner journey** **Quality of life** **Patient/carer's agenda**				
S - Social Support **Benefits/Financial** **Care for carers** **Practical support**				
I - Information/Communication **Within Domiciliary care team** **Between professionals** **To and from service user** **To and from carers**				
C - Control **Choice, dignity** **Treatment options/Management plan** **Advanced directive** **Place of death**				
O - Out of Hours/Emergency **Continuity** **Communication to out of hours/service users/family/carers** **Carer support** **Medical support** **Drugs and equipment**				
L - Late **End of life/Terminal care** **Stopped non-urgent medication** **Patient and family aware** **Comfort measure Spiritual care** **Rattle, agitation**				
A - Afterwards **Bereavement Follow-up/others informed** **Family support** **Assessment/Audit** **Support team**				

This page is intentionally left blank.

SCR5 TO BE INSERTED HERE

SCR7 TO BE INSERTED HERE

Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalise.

How to use scale: While observing the resident, score questions 1 to 6

Name of resident: .....

Name and designation of person completing the scale: .....

Date: .....**Time:** .....

Latest pain relief given was.....**at** .....**hrs.**

Q1. **Vocalisation**
eg. whimpering, groaning, crying **Q1** ☐
Absent 0 Mild 1 Moderate 2 Severe 3

Q2. **Facial expression**
eg: looking tense, frowning grimacing, looking frightened **Q2** ☐
Absent 0 Mild 1 Moderate 2 Severe 3

Q3. **Change in body language**
eg: fidgeting, rocking, guarding part of body, withdrawn **Q3** ☐
Absent 0 Mild 1 Moderate 2 Severe 3

Q4. **Behavioural Change**
eg: increased confusion, refusing to eat, alteration in usual patterns **Q4** ☐
Absent 0 Mild 1 Moderate 2 Severe 3

Q5. **Physiological change**
eg: temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor **Q5** ☐
Absent 0 Mild 1 Moderate 2 Severe 3

Q6. **Physical changes**
eg: skin tears, pressure areas, arthritis, contractures, previous injuries. **Q6** ☐
Absent 0 Mild 1 Moderate 2 Severe 3

Add scores for 1 – 6 and record here ⇨ **Total Pain Score** ☐

Now tick the box that matches the Total Pain Score ⇨

0 – 2 No pain	3 – 7 Mild	8 – 13 Moderate	14+ Severe

Finally, tick the box which matches the type of pain ⇨

Chronic	Acute	Acute on Chronic

Dementia Care Australia Pty Ltd
Website: www.dementiacareaustralia.com

Abbey, J; De Bellis, A; Piller, N; Esterman, A; Giles, L; Parker, D and Lowcay, B.
Funded by the JH & JD Gunn Medical Research Foundation 1998 – 2002
(This document may be reproduced with this acknowledgment retained)

This page is intentionally left blank.

DOLOPLUS-2 SCALE

BEHAVIOURAL PAIN ASSESSMENT IN THE ELDERLY

NAME : Christian Name : Unit :

Behavioural Records

		DATES			
SOMATIC REACTIONS					
1• Somatic complaints	• no complaints	0	0	0	0
	• complaints expressed upon inquiry only	1	1	1	1
	• occasionnal involuntary complaints	2	2	2	2
	• continuous involontary complaints	3	3	3	3
2• Protective body postures adopted at rest	• no protective body posture	0	0	0	0
	• the patient occasionally avoids certain positions	1	1	1	1
	• protective postures continuously and effectively sought	2	2	2	2
	• protective postures continuously sought, without success	3	3	3	3
3• Protection of sore areas	• no protective action taken	0	0	0	0
	• protective actions attempted without interfering against any investigation or nursing	1	1	1	1
	• protective actions against any investigation or nursing	2	2	2	2
	• protective actions taken at rest, even when not approached	3	3	3	3
4• Expression	• usual expression	0	0	0	0
	• expression showing pain when approached	1	1	1	1
	• expression showing pain even without being approached	2	2	2	2
	• permanent and unusually blank look (voiceless,staring, looking blank)	3	3	3	3
5• Sleep pattern	• normal sleep	0	0	0	0
	• difficult to go to sleep	1	1	1	1
	• frequent waking (restlessness)	2	2	2	2
	• insomnia affecting waking times	3	3	3	3
PSYCHOMOTOR REACTIONS					
6• washing &/or dressing	• usual abilities unaffected	0	0	0	0
	• usual abilities slightly affected (careful but thorough)	1	1	1	1
	• usual abilities highly impaired, washing &/or dressing is laborious and incomplete	2	2	2	2
	• washing &/or dressing rendered impossible as the patient resists any attempt	3	3	3	3
7• Mobility	• usual abilities & activities remain unaffected	0	0	0	0
	• usual activities are reduced (the patient avoids certain movements and reduces his/her walking distance)	1	1	1	1
	• usual activities and abilities reduced (even with help, the patient cuts down on his/her movements)	2	2	2	2
	• any movement is impossible, the patient resists all persuasion	3	3	3	3
PSYCHOSOCIAL REACTIONS					
8• Communication	• unchanged	0	0	0	0
	• heightened (the patient demands attention in an unusual manner)	1	1	1	1
	• lessened (the patient cuts him/herself off)	2	2	2	2
	• absence or refusal of any form of communication	3	3	3	3
9• Social life	• participates normally in every activity (meals, entertainment, therapy workshop)	0	0	0	0
	• participates in activities when asked to do so only	1	1	1	1
	• sometimes refuses to participate in any activity	2	2	2	2
	• refuses to participate in anything	3	3	3	3
10• Problems of behaviour	• normal behaviour	0	0	0	0
	• problems of repetitive reactive behaviour	1	1	1	1
	• problems of permanent reactive behaviour	2	2	2	2
	• permanent behaviour problems (without any external stimulus)	3	3	3	3
	SCORE				

DOLOPLUS-2 SCALE : LEXICON

Somatic complaints
The patients expresses pain by word, gesture, cries, tears or moans.

Protective body postures adopted at rest
Unusual body positions intended to avoid or relieve pain.

Protection of sore areas
The patient protects one or several areas of his/her body by a defensive attitude or gestures.

Expression
The facial expression appears to express pain (grimaces, drawn, atonic) as does the gaze (fixed gaze, empty gaze, absent, tears).

Investigation
Any investigation whatsoever (approach of a caregiver, mobilization, care procedure, etc.).

Washing/dressing
Pain assessment during washing and/or dressing, alone or with assistance.

Mobility
Evaluation of pain in movement: change of position, transfer, walking alone or with assistance.

Communication
Verbal or non-verbal.

Social life
Meals, events, activities, therapeutic workshops, visits, etc.

Problems of behaviour
Aggressiveness, agitation, confusion, indifference, lapsing, regression, asking for euthanasia, etc.

DOLOPLUS-2 SCALE : INSTRUCTIONS FOR USE

1 • Scale use requires learning

As is the case with any new instrument, it is judicious to test it before circulating it. Scale scoring time decreases with experience (at most a few minutes). Where possible, it is of value to appoint a reference person in a given care structure.

2 • Pluridisciplinary team scoring

Irrespective of the health-care, social-care or home structure, scoring by several caregivers is preferable (physician, nurse, nursing assistant, etc.). At home, the family and other persons can contribute using a liaison notebook, telephone or even a bedside meeting. The scale should be included in the 'care' or 'liaison notebook' file.

3 • Do not score if the item is inappropriate

It is not necessary to have a response for all the items on the scale, particularly given an unknown patient on whom one does not yet have all the data, particularly at psychosocial level. Similarly, in the event of coma, scoring will be mainly based on the somatic items.

4 • Compile score kinetics

Re-assessment should be twice daily until the pain is sedated, then at longer intervals, depending on the situation. Compile score kinetics and show the kinetics on the care chart (like temperature or blood pressure). The scale will thus become an essential argument in the management of the symptom and in treatment initiation.

5 • Do not compare scores on different patients

Pain is a subjective and personal sensation and emotion. It is therefore of no value to compare scores between patients. Only the time course of the scores in a given patient is of interest.

6 • If in doubt, do not hesitate to conduct a test treatment with an appropriate analgesic

It is now accepted that a score greater than or equal to 5/30 is a sign of pain. However, for borderline scores, the patient should be given the benefit of the doubt. If the patient's behavior changes following analgesic administration, pain is indeed involved.

7 • The scale scores pain and not depression, dependence or cognitive functions

Numerous instruments are available for each situation. It is of primary importance to understand that the scale is used to detect changes in behavior related to potential pain.
Thus, for items 6 and 7, we are not evaluating dependence or independence but pain.

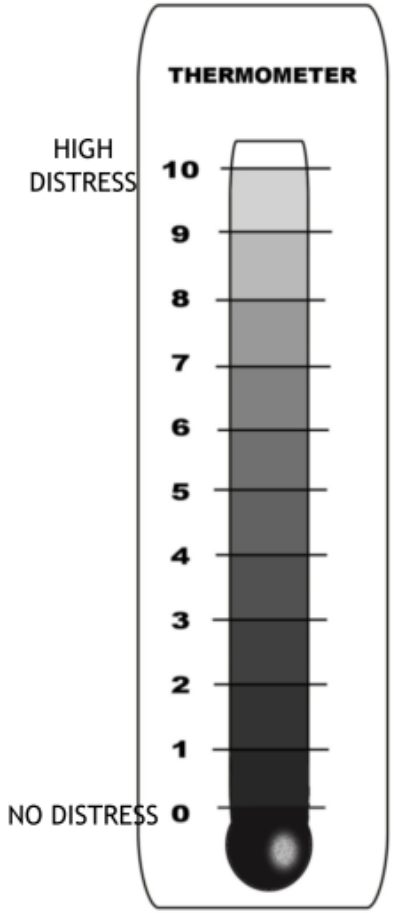
8 • Do not use the DOLOPLUS 2 scale systematically

When the elderly patient is communicative and cooperative, it is logical to use the self-assessment instruments. When pain is patent, it is more urgent to relieve it than to assess it ... However, if there is the slightest doubt, hetero-assessment will avoid underestimation.

This page is intentionally left blank.

Distress Thermometer for the Elderly GSFDC Programme **Service User's name:** **Date:**

1. **Please circle the number (0-10) that best describes how much distress in general you have been experiencing over the past week, including today.**



2. **If any of the following has been a problem for you over the past week, including today, please tick the box next to it. Leave it blank if it does not apply to you. Then priority rank your top 4 difficulties (1 would be the biggest problem, 4 would be your fourth biggest concern)**

RANKING	
	Practical Issues
	☐ Environment – in the home / your room
	☐ Independence
	☐ Bathing / dressing
	☐ Caring for yourself
	☐ Money
	☐ Activities in home
	☐ Other concerns
	Social / Relationship Issues
	☐ with family / partner
	☐ with children / grandchildren
	☐ with others
	☐ with friends outside the home
	☐ with staff
	Emotional Concerns
	☐ Anxiety / worry
	☐ 'Bad nerves' / nervousness
	☐ Fears
	☐ Sadness
	☐ Undecided about future plans
	☐ Lack of self worth
	☐ Bereavement
	☐ Depression
	☐ Other feelings or concerns:
	Spiritual / Religious Concerns
	☐ Loss of religious faith
	☐ Difficulty relating to God
	☐ Loss of meaning or purposes of life

RANKING	
	Physical Problems
	☐ General appearance
	☐ Fatigue / tiredness
	☐ Pain
	☐ Skin – dry / itchy / discoloured
	☐ Broken skin / pressure sores
	☐ Hearing / sight
	☐ Circulatory problems
	☐ Appetite / eating
	☐ Weight loss or gain
	☐ Swallowing difficulties
	☐ Breathing / breathlessness
	☐ Continence – passing water
	☐ Bowels – constipation / diarrhoea
	☐ Joint problems
	☐ Mobility – getting around
	☐ Ankle swelling
	☐ Mouth sores / denture problems
	☐ Nausea / sickness / indigestion
	☐ Nose dry / congested
	☐ Cough
	☐ Sleep
	☐ Other, please state:
	Memory / Related Concerns
	☐ Forgetfulness/memory
	☐ Feeling Confused/ muddled
	☐ Not knowing time of day/day of the week
	☐ Finding my way around

3

Service User Name:	Completed by: (tick appropriate) ☐ Staff and service user ☐ Staff, service user and relative ☐ Staff and relative ☐ Other please state..... Signed by staff member:	Relevant Diagnoses:
Service User DOB:		What was the duration of the interview (in minutes)?

Highest ranked concerns	Thermometer Rating for this concern	Description and history of problem	Plan of action	Progress with plan and outcomes (complete with Thermometer Rating and date as appropriate)
1.				
2.				
3.				
4.				

Geriatric Depression Scale (short form)

Resident Name:	Today's Date:
Care Home	
Signature and position of person completing Form:	

Introduce the Geriatric Depression Scale as a short assessment of mood. Ask the resident to best answer for how they have felt over the past week. Ask them to give a yes/no answer to each question in turn (refer to guidance notes).

1. Are you basically satisfied with your life? YES / **NO**

2. Have you dropped many of your activities and interests? **YES** / NO

3. Do you feel that your life is empty? **YES** / NO

4. Do you often get bored? **YES** / NO

5. Are you in good spirits most of the time? YES / **NO**

6. Are you afraid that something bad is going to happen to you? **YES** / NO

7. Do you feel happy most of the time? YES / **NO**

8. Do you often feel helpless? **YES** / NO

9. Do you prefer to stay at home, rather than going out and doing new things? **YES** / NO

10. Do you feel you have more problems with memory than most? **YES** / NO

11. Do you think it is wonderful to be alive now? YES / **NO**

12. Do you feel pretty worthless the way you are now? **YES** / NO

13. Do you feel full of energy? YES / **NO**

14. Do you feel that your situation is hopeless? **YES** / NO

15. Do you think that most people are better off than you are? **YES** / NO

Any additional notes: (see guidance notes)

Demographic and Clinical information

Resident Name:		Today's Date:	Resident Age:
Care Home		Date of admission to care home:	
Signature and position of person completing Form:			

Note: If you already have tools or assessment scores that would be useful in describing any relevant impairments; please state the name of the scale, score and date e.g. *Doloplus-2 scale score: 19. (05/05/08).* This is not essential but may be useful.

List of any illnesses or diagnoses (mental and/or physical) or suspected or queried illnesses or diagnosis	Date of diagnoses (if known or applicable)

List of any physical, cognitive or mental impairment or disability:

Ten Top Tips in End of Life Care and Dementia

Every patient and carer is individual. Barbara Pointon, who cared for her husband Malcolm, offers these ten top tips which worked for them:

Feeding

It is the most trustful thing in the world to open your mouth to be fed. Malcolm would refuse food from a new carer, so continuity of staff is vital. Up to one hour may be required to patiently feed pureed food by the teaspoonful; cold thickened drinks may be more easily sensed and controlled than tepid ones. Use metal not plastic teaspoons in case of clamping down.

Space

84% of people with Alzheimer's have visuo-spatial perceptual problems and don't know where they are in space. Rolling a patient on the bed to change an incontinence pad can be alarming and cause resistance for some - we used a standing hoist right to the end. (Each person will be different in this) The change of position also helped Malcolm to cough productively. A mobile hung from the ceiling helps to give some sense of position.

Weight loss

in severe dementia is inevitable. Relatives of care home residents need to understand that it is not necessarily a sign of neglect.

Medication

All of Malcolm's medication had to be reduced to paediatric sized dosages/preparations in line with weight loss and /or severity of dementia. Adult doses became the equivalent of overdosing, with unwanted side effects. Even Malcolm's final syringe driver had only a half dose in it. This is very individual.

Loss of mobility

should not mean confined to bed. Alternate with a recliner chair and wheelchair. Good pressure relief, the right size and absorbency of incontinence pads, scrupulous cleansing and six major changes of position each day

Constipation

It is not your normal constipation; the brain no longer understands the signals from the gut to co-ordinate muscles for consciously bearing down. An assessment by a dementia-aware continence adviser can help as can a special regimen, similar to that for a paraplegic.

Sounds

Even if the patient is mute and may have little understanding of speech, continue to talk to them. The sound of a kindly voice is a fundamental human need. Music (of their taste) will still get through.

Stimulation

With normal levels of cognition shot to pieces, sensory and emotional needs become more important. Stimulate each of the five senses in an appropriate way – Malcolm loved his aromatherapy sessions – and encourage eye-contact, talking and gentle touch, especially from visitors who are unsure what to do.

Familiarity

Most people with dementia become terrified of being anywhere other than in familiar surroundings. Breaks for the carer should be arranged through having replacement care at home, preferably given by the same person each time. For the same reason, at the very end of life, admission to a noisy, busy hospital should be avoided if possible. A calm and tranquil environment is important.

Making time

At any stage, time is the greatest gift you can give to people with dementia. Make time just to be alongside as a tangible, comforting presence, especially when life is drawing to a close.

Barbara Pointon 2008

This page is intentionally left blank.

Session Four

Key Question

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

Learning Outcome

To learn about communication skills in Advance Care Planning, the role of listening and reducing hospitalisation.

Activities

1. Your ACP
2. Stanley ACP
3. ACP in groups

This session helps meet the following national policy standards:

National Occupation Standards (NOS):

HSC385
HSC3100
HSC3116
HSC45
HSC414
HSC426
HSC428
HSC387
HSC3104
HSC41
HSC410
HSC416
HSC427

National Institute for Clinical Excellence (NICE) Quality Standards in End of Life Care (see appendix): 2,3,5,6,7, 11, 15

Department of Health End of Life Care Strategy Quality Markers:

4. Ensure that individuals' preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals

Action Plan

- 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

Take Home Message

We can listen better to people and help their voice be heard

An Overview of Advance Care Planning Discussions

To assess people's personal needs and preferences through Advance Care Planning including preferred place of care

"Failing to plan is planning to fail"

Advance Care Planning (ACP) is essentially a process of discussion between an individual and their care providers, which may include family/ friends, about the kind of care they would like to receive now and in the future.

DH Guidance on Advance Care Planning,
End of Life Care Programme 2008

The aim is to increase the number of people who are offered Advance Care Planning discussions within primary care, especially those with dementia or who have declining capacity to make decisions in future.

To do this, it is recommended that every patient on the GSF Supportive/ Palliative care register is offered an ACP discussion.

By having this discussion, a **shared understanding** can be reached, so that current and future care can be tailored to the person's individual needs and preferences, some difficult situations or crisis events can be averted and communication with others is made easier. The process of holding Advance Care Planning discussions to ascertain wishes is strongly recommended as it enables the decision making process to be initiated, recorded and communicated to others involved in care. This then ensures that the person's wishes are more likely to be met, and they receive a higher quality of End of Life Care.

The opportunity to discuss ACP should be *offered* to everyone as normal practice, with the appropriate degree of respect and sensitivity, though everyone has the option to decline.

Some may decline or defer to another time, and staff should always be sensitive to this.

With the individual's agreement this discussion should be documented, regularly reviewed and communicated to key persons involved in their care.

This is particularly relevant for service users in the last year of life. GPs and primary care teams might be involved in confirming these ACP discussions and helping to provide care aligned to preferences.

Advance care planning discussions are different from resuscitation/ DNACPR forms and policies. If your service users want to talk about this you will need to refer this to their GP or district/community nurse.

The service user's wishes are paramount, but it is also helpful to confirm who else might be involved in the decision-making process, and might be consulted in case of lack of capacity of the person in future.

The benefit of ACP is that others caring for the person in differing situations e.g. in care homes, hospitals etc. can refer to the ACP to produce a consistent approach to care - to know what the person wants and / or who to ask if they are unable to express their views.

The Mental Capacity Act (2005) requires staff to support people so that they can make decisions for themselves as far as they are able. The process of ACP is important here as it relates to the possibility of future lack of capacity of the resident. If they can make a decision they should – if they cannot, it ensures that their wishes are already noted through the earlier ACP discussion, and are thereby more likely to be respected.

Three Key Principles Of Advance Care Planning Are Suggested:

Individual - the ACP process is tailored to individual's needs and preferences

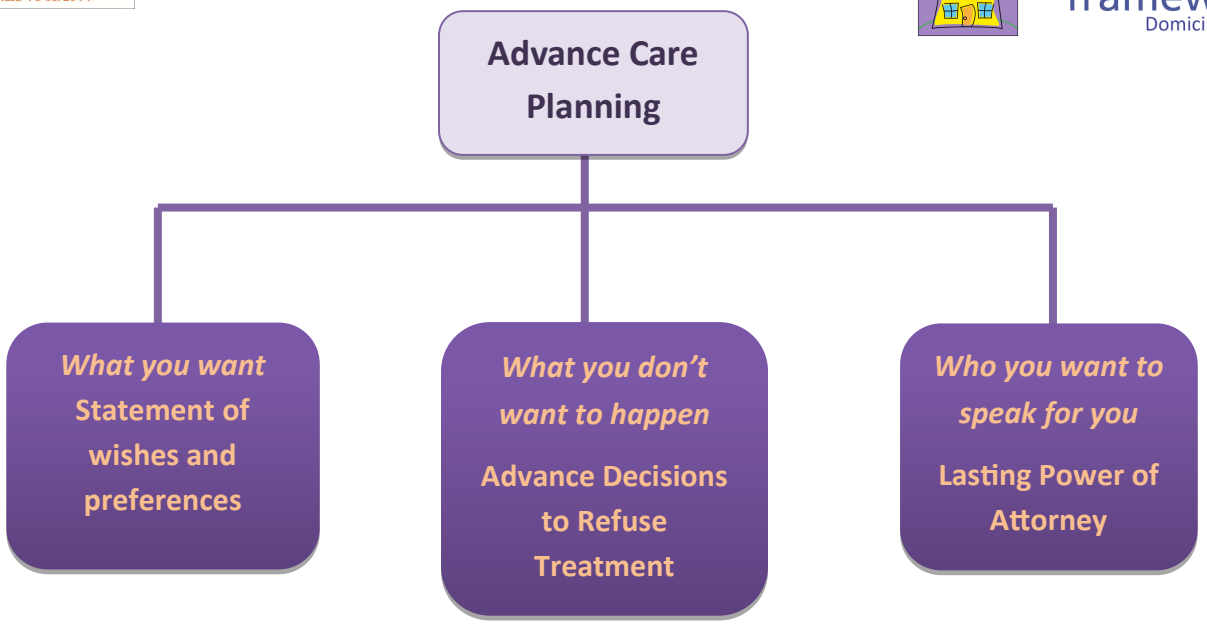
Inclusive - there is a move to a shared understanding of wishes and concerns between residents, relatives, staff and others such as the GP. It is important to respect the views of those close to the service user and include their considerations, though the service user's views are paramount

Integrated - ACP should be integrated into usual procedures, and views upheld at crucial times as in discussion with GPs, out of hours services or on admission to hospital

Advance Care Planning or decision making is the process itself. Simply put, this divides into two areas - clarifying a statement of preferences i.e. what the patient would like to happen (as in the Thinking Ahead document used here) and secondly a specific refusal of treatment, now known as an Advance Decision to Refuse Treatment or ADRT. These should be done with a Doctor using the principles of informed consent, where the person must be given full information about what the treatment involves, including the benefits and risks, whether there are reasonable alternative treatments and what will happen if treatment does not go ahead. Healthcare professionals should not withhold information just because it may upset or unnerve the person. Included in refusals can be a decision not to attempt cardio pulmonary resuscitation or a decision to 'Allow Natural Death'.

There are many differing tools used, but the principles remain the same. The tools here include:

- **Advance Care Planning discussion document** e.g. the GSF Thinking Ahead document. This includes the person's wishes for care (not just health related), an indication of their beliefs and values related to care, their preference for place of care near to death, and possibly after death, noting who was consulted / not to consult / Lasting Power of Attorney, if incapacity who to consult and to note if this is declined
- **A specific ADRT document** - see www.adrtnhs.co.uk/
- **An agreement not to resuscitate** (DNACPR, AND)



- **Statements of wishes and preferences** help formalise what people (and their families/carers) **do wish** to happen to them as they near the end of life
- It helps to provide personalised, individual care, tailored to their needs and preferences as death approaches
- Although not legally binding, it indicates preferences and under the Mental Capacity Act, can be used if the person no longer has capacity in the future
- **Advance Decisions** helps formalise what people **do not wish** to happen to them and is a legally binding document. It can include guidance on resuscitation (DNACPR)
- Advance Decisions to **refuse** treatment must be valid and applicable and drawn up correctly
- Must be specific to circumstance and treatment and identify that the person knows that their life may be at risk if they refuse treatment
- **Lasting Power of Attorney** is a formal confirmation of a named person who might speak for you if you no longer have capacity to make decisions yourself

Advance Care Planning Benefits

- Improves communication with service users and families early on
- Improves planning of care
- Reduces crises and inappropriate hospital admissions
- Helps formalise discussion using a tool
- Can initiate realistic communication about 'allow a natural death' vs resuscitation
- People have a sense of relief once they are doing and they can give hope to that person

Advance Care Planning Discussion

How?

- Opportunistic informal conversations
- Formalised systematic

What?

- What matters to you?
- What do you wish to happen?
- What do you do not want to happen?

Who?

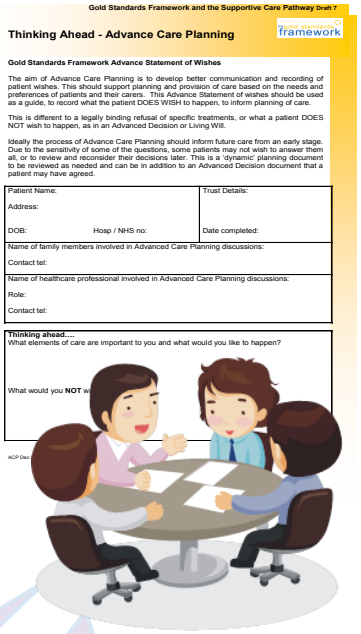
- Named spokesperson (informal)
  Can tell those who act in best interests what sort of person you are
- Lasting Power of Attorney (formal)
  Can make legal decisions regarding your health

Where?

- Preferred Place of Care
- Carer's Preferred Place of Care

Other?

- Special instructions-Organ / tissue donation


Gold Standards Framework and the Supportive Care Pathway Draft 7

Thinking Ahead - Advance Care Planning

Gold Standards Framework Advance Statement of Wishes

The aim of Advance Care Planning is to develop better communication and recording of patient wishes. This should support planning and provision of care based on the needs and preferences of patients and their carers. This Advance Statement of wishes should be used as a guide, to record what the patient DOES WISH to happen, to inform planning of care.

This is different to a legally binding refusal of specific treatments, or what a patient DOES NOT wish to happen, as in an Advanced Decision or Living Will.

Ideally the process of Advance Care Planning should inform future care from an early stage. Due to the sensitivity of some of the questions, some patients may not wish to answer them all, or to review and reconsider their decisions later. This is a 'dynamic' planning document to be reviewed as needed and can be in addition to an Advanced Decision document that a patient may have agreed.

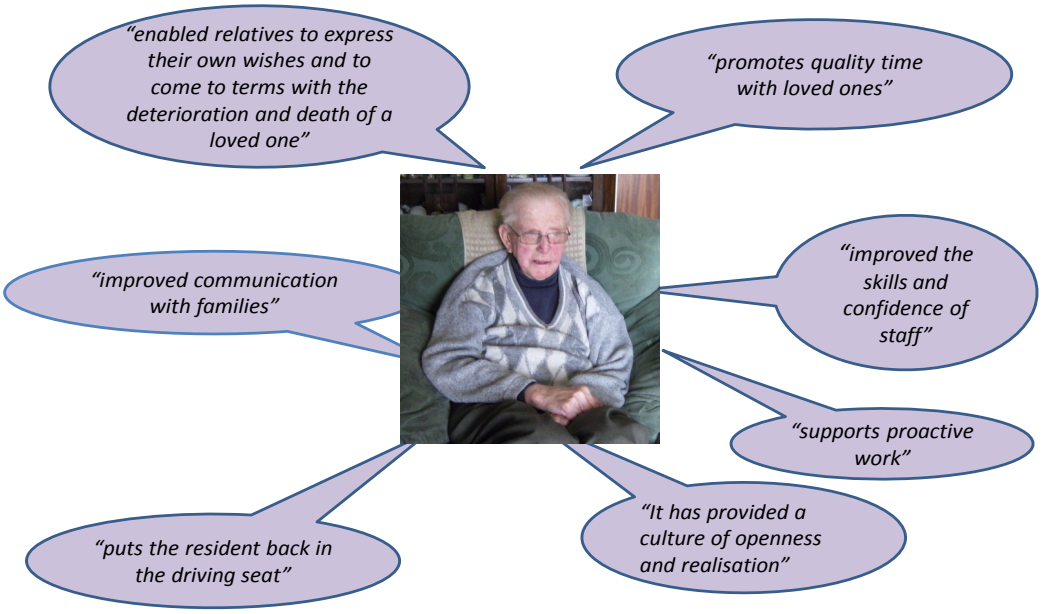
Patient Name:
Address:
DOB: Hosp / NHS no:
Trust Details:
Date completed:
Name of family members involved in Advanced Care Planning discussions:
Contact tel:
Name of healthcare professional involved in Advanced Care Planning discussions:
Role:
Contact tel:
Thinking ahead....
What elements of care are important to you and what would you like to happen?
What would you NOT w

"Introducing Advance Care Planning into our work place as normal practice has been one of the most important things we have done - it's crucial to helping us focus on the needs of service users, it helps discussions with families and it changes the way we do everything. Even though it may be hard at first, we would very strongly recommend it for every care provider." Care Home Matron Phase 3

"How can we give best care towards the end of life if we don't know what people want? How can you know what people want unless they are asked?"

Care Home Nurse Phase 4

What difference does it make – comments



Advance Care Planning With People With Dementia

ACP discussions can be very helpful for people with Dementia. Such decisions can take place even though the individual may have quite advanced Dementia, as long as they have capacity – the ability to understand and speculate about the decision to be made. Evidence suggests that people with early Dementia are interested in participating in ACP discussions and that they make similar decisions to people without Dementia. Therefore we should not hold back from asking people with Dementia their views.

Staff who care for people with Dementia have difficulty in ascertaining wishes and preferences especially for those people who have no family. They also spoke of difficulties that arose when GPs were reluctant to make advance decisions. Staff were well aware of unnecessary distress that can be caused by sending a person with Dementia out of their environment to hospital and were, in many cases, keen to have advance discussions documented. Staff spoke of their own distress and powerlessness at seeing people with Dementia being sent to hospital in their last 48hrs of life because of a lack of documentation relating to resuscitation status.

A Note about Advance Care Planning in Dementia

Many of the best practice points generally applicable to Advance Care Planning (ACP) discussions will apply to people with Dementia but there are others that also need to be taken into account in addition:

Skilled Interviewer

Those undertaking ACP with people with dementia will need to have appropriate knowledge and skills to understand the issues around communication in Dementia.

The Right Time

As with all ACP discussions they need to be held at the right time but in Dementia these discussions need to be held early on in the illness when the person still has the capacity, cognition and language to hold meaningful discussions and make informed decisions. Ideally the ACP discussions in people with Dementia should be part of a supportive post diagnostic counselling processes within e.g. a Memory Clinic.

The Right Place

People with Dementia often have visuospatial problems that are associated with their Dementia so it is important to hold the discussions in a quiet and unthreatening place with no distractions of noise and interruptions that can hinder their concentration.

Involvement of Family

Once a person is deemed and assessed to no longer have capacity, decisions will need to be made in their 'best interest' and the Mental Capacity Act framework for determining best interests applied. A Lasting Power of Attorney (LPA) with appropriate authority (Personal Welfare) may be empowered to make decisions on behalf of a person with Dementia based on their knowledge of the person and on what they believe the person would or would not have wanted for themselves.

Take Time

People with Dementia will require more time for any ACP discussions; these may need to be done over some period of time with some repetition and clarification.

Karen Harrison-Dening, Consultant Admiral Nurse

Goals of Care

When we consider Advance Care Planning we should also consider Goals of Care and how the person feels about the burden of their disease or age.

Moving from disease-focused to person-focused care

In all aspects of clinical care, there can be a tendency to over treat at times – just because something is available does not always mean that it is appropriate for this particular person, or would be their choice or in their best interests long term. Achieving the right balance for each person can be difficult, and takes reflection, planning and careful consideration, rather than the knee jerk reaction of sometimes 'over-medicalised' care. Too many people, especially the frail elderly, receive excessive interventions, resuscitation or find themselves in hospital wards or in ITU when this would not have been their choice, whilst others might seek such appropriate interventions that might not be available due to heavy demand. It is a fine balance and a growing problem, with the increasing complexity of options for clinical interventions and treatments available to us, and as an ageing population with increasing co-morbidities.

Most people in our society now die from cumulative co-morbid conditions. As we move from the clinically focused 'disease orientated' model of care (*ref. Tinetti 2003*) to the era of an integrated individually tailored model, we may need to refocus our care on the person's goals of care, in line with a less medicalised view of the kind of care they require.

One Means Of Achieving This - Assessment Of The Patient's Goals Of Care

Assessment of the 'goals of care' for each person is a way to enable the focus to remain on their priorities and not ours. It can help focus on the purpose and level of appropriate intervention required, in line with the patient's personal preferences, as discussed in their Advance Care Planning discussion. This will vary at different stages of people's lives, at different stages on the illness trajectory, for different people in different settings. Using these goals of care can help reduce the chances of over-intervention and over-medicalisation of care and can help redirect appropriate intervention at other times. These discussions about the goals of care are best negotiated with the person and their families and need to be reconsidered at times of key decision making and changes of plan.

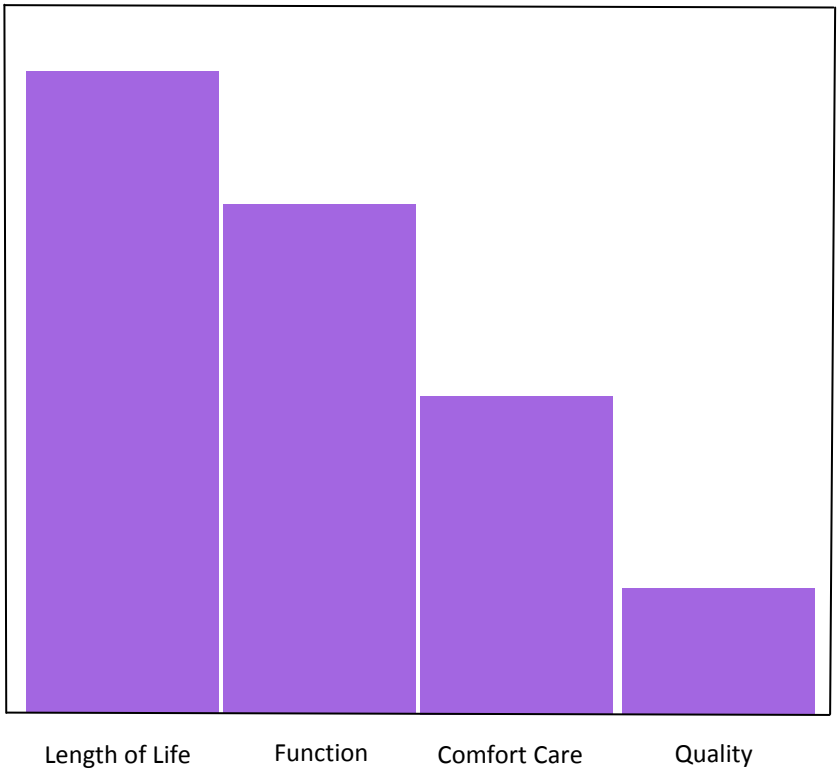
The concept of 'goals of care' is used in many countries to support such decision making and varies in some details, with some having a section for patient noted priorities. One example, used by Brogan at al in Australia, is shown below :

The 4 goals of care:

1. **Length of life** — **To extend length of life as long as possible**
2. **Functioning** — **To maintain as 'normal' a life as possible**
3. **Comfort care** — **To remain symptom free and comfortable with minimal interventions**
4. **Quality of life** — **To maintain quality of life in the present moment**

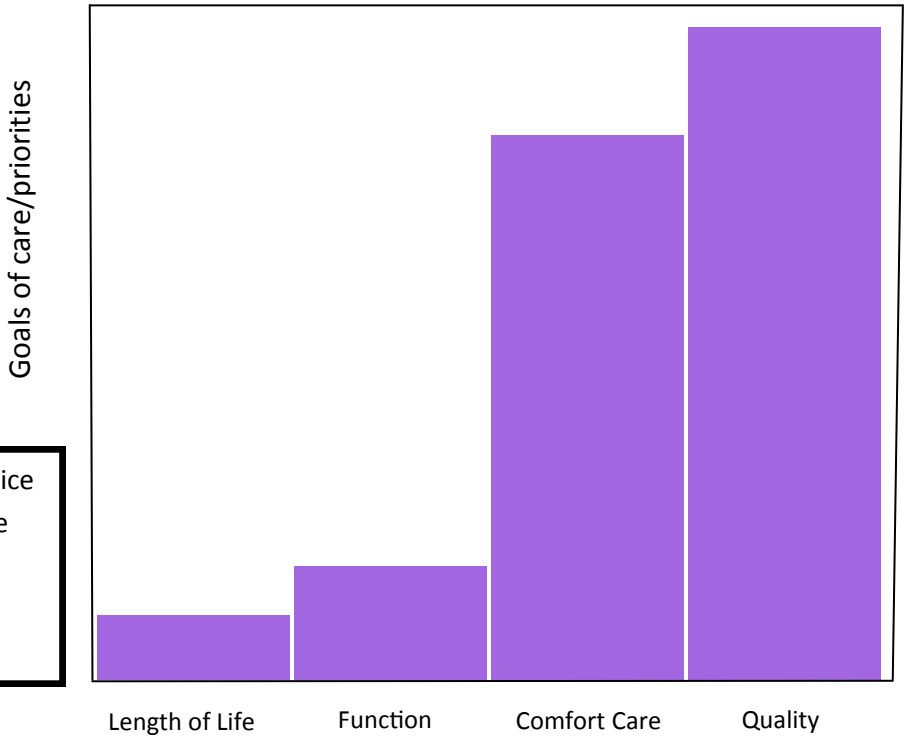
Considering these Goals of Care, along with the Advance Care Planning discussion, can therefore help determine the most appropriate response, such as when considering admission to hospital, consideration of PEG feeding, DNAR status and prevent inappropriate interventions when the person's confirmed option is for comfort care and quality of life. At other times length of life is more important and a period of abnormal functioning can be sacrificed in the short term in order to gain longer term benefits.

Goals of Care Examples



Person A: A 40 year old young mother with potentially curable breast cancer - sacrificing quality of life and comfort for future length of life.

Person B: A frail 90 year old service user with dementia, where some hospitalisation may be inappropriate and in fact detrimental to health.



Home Work

Following on from Session 4 of the Domiciliary Care Training Programme we are asking you to complete the following tasks:

- Consider how Advance Care Planning can help you improve the care you give
- Identify areas of strength and areas for development
- Think about how Advance Care Planning might change current practice
- Start having Advance Care Planning discussions with some of your service users

Take Home Message 4

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

This page is intentionally left blank.

Action Plan – Session 4

	To do		By when
1	How can we listen better to people?		
2	Advance Care Planning - how do we communicate this to others?		
3	Do we need to do this differently?		
4	Other queries		

This page is intentionally left blank.

Resources for Session 4

Activity

Activity 1 - Advance Care Planning

Activity 2 - Stanley - Part 2

Document

Thinking Ahead document

Enabling Care Priorities

Guidance notes on completing ACP

This page is intentionally left blank.

Activity 1 - Advance Care Planning

Consider the following questions:	**Reflections**
What is important to discuss with patients about Advance Care Planning?	
How might you start a discussion with patients about these issues?	

This page is intentionally left blank.

Stanley Part 2

Session 4 - Activity 2 Personal Preferences

One Saturday Jane has come to take Stanley and Ada out to the pub for lunch. Whilst there, Stanley has another 'funny turn'. He comes round and insists that he does not want to go to hospital again and that he's OK. Jane manages to get him home and puts him to bed. She contacts the GP but the call goes to the out of hour's service and she explains the situation with her father. It is suggested that he should go to hospital to be checked out but he does not want to go, so it is agreed that the OOH GP should visit. When he visits he diagnoses Stanley as having had another TIA. As Stanley is adamant that he doesn't want to go to hospital the GP agrees that he can stay at home and refers him to his own GP for a visit on Monday. Jane stays for the weekend to look after her parents.

On the Monday, when you visit, Stanley has picked up slightly but not as well as he has done previously. Stanley tells you about his previous hospital admission and tells you that he would not want to go back in. Although you haven't known Stanley for very long, you have a very good rapport with him and he has told you a lot of personal information while you have been doing his personal care as he feels he can confide in you. He tells you that that he didn't see the point of his last admission as they didn't do anything for him and haven't made him any better. He also worries about Ada when he is in as she doesn't cope very well when she is on her own and she wasn't able to get in to visit him.

Stanley's GP has known Stanley for some years and recognises that further hospital admissions would not particularly be of benefit to Stanley. The GP talks with Ada and Jane about Stanley's future care. It is agreed that Stanley should not go back into hospital unless for a specific reason, such as a fracture, and that he should not be for resuscitation and that this will be documented on his notes so that everyone is aware of Stanley's wishes.

At the practice GSF meeting later that day the GP discusses Stanley with the wider team - including the District Nurse, Social Worker and your manager. They are made aware that Stanley's preferred place of care is home. His coding remains at a code C and the GP refers him to the out of hours service and signs a DNAR decision form. Anticipatory drugs are prescribed particularly for Stanley's continuing pain relief. A 'just in case box' is prescribed so that it can be left in the house ready for use if required

The District Nurse contacts the PCT for a hospital bed to make transferring in and out of bed easier for him.

Over the next week Stanley is reluctant to get out of bed even for you and your team are now visiting three times daily to see to his personal hygiene needs and the District Nurse is visiting alternate days to review the situation. Jane is sleeping at the house so that her mother can rest at night. She also prepares meals for her parents to ensure that they are eating something.

This page is intentionally left blank.

Session 4 - Activity 2 Personal Preferences

Consider the following questions:	**Reflections**
How would you approach an Advance Care Planning discussion? Consider cues and timing.	
Who should be involved in these discussions? Consider everyone's needs and what approach might be best.	
Who would be the most appropriate person(s) to undertake and lead on these discussions?	
How would you communicate the outcomes of these discussions? Who needs to know, how would it be reviewed?	

This page is intentionally left blank.

Thinking Ahead - Advance Care Planning Discussion

Advance Care Planning Tool v 1

GSF Advance Care Planning Discussion Paper

We wish to be able to provide the best care possible for all residents and their families, but to do this we need to know more about what is important to them and what are their needs and preferences for the future.

The aim of any discussion about thinking ahead, often called an Advance Care Planning Discussion, is to develop a better understanding and recording of their priorities, needs and preferences and those of their families/carers. This should support planning and provision of care, and enable better planning ahead to best meet these needs. This philosophy of 'hoping for the best but preparing for the worst' enables a more proactive approach, and ensures that it more likely that the right thing happens at the right time.

This example of an Advance Statement should be used as guide, to record what the patient DOES WISH to happen, to inform planning of care. In line with the new Mental Capacity Act, this is different from a legally binding refusal of specific treatments, or what a patient DOES NOT wish to happen, which is called an Advance Decision (sometimes previously called a Living Will).

Ideally an Advance Care Plan should be discussed to inform future care at an early stage, preferably on admission to a home. Due to the sensitivity of some of these issues, some may not wish to answer them all, or may quite rightly wish to review and reconsider their decisions later. This is a 'dynamic' planning document to be adapted and reviewed as needed and is in addition to Advance Directives, Do Not Resuscitate plan, or other legal document.

Patient Name: Address: DOB: Hosp / NHS no:	Date completed: Care Home: GP Details Hospital contact:
Family members involved in Advance Care Planning discussions: **Name:** **Contact tel:**	
Name of healthcare professional involved in Advance Care Planning discussions: **Role:** **Contact tel:**	

Patient signature	Date
Next of kin / carer signature (if present)	Date
Care home / Healthcare professional signature	Date
Review date:	

ACP Feb10 v 20 - © National Gold Standards Framework Centre England Date: Feb 10

Thinking Ahead - Advance Care Planning Discussion

Thinking ahead....

1. At this time in your life what is it that makes you happy or you feel is important to you?

2. What elements of care are important to you and what would you like to happen in future?

3. What would you **NOT** want to happen? Is there anything that you worry about or fear happening?

4. *Do you have a Living Will or Legal Advance Decision document?* **(This is in keeping with the new Mental Capacity Act and enables people to make decisions that will be useful if at some future stage they can no longer express their views themselves)** ***No / Yes***

If yes please give details (eg who has a copy?)

5. Proxy / next of kin

Who else would you like to be involved if it ever becomes difficult for you to make decisions or if there was an emergency? Do they have official Lasting Power of Attorney (LPoA)?

Contact 1 ..... Tel..... LPoA Y / N

Contact 2 ..... Tel..... LPoA Y / N

6. Preferred place of care

If your condition deteriorates where would you most like to be cared for?

1st choice

2nd choice

Comments

1. Do you have any special requests, preferences, or other comments?

2. Are there any comments or additions from other people you are close to? (please name)

NB See also any separate DNAR/AND or ADRT documents .

ACP Feb10 v 20 - © National Gold Standards Framework Centre England Date: Feb 10

The Enabling Care Priorities document

We wish to be able to provide the best care possible for all residents and their families, but to do this we need to know more about what is important to them and what their needs and preferences are.

For residents without mental capacity this will be known as an Enabling Care Priorities form [E.C.P].The rationale for this is to enable decisions to be made in the resident's 'best interests' with as much input from the resident & their relatives as possible

The aim of any discussion is to develop a better understanding and recording of a person's priorities, needs and preferences with the help of their families/carers; this should support the provision of care and enable us to best meet their needs.
This philosophy of 'hoping for the best but preparing for the worst' enables a more proactive approach, and ensures that it is more likely that the right thing happens at the right time.

This is a 'dynamic' tool that can be adapted and reviewed as needed and is in addition to Advanced Directives, Do Not Resuscitate plan, or other legal document.

Patient Name: Address: DOB: Hosp / NHS no:	Date completed: Care Home: GP Details: Hospital contact:
Family members involved in Enabling Care Priorities discussions: Name: Contact tel:	
Name of healthcare professional involved in Enabling Care Priorities discussions: Role: Contact tel:	

Patient signature	Date
Next of kin / carer signature (if present)	Date
Care home / Healthcare professional signature GP signature	Date Date
Review dates:	

1. At this time in your loved one's life what makes them happy/comfortable?

2. What elements of care are important to them and what would they like to happen?

3. Is there anything that you feel they would worry about or dread happening in their care? What would you **NOT** want to happen?

4. *Is there* a Living Will or Legal Advance Decision document? *(This is in keeping with the new Mental Capacity Act and enables people to make decisions that will be useful if at some future stage they can no longer express their views themselves)* No / Yes

If yes please give details (eg who has a copy?)

5. Proxy / next of kin

Have you discussed who else your loved one would you like to be involved if it becomes difficult for him/her to make decisions or if there was an emergency? Do they have official Lasting Power of Attorney (LPoA)?

Contact 1 ..... Tel..... LPoA Y / N

Contact 2 ..... Tel..... LPoA Y / N

6. Preferred place of care

If their condition deteriorates where would you most like them to be cared for?

1st choice

2nd choice

Comments

7. Are there any other special requests, preferences, or other comments?

8. See also separate DNAR document

Talking with service users about their views on how they would like to be cared for towards the end of their lives is rarely an easy task. What follows is a basic structure which might help you to engage in such conversations. It is important to remember, though, that no two discussions on this topic will be the same and that you need to take your cue from the person and to be flexible in responding too.

Guidance Notes on Completing the GSF Advance Care Plan

1. At this time in your life what is it that makes you happy?

- What do you hope for? What do you enjoy doing?
- What or who is really important to you?
- Is there anyone you're especially worried about?
- Has your illness changed the ways you can get close to people you care about?

2. What elements of care are important to you and what would you like to happen in the future?

- Statements of wishes and preferences can include personal preferences, such as where one would wish to live, having a shower rather than a bath or wanting to sleep with the light on. Such statements may also include requests and/or types of medical treatment they would or would not want to receive
- Sometimes people may have views about treatments they do not wish to receive but do not want to formalise these views as an advance decision
- Discussion should focus on the views of the individual, although they may wish to invite their carer or another close family member or friend to participate
- Some families are likely to have discussed preferences and would welcome an approach to share this discussion

3. Is there anything that you worry about or fear happening? What would you not want to happen?

- What worries you most about your illness?
- Can you help me understand a bit better?
- What else would help you cope?
- What is helping most at the moment?
- Has being ill made any difference to what you believe in?
- Do you find yourself thinking about what is going to happen to you?
- Are there things that bother you that you find yourself dwelling on?
- Know when you have reached the limits of your knowledge
- Normalising can help, e.g. "Many people feel like you"

4. Ending difficult conversations but enabling on-going discussion later

- Acknowledge emotional intensity of conversation – "We've talked about a lot of important things today"
- Help person to rehearse what they need to do, who to talk to?
- Try and close the conversation on a positive note
- End conversation in a safe place for them – refer to everyday, practical topics
- "What you have said is very important, can we continue this tomorrow?"
- "Unfortunately I have to leave in five minutes and this is a very important conversation; is there anything else you want to say?"
- "I'm sorry but I think we've got as far as we can at the moment and we will have to leave it there for now"

Adapted from Deborah Holman, Palliative Care Clinical Nurse Specialist, St Christopher's Hospice, London

"We have to learn how to feel 'with' patients without feeling 'like' them if we are to give them a kind of listening and steady support that they need to find their own way through" Cicely Saunders (2003)

"Systematic implementation of ACP involving communication between resident/family/ doctor increases satisfaction with End of Life Care"

Talking with people about their views on how they would like to be cared for towards the end of their lives is rarely an easy task. What follows is a basic structure which might help you to engage in such conversations. It is important to remember, though, that no two discussions on this topic will be the same and that you need to take your cue from the patient and to be flexible in responding to their needs.

Preparing the Ground

Speak to the patient beforehand to explain what it's all about. This might also be a good time to check their understanding of their situation and get a feel of the language they use to talk about it.

NB. If the patient has specific communication needs, e.g. they have limited English or they are hearing impaired, you should check whether an interpreter or signer is needed, both for this interaction and the main meeting.

Set up a time to meet and ask who (if anyone) they would like to be present. This might include family, friends or even an advocate.

Make sure that you can meet in a private and comfortable room and that you have set aside enough time for the meeting.

Using the Plan

Start with general greetings and by introducing yourself, if necessary, to any family, friends or others who have attended. Find out who they are too! Remind all present of the purpose of the meeting. Let them know that you will be making some notes in the meeting so that you can be sure you have an accurate record of what is said.

Ask the patient whether s/he has given any thought to how s/he would like to be cared for in the future. This will give you some idea of their priorities.

Address the issues outlined in the Advance Care Plan. You might want to work through systematically, or you might prefer the patient to talk for a while and then to bring up any aspects that have not been touched on. Adjust the language used in the Advance Care Plan as appropriate for the patient's understanding. You might need to check that they understand terms like Advance Directive and Lasting Power of Attorney or you might need to explain what resuscitation involves.

Check that you understand what the patient says, e.g. if they use the term 'dying with dignity' you might need them to explain what that means to them.

Make notes as appropriate, but try not to do this while the patient or others are speaking. Ensure that your notes are legible and unambiguous to others who might need to refer to them.

Wrapping Up

Summarise the main points of what has been said and check that you have understood them correctly.

Ask if there are any questions.

Make it clear that you know that the patient's views might change over time and they should let you know if this should happen, so that the Plan can be amended.

Either read aloud what you have written or, if they prefer, let the patient and one other person present read it themselves before asking them to sign the Advance Care Plan.

"Introducing Advance Care Planning into our work place as normal practice has been one of the most important things we have done- it's crucial to helping us focus on the needs of service users, it helps discussions with families and it changes the way we do everything. Even though it may be hard at first, we would very strongly recommend it for every care provider."

Care Home Matron GSF Phase 3

"How can we give best care towards the end of life if we don't know what people want? How can you know what people want unless they are asked?"

Care Home Nurse Phase 4

Session Five

Key Question

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

Learning Outcome

To learn about care in the final days and anticipatory care - 'Just in Case thinking'

Activities

1. CPR and Photo
2. Identifying dying and symptoms of dying
3. Stanley - minimum protocol
4. Dignity in dying

This session helps meet the following national policy standards:

National Occupation Standards (NOS):

HSC384 HSC385
HSC387 HSC399
HSC3100

National Institute for Clinical Excellence (NICE) Quality Standards in End of Life Care (see appendix): 6, 11, 12, 13, 15

Department of Health End of Life Care Strategy Quality Markers:

9. Adopt a standardised approach to care for people in the last days of life

4. Ensure that individuals' preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals

Action Plan

- Being aware of Resuscitation and DNACPR discussions
- Care in the final days – what can you do?
- How can you support carers and families in bereavement?
- Other areas

Take Home Message

We can support people when they are dying at home

Discussion of Resuscitation - DNAR and AND (Allow Natural Death)

(with reference Madeline Bass, Head of Education, St Nicolas Hospice Care, Bury St Edmunds

During Advance Care Planning discussions your service users may talk about resuscitation - either that they would not want it to be carried out or that they would. People can refuse treatments but they cannot demand them and this also applies to resuscitation.

If a service user raises the subject of resuscitation whether in a positive way - e.g. 'I want everything to be done' or a negative way- e.g. 'I don't want to be messed about with', you should refer them to their GP as it is a clinical decision.

Until October 2007, in England, an adult with capacity could not appoint a person in advance to make a later decision for them regarding refusal of treatment should they lack capacity to make that decision later.

All someone could do was to express their wishes, which healthcare professionals then should have taken into account.

Since 1st October 2007, under the Mental Capacity Act (MCA) 2005, it has been possible for an adult with capacity to appoint another person under a Lasting Power of Attorney for Personal Welfare Decisions to make healthcare decisions. However they can only ever represent the view the service user would have taken if they still had capacity to make the decision. The MCA also gives a statutory basis for an adult to decide in advance to refuse a treatment should they later lack capacity to make that decision. There are requirements for each, which should be complied with, in order to make them valid and applicable to a particular treatment.

Summary

- Resuscitation applies only to cardiac massage and artificial respirations. It does not include other aspects of nursing or medical care, or medication changes.
- In cases where the circumstances of an arrest can be anticipated and there is a chance of it being successful, it is essential to obtain the service user's view. The only exceptions to this are: if the service user is not competent, or the service user does not want to discuss the matter
- Outside of specialist areas in hospital, such as ITU or A&E, resuscitation attempts are notoriously unsuccessful, in fact only 25% of ALL resuscitation attempts in hospital are successful but only a small amount of these survive to discharge. If the event is due to irreversible disease or damage CPR will not succeed.
- The senior clinician in charge of the service user's care is the only one who has the authority to make the final resuscitation decision (this is probably going to be their GP).
- It is unethical to simply carry out CPR in the absence of a previous decision. If a decision has not been made, and the service user's wishes are unknown, basic life support should be carried out and an ambulance called. CPR should be stopped if it is felt to be inappropriate.

"DNACPR decisions can be a source of misunderstanding and dissent amongst Doctors, Nurses and others involved in a person's care. Many of these difficulties can be avoided if advance decisions are made appropriately and sensitively, especially when the person is in the terminal phase of their illness and is not expected to recover. In such cases it is not usually appropriate for healthcare professionals to attempt CPR procedures" (BMA et al 2001).

When death occurs as a result of illness it may still be an expected and natural event, especially at the end of a terminal condition from which the individual was not expected to survive (BMA et al 2001).

It can be difficult discussing DNAR with people but it is important to discuss this beforehand to try to prevent a distressing situation that arises out of a crisis

Care in the Final Days and Hours of Life

Care in the final days and hours of life, the 'terminal phase', is a vitally important area requiring clear and specific measures to be undertaken, to enable the patient to 'die well'. The quality of care at this time can have a considerable impact on the family and others, including members of staff.

In order to give best care in the final days in someone's life we need to plan ahead as early as we possibly can. **If we get it right early, we can it right at the end.**

The District Nurses in your area may be using an integrated care pathway that has been developed for the final days of life.

The GSF Minimum Protocol of the Dying is a prompt that has been developed, in consultation with others, as a 10 point checklist to ensure that all aspects of care have been considered when a person enters the terminal 'dying' stage.

It is difficult to determine when someone has reached the dying phase and this should always be an MDT decision. Patients coded as 'D'/Red/Dying i.e. in the final days would be included in this, and special measures then commenced.

Guidance of what is happening and what is likely to happen at this time is vital and there are several information leaflets available as a resource.

Symptom management, psychological and spiritual support, continual reassessment of needs and family and carer support is essential for this part of care.

Home Work

Following on from Session 5 of the Domiciliary Care Training Programme we are asking you to complete the following tasks:

- If you have service users who are dying consider using the minimum protocol
- Ask your District Nurses if they have an end of life plan of care and how you can be involved in its use
- Look at what bereavement information is available to support people in bereavement, can you create and personalise your own to use with your service users/families?

Take Home Message 5

We can support people when they are dying at home.

Action Plan – Session 5

	To do		By when
1	Being aware of resuscitation and DNACPR discussions?		
2	Care in the final days – what can you do?		
3	How can you support carers and families in bereavement?		
4	Other areas		

This page is intentionally left blank.

Resources for Session 5

Activity

Activity 1 - Preventing a Crisis Event

Activity 2 - Identifying Dying and Symptoms of Dying

Activity 3 - Stanley (part 3), Care of the Dying

Document

GSF Minimum Protocol for Care in the Final Days

Decisions about cardiopulmonary resuscitation - Model patient information leaflet - download from www.resus.org.uk

This page is intentionally left blank.

Session 4 - Activity 1 Preventing a Crisis Event

Consider the following questions:	**Reflections**
What do you see at the end of the video?	
How might this be prevented?	

This page is intentionally left blank.

Session 4 - Activity 2 Identifying Dying and Symptoms of Dying

Consider the following questions:	**Reflections**
Why is it important to identify when someone is dying?	
What changes and symptoms may be observed when someone is dying?	

This page is intentionally left blank.

Stanley Part 3

Activity 3 – Care of the Dying

A week later the District Nurse visits and feels that Stanley has deteriorated further. Stanley is much weaker and has not taken anything by mouth since the day before. She contacts the GP about her concern and they agree to do a joint visit. At the visit they agree that Stanley is dying and should be coded as D. They talk with Ada and Jane and tell them their concerns about Stanley and that they now consider Stanley to be dying. Ada asks if he should be sent to hospital but Stanley has told them again that he wants to stay at home. The GP reassures Ada that hospital would not be the right place for Stanley at this time and that he will receive all the care he needs at home to keep him comfortable.

The nurse asks the GP to prescribe drugs for a syringe driver as she feels that although Stanley can just about take his tablets today she is concerned that his pain will become a problem if he is unable to take tablets. She will visit later to set up the driver when the drugs are available from the chemist.

While the nurse is still there you arrive for the lunchtime visit. You are told of the new circumstances. You contact your supervisor and it is agreed that Stanley's care should be shared between the agency and the District Nurses with a joint visit being done every morning at a set time.

Before the nurse leaves she ensures that Ada and Jane have an information leaflet that explains about symptoms that Stanley may experience, how the syringe driver works and that they have all the contact numbers that they may need. She tells them that she will let the out of hours service know of Stanley so that they have all his details if they are called out. She also arranges for the evening night nurses to visit and tells Ada and Jane that she will return in the morning. She gives them time to ask any questions that they may have

The District Nurse applies for continuing health care funding to support extra visits from the care agency. She arranges for a night sitter 2 nights a week from the hospice at home service so that Jane can go home to sleep and see her family. Jane has been signed off work to care for her father but is aware that her own family are being neglected because of the time spent with her father. Jane has spoken with her brother and he has come up to see Stanley.

The following morning there has been no further change in Stanley.

The carers continue to visit 4 times daily to attend to Stanley's personal needs and the District Nurses visit in the morning the same time as the carers, to refill his syringe driver and do a general assessment. The evening District Nurses also visit every evening to check that everything is going to plan and that Ada and Jane are coping. The carers have been allotted extra time by their supervisor so that they can spend more time with Stanley and are able to stop and talk with Ada and Jane.

Although Stanley only went to church at Christmas and Easter to support Ada, he had been a regular church goer as a child as he was in the choir and bell ringing team. Ada's vicar was aware of Stanley's poorly condition and had been visiting Ada to give her support. While he was there one day Stanley asked to see him for a chat. Before the vicar left he gave Ada and Stanley communion together.

One evening Stanley had an increase in pain. Jane was very concerned and called the out of hour's service as she had forgotten who to contact in her panic about her father. The receptionist she spoke to was aware that Stanley was dying and that his preferred place of care was home. She told Jane that she would contact the District Nurse to come and visit and assess the change of symptoms and make Stanley comfortable. When the nurse arrives she finds Stanley very agitated and in pain. She gives him an injection of pain killers and he settles again. She contacts the District Nurse in the morning and tells her what has happened so that she can increase the dose in his syringe driver and replace the drugs that have been used.

After four days, when you and the nurse visit in the morning to tend to Stanley, he dies while you are there. The nurse is able to verify his death as it was expected, so she does this rather than waiting for the doctor. You lay Stanley out so that Ada and Jane can come and sit with him before he leaves for the funeral parlour. Jane helps do this as it is the last thing she can do for her father. The District Nurse talks with Ada and Jane and tells them what they have to do next to register the death. The agency that you work for has some leaflets about bereavement and what needs to be done and you leave one of these for Ada and Jane to read when they are alone.

At your team meeting the following week you reflect on the care that Stanley and Ada have received and do a Significant Event Analysis. You all express that you are pleased that Stanley died at home as you knew that that was what he wanted. You felt that the teamwork with the District Nurses had been greatly improved and that they recognised your value in caring for Stanley in his final days. You were also aware that Ada found it very difficult at times to care for Stanley and needed a lot of support from Jane. Jane had been sleeping at her parents' house on alternate nights but she had to sleep on the sofa so she wasn't properly rested before going to work in the morning. It had also had a negative impact on her family, although she had rationalised her decision by telling everyone that it wasn't going to be forever. If a similar situation occurred, as a team you would look at offering more support to someone like Ada so that she could cope with the situation and try and arrange night sitters at an earlier stage to take some of the pressure of Jane.

Consider the following questions:	**Reflections**
What should you do now?	
Whom should you contact?	
Can the minimum protocol be applied to Stanley's care?	

This page is intentionally left blank.

GSF C7 Care in the Dying Phase - Minimum Protocol for Care in the Final Days

Name of resident ..... Date .....completed by.....

Check list	Achieved Date/signature	To do	Actions/ Comments
Diagnosis and recognition of dying – awareness of signs of terminal phase ✦ Agreement by clinical team ✦ Bed bound / increasing sleepiness, semi-conscious / only taking sips of fluids / not taking oral medicines/ other factors			
Advance Care Planning ✦ Use of an Advance Care Plan / Statement with preferences/statements noted and respected ✦ DNACPR discussed, noted and communicated to others ✦ Other refusal of treatment / Advance Decision if appropriate			
Medication re-assessed ✦ Non-essential medication discontinued ✦ Essential treatment converted as appropriate to subcutaneous (e.g. syringe driver) /transdermal/sublingual /rectal route			
Nutrition and Hydration Assess the individual's ability to swallow, if safe and appropriate offer regular fluids; ice creams, jellies, smoothies etc. if wanted. If there is a risk of aspirating, just give water to moisten the mouth.			
Anticipatory medication - PRN ✦ Standard protocol for 'as required' medication in anticipation for the dying phase written up and available, including pain, agitation, respiratory secretions, nausea and vomiting and breathlessness.			
Spiritual, religious needs ✦ Spiritual and religious needs assessed and met regarding patient and carers ✦ Support from clergy or other spiritual advisors			
On-going assessment ✦ Regular assessment of pain, agitation, respiratory tract secretions, mouth-care, pressure areas, psychosocial support ✦ Evaluate care plans for all care including mouth-care, pressure relieving for comfort, urinary management etc.			
Family awareness ✦ Family / carers are aware that the patient is dying ✦ Family to be enabled to be involved in some patient care, if appropriate ✦ Family contact increased - arrangements for contact before / at time of death confirmed and practical arrangements arranged e.g. staying overnight ✦ Ensure information provided e.g. pre-bereavement care, advice sheet			
Communication ✦ GP aware resident is dying and handover form for out-of-hours providers sent ✦ Other residents prepared ✦ 'Expected death' form: Code 'D' - expected death discussion - recorded and signed. Local policies / guidelines followed			
After care and bereavement ✦ Verification of death procedure and funeral director notified ✦ Staff protocol for after-death care - religious / cultural rituals ✦ Follow up care for family - leaflet / information for relatives, access to bereavement support services ✦ Support for residents e.g. Memorial Service / acknowledgement ✦ Secondary / specialist services informed and hospital appointments cancelled after a death ✦ Support and debriefing for staff			

This page is intentionally left blank.

Session Six

Key Question

- Are we working well enough to provide well coordinated care?

Learning Outcome

To understand the importance of good team working and cross boundary care and communication

Activities

1. Coordinated care
2. SEA
3. Supporting carers
4. Target

This session helps meet the following national policy standards:

National Occupation Standards (NOS):

HSC385 HSC387
HSC399 HSC3100

National Institute for Clinical Excellence (NICE) Quality Standards in End of Life Care (see appendix):
4, 5, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16

Department of Health End of Life Care Strategy Quality Markers:
6. Have mechanisms in place to ensure that care for individuals is co-ordinated across organisational boundaries 24/7.
7. Have essential services available and accessible 24/7 to all those approaching the end of life who need them.

Action Plan

- 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?

Take Home Message

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

Cross Boundary Care and Collaboration

As people move across different areas of care there may often be gaps in the transitions which can lead to significant problems. It's rather like travelling across different countries with different languages, cultures and currencies and people often struggle across the boundaries of care. It can be a nuisance and sometimes distressing to have to repeat information on several occasions. But serious failures in information transfer and service provision can lead to inadequate clinical care, excessive hospitalisation and poor quality of life.

Cross boundary care often remains the 'missing link' in care. Good planning and communication between health and social care providers is essential in ensuring people receive a 'gold' standard of care in whichever setting they find themselves.

To improve cross boundary care requires active efforts to be able to support the transfer of information and care planning to other areas, specifically with out of hours providers. The information that needs to be transmitted is in two broad categories:

Clinical information: diagnosis, medication, prognosis and predicted management plan - as determined by the clinical assessment of the service user

Personal information: Person's own wishes for care, preferred place of care, deeper needs and other wishes and preferences, as discussed in the Advance Care Planning discussion, home circumstances

As part of the efforts to improve communication, various suggestions are made e.g.:

- "Passport Information": examples of passports have been developed which would include information related to these two categories above, i.e. clinical information plus Advance Care Planning preferences of care. These can take various forms:
- Electronic summary care record or locality register
- Patient held record
- Access to external source of information e.g. central contact phone number or webpage etc.
- The GSF Home Pack has been used in a number of areas and is available from the Central Team. This can be adapted for local needs with local phone numbers and contact details and provides a template for you to provide your own information to your service users, and to help anticipate possible problems and advise how to deal with them.

You should, however, be aware of your company and local policy with regard to the sharing of information and the principles of confidentiality and data protection.

In order to share information that one of your service users has shared with you, you should first gain their consent and ensure they are happy for the information to be documented and shared with other relevant health professionals.

Improving Cross Boundary Care

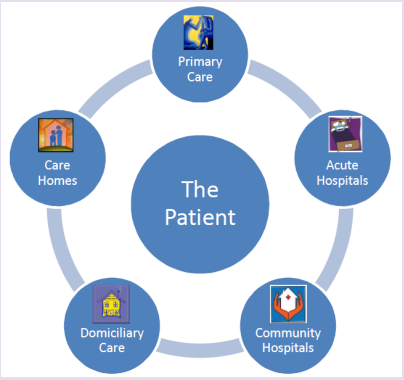
There are 3 other major GSF programmes you may be aware of:-

- **The GSF Primary Care Quality Improvement Training Programme.** After 10 years of use of GSF in Primary Care, and several developments in many other areas, such as the National End of Life Care Strategy, successful GSF Programme in Care Homes, increasing emphasis on reducing hospitalisation, on Advance Care Planning and other developments, we felt we needed to undertake a full review and update of the GSF in Primary Care Programme.

- **The GSF in Care Homes Training Programme.** This involves over 2000 care homes currently and one of the key elements is improving collaboration with Primary Care teams. There might be several care homes in your area in training or already accredited. Homes progress towards accreditation following a 9 month training period.

- **The GSF Acute Hospitals Training programme.** The aim is to develop a structured GSF Acute Hospital Training Programme building on, and dovetailing with, well used GSF principles from other programmes in Primary Care and Care Homes to support the goal of improving cross boundary care.

- **The GSF Community Hospital programme.** The aim is to develop a structured GSF Community Hospital Training Programme building on and dovetailing with GSF principles used in other programmes to further support the goal of improving cross boundary care.



Aims of the GSF Training Programmes

To improve the **quality** of care for all people in the final year of life

To **reduce hospitalisation** and costs - rapid discharge and admission avoidance etc.

To improve the **cross boundary collaboration and ordination** **of care** for these patients

3. GSF Measures and Metrics

A range of adapted measurement tools to enable benchmarked assessment of progress in

- Quality of care
- Structure, process, patterns
- Patient outcomes and experience of care

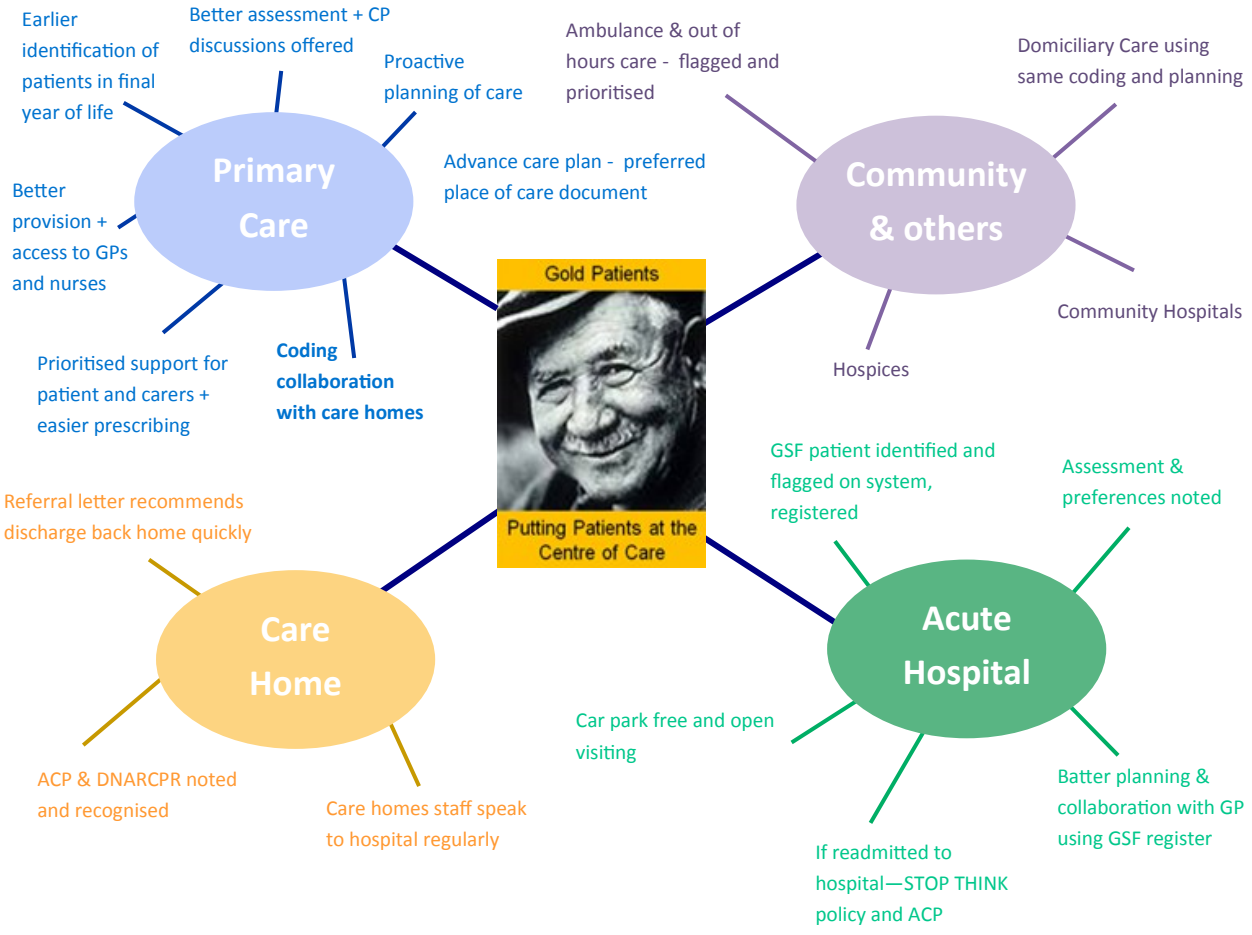
These include the well used **After Death Analysis Audit tool (ADA)** , demonstrating changes in hospitalisation and other key outcomes .

Benefits to Patients

- Improved quality and experience of care
- Empowerment and better listening through Advance Care Planning discussions
- Enabling more to live and die where they choose and reduce hospitalisation
- Recognised as VIPs - 'gold patients'
- Earlier identification and clarification of needs
- Fewer crises and unplanned events
- Better experience for families and carers

Benefits of Cross Boundary Integrated Care using GSF

A vision of patient centred best practice



How Using GSF Across Boundaries Of Care Can Help

Use of common GSF principles, tools and systems will enable a better common language across the boundaries of care and ensure a better experience for service users.

These include:

⇒ Common principles of GSF in different settings for all people in final year

⇒ Focus on improving quality and collaboration and reducing hospitalisation

⇒ Earlier identification of people nearing the final months, weeks and days

⇒ Needs based coding enabling a common language of staging

⇒ Use of Needs Support Matrices - active support at different times

⇒ Advance care planning discussions and recordings

⇒ Common assessment and planning tools

⇒ Common measurement tools e.g. After Death/Discharge Analysis

Questions:

How can you improve communication and cross boundary care with hospitals, primary care, out of hours and others in your area?

What are the benefits for service users and their families?

How might this reduce duplication and hospitalisation and thereby reduce costs?

C4 Continuity
Systems and protocols should be developed to ensure continuity of care delivered by inter-professional teams and Out of Hours providers.
Practices will transfer information to the Out of Hours (OOHs) service for people identified on the GSF Supportive Care Register, for example using a handover form and out of hours protocol, according to local agreement.
The GSF Supportive Care Register summary sheet (SCR2) can be used as an OOHs handover. It includes a basic patient summary, carer details, key clinical contacts and information on preferred place of care. This will often be done by the GP or DN, it would be useful for you to keep a copy of this in the records in the person's home. Use of the GSF Home care pack could facilitate this sharing of information.
This builds in anticipatory care to reduce crises and inappropriate admissions. Information should also be passed on to other relevant services.
Record and minimise the number of professionals involved, for example note the lead GP, lead District Nurse and deputy for each person (this is especially important in larger practices).

Summary of 4 Point Plan for Out of Hours Palliative Care		
1	Communication	a) Use handover form – GP/DN to write and fax to on call service, keep in DN notes and Domiciliary Care records within the home. b) Inform others e.g. hospice c) Does the carer know what to do in a crisis?
2	Carer support	a) Co-ordinate pre-emptive care e.g. night sitters, 24 hour District Nursing service b) Give written information to carers c) Emergency support e.g. Rapid Response team
3	Medical support	a) Anticipated management in handover form b) Crisis pack, guidelines etc. and on-going teaching c) 24 hour specialist advice available from hospice
4	Drugs/equipment	a) Leave anticipated drugs in home b) On call stocked pharmacists C) Ensure all required equipment is available in the home

Communication - Handover Form

The handover form has two important functions to:

1) Improve information transfer. The handover form informs the visiting on-call doctor of the GP's care plan for the patient and the current medication and proposed changes. When faced with a difficult medical symptom, the drugs left in the patient's home (e.g. Just in Case Boxes) or kept in the on call cars with guidance on use can be invaluable and anticipatory medication is a key part of preventing admissions.

Palliative care advice line - most specialist palliative care services are available for on call advice, either from a nurse or on call doctor, often via local hospices - ***what is the specialist advice number for you to call?***

2) Build in anticipatory care. The process of completing it is part of the benefit – if the GP thinks that a person might become agitated or develop a rattly chest over a weekend, then they should leave some medications in the home, for administration either by the on call doctor or district nurse.

3) If the on call doctor is presented with the handover form that states that the person has a preference to remain at home, then there is more chance that they will be enabled to do so.

The Home Pack contains an out of hours section to be completed by the primary care team, to help the person and their carers know what to do and who to call in a crisis. This information can be standardised e.g. surgery and co-op number, with customised information for the patient. For example, the wife of a person who was concerned about epileptic fits was shown how to place her husband in the recovery position, how to give rectal diazepam, which number to call and where the medication was kept should one occur. With this information written down, they felt reassured and less anxious.

Another suggestion to improve communication is a fridge magnet or a message in a bottle with the important phone numbers to hand immediately e.g. who to phone, including nearest relatives etc. Some have added 'not for CPR' so that ambulance staff are aware of this request, if agreed.

2. Carer support

Twenty four hour access to District Nursing or alternative nursing care is a basic pre-requisite for good palliative care out of hours. We know, despite numerous recommendations, many areas still have no service after midnight, or inadequate evening provision. Some areas have Rapid Response Teams, an excellent needs-based crisis-only service for use by patients who would otherwise be admitted to hospital, or Hospice at Home services.

Model of a Good Palliative Care Service In and Out of Hours

- Good anticipatory care and proactive planning by the Primary Health Care Team
- Efficient transfer of information between those working in hours and out of hours
- Appropriate advice, information and support to people and their carers from health professionals, who are well informed about their condition, medication and future management needs
- Quick responses to requests for help, with information being passed on to relevant colleagues and revisits when necessary
- Carer support in the form of 24 hour availability of District Nurses and access to night sitters
- High quality symptom control with access to specialist palliative care advice when needed
- Easy availability of appropriate drugs and equipment in and out of hours without the need for the carer to leave the person
- Easy access to and good co-ordination of the provision of care available, so that all have equity of access to services

Admission Avoidance Measures

These include:

- Use of Advance Care Plan with patient and family - preventing difficult discussions in crisis and knowledge of a persons preferences for care
- Coding of service users to anticipate likely stage of illness and alerting to needs
- Planning meetings
- Use of Needs Support Matrix - especially for those in Code C (weeks) to prevent crises in final days
- Anticipation of problems and enabled to die in place of choice
- Discussion and GP recording of Do Not attempt Resuscitation/Allow a Natural Death (DNaCPR/AND)
- Training and education to increase confidence of staff in caring for seriously ill people
- Guidelines and policy for acute illness
- Staff policies on crisis calls to 999
- Anticipatory prescribing especially for OOH
- Handover form sent to OOH provider
- Handover form sent to ambulance
- Regular audit/ reflection of admissions
- Close communication with family related to ACP
- Use of care pathway/GSF minimum protocol for the dying to ensure care in dying phase is of high standard
- Communication and involvement of out of hours providers, night staff etc.
- Collaboration with primary care teams, DNs etc.

Reducing Length Of Stay And Encouraging Rapid Discharge

These include:

- Develop close link with Social Worker/hospital to enable rapid transfer back home
- Copy of their ACP/Leaflet/letter to go with person into hospital to explain plans for earliest transfer back
- Advance Care Plan, noting preferred place of care, highlighted to staff
- GSF coordinator/team leader phoning ward/visiting to discuss with staff

Spiritual Care

Many of us struggle to articulate quite what spiritual care is. Research carried out by Faith in Older People (08) www.faithinolderpeople.org.uk found that many staff tended to assume that spirituality meant religious observance. This meant that they did not recognise how they were already delivering spiritual care in their everyday contact with people.

Spirituality encompasses the following aspects:

- Religious/cultural
- Sacramental/ritual
- Inner life/transcendent

Spirituality, is also about being recognised as a person with a full history and individual needs and values. Basic spiritual needs that might be addressed within the normal course of providing care are:

- The need to give and receive love
- The need to be understood
- The need to be valued as a human being
- The need for forgiveness, hope and trust
- The need to explore beliefs and values
- The need to express feelings honestly
- The need to find meaning and purpose in life

Guidance on spiritual care NHS Scotland (CEL, 2008, 49)

Spiritual Care

The Preb Revd Mark Thomas, Church of England Parish Priest

What Is Spiritual Care?

- We start with two factors that are universal and common to us all: we are all human: we are all mortal. Spiritual care starts there.
- Every person has spirituality and an inner life, even if it is hard to express in a formal way.
- Spirituality includes religious practice; this is important for some more than others – what is the person's religious belief? These are the 'outer' ways in which they might express something deeper or their 'inner life' – they might find the words or rituals represent a bigger truth or meaning. For others, they may not have such ways of expressing their deeper thoughts in this way, but may express them through other means.
- The Advance Care Planning conversations and follow up discussions can help you better understand what is really important to the person, to grow closer to them, to sense how they feel about the deeper things of life. That is why it often begins with - 'tell us what makes you happy or is important to you… and what would be important to you in future?'
- We are trying here to encourage people to feel comfortable and at peace within themselves and with that which is greater than themselves, either through their own religious faith and practices or through other ways of recognising their inner being.

Spiritual Resources

- Spirituality provides resources and a language for living well now in the present as well as nearing the time of dying. Making sense of things, moving towards a sense of peace, prioritising those things that are most important to improve quality of life now, forgiving and being forgiven, thanking and being thanked, loving and being loved.
- Spiritual resources may include:
  1. Belief in something greater than ourselves, 'the transcendent' and something beyond death
  2. Membership of a faith community
  3. Prayer, relationship, communication, being in the presence of God
  4. The sacraments - outward and physical signs of an inward and spiritual truth e.g. Eucharist
  5. A language with which to express our feelings about illness and death
- **Rituals** are activities that represent something of a deeper meaning and importance e.g. funerals, a toast for a deceased person at the meal, the way you remember someone, how the body is removed, how you inform others etc. Consider the ordinary rituals you have been involved in that represent something deeper. What are you saying through these activities and would you like to reflect on how these might be improved? What is important to the person, their families and your staff?
- **Resolution** Many feel that this is an important time to try to talk about unresolved issues and 'putting your emotional house in order'- regarding relationships, or seeking forgiveness for something that occurred in the past. It is suggested that it can be important to help people express 'the four things that matter most' (Ira Byock) - forgive me, I forgive you, thank you, I love you…and then to be able to say goodbye.

Being With People

- We need to give our full calm 100% attention to the person cared for as a fellow human being - we bring our humanity to our jobs as carers (no small task), to provide the kind of care we would like to receive ourselves or for our mother/ father/loved one.
- We must try to be fully present with them at that moment, to be able to 'be' with them as well as 'do' for them. This presence is transmitted in ways other than words – by a touch, the way we listen and look, the inner stillness we bring.
- Silence is an important part of being with people, accompanying them as they try to make sense of things for themselves.
- Questions gently asked are as important as answers received:
  1. What is your understanding of what's wrong with you/your condition?
  2. What have you found helpful in the past at times of crisis, or when things have been tough for you?
  3. Are any of those things going to be helpful now?
  4. Is there anything else that might be helpful now?
- We are concerned with life stories not just medical stories. We don't compartmentalise medical/physical and spiritual – one affects the other. We are looking for themes and meaning – making sense of a persons life and what is important to them.

Hearing:
Listening Intuitively
Key Questions:
- Is there a sacred component to the patient's story and how can I honour this in my care giving?
- How can I attune to the work that God, Higher Power, Spirit might be doing in this patient?

Sight:
Seeing Soulfully

Key Questions:
- Who is the person behind the disease?
- What visual cues of the patient's story are available to inform my care giving?

Presence:

The Essence of Spiritual Care
Key Questions:
- How is my presence permeating my clinical care?
- How is my patient's presence affecting the clinical encounter?

Speech:
Taming my tongue
Key Questions:
- How can I communicate in a language that is understandable and meaningful to the person in my care?
- What are the issues in this clinical encounter I can address with words and what are the issues that are best met with silence?

Touch:
Physical Means of Spiritual Care
Key Questions:
- How is my physical care impacting spiritual well being? What intrinsic qualities are reflected in my physical care?
- How can I effectively and respectfully provide comfort through physical means?

Drawing On Ourselves As Carers

- Carers of people approaching their death have an important role and can be very important in what they say, in what they do, but even more importantly in who they are. Your inner being is important here and this is transmitted to others. So the carer needs to ask him/herself:

  1. Where do I get my spiritual strength from?

  2. How do I find conversations with dying people about spiritual matters?

  3. What inhibits those conversations?

  4. What would help facilitate them?

  5. When is it appropriate to call in a professional (chaplain, pastor, priest)?

Compassion for oneself leads to empathy for others, leads to harmony in the home, leads to joy in living, leads to acceptance of dying, leads to a sense of peace for all.

SOME CONCRETE STEPS AS CARERS

1. **Relate** to people as fellow humans who are on the same journey as us. Do our jobs well, with kindness, humanity, and awareness of deeper needs. Offer **companionship** - attentive listening and 'being', openness not answers.
2. **Inner Life -** Seek ways to nurture the inner life of your service users through Advance Care Planning discussions, life stories, music, story-telling, art, dealing with unfinished business etc. Consider transcendence and transformation.
3. **Spiritual Resources, rituals and sacraments –** Consider what rituals and sacraments your service users may have, and other ways of conveying something of deeper meaning.
4. **Involve local religious leaders** e.g. in services/sacraments and ask for help if appropriate or there are unmet needs.
5. **Nurture your own** spirituality and inner life - draw strength and seek support from others.

Supporting Families And Carers In Bereavement

Bereavement care is rewarding as well as challenging. Parkes and colleagues point out that *'with proper training and support we shall find that repeated grief, far from undermining our humanity and our care, enable us to cope more confidently and more sensitively with each succeeding loss'.*

From the National Primary Care Snapshot Audit 2008

Supporting patients and carers

- **Only 50% of carers of those on the register had their needs assessed**
- **Only 46% of people or carers were signposted to benefits**
- **Only 34% of all carers and 52% of those on register were offered bereavement support**

Bereavement Support For Relatives, Staff And Other Residents

As carers, we meet death more often than most - and we should never underestimate its impact. Unresolved grief can have significant consequences in terms of psychological and physical symptoms.

Loss takes many forms, but there are common themes in our reactions to it, as Bowlby reminds us:

" The loss of a loved person is one of the most intensely painful experiences any human being can suffer, and not only is it painful to experience, but it is also painful to witness"

If we are unsure how to help when exposed to the raw grief of the recently bereaved, then our natural tendency is to avoid the situation. Then we may feel guilty, and we miss the chance to help the person who may appear perfectly normal outwardly, but who has the desperate wound of grief burning in their chest, as they present small clues as cries for help -'not waving but drowning'.

Emotional pain can also commonly be expressed as physical pain - the "pit" in the stomach, palpitations, anorexia or even physical symptoms similar to those of the person who died. However, by easing the associated strains of grief, the bereaved can be buffered against the most dire consequences of loss. Many studies have shown that the right help given to people at the right time can be effective in reducing physical and mental symptoms and can improve the quality of life before and after bereavement.

The aim when helping people grieve is that they will achieve some restitution and adjustment to a new way of being, 'emotionally relocating the deceased'. They will be permanently changed, but many will be stronger and wiser after grief and may wish to use their experience to help others.

Timescales are difficult to estimate. Two years is considered average, although many, especially parents, may need much longer - either way we should be alert to long-term consequences.

What Helps?

When a death is anticipated, helping those closest prepare for bereavement can greatly improve outcomes.

Useful suggestions that take little organisation but can be so greatly appreciated are:

- Ensuring that carers have contact numbers and information of where they can access help and support e.g. through the hospice, hospital chaplain etc. This could include local clergy, chaplains and other religious leaders, social services, voluntary self help groups etc.
- GP may very often be the first point of contact for the bereaved. Use of assessment tools such as the Distress Thermometer can help to identify any concerns or problems the carer may have.

1. Risk Factors

- Ambivalent or dependent relationship
- Multiple losses
- Previous mental illness such as depression
- Sudden traumatic death
- Long terminal illness (more than 6 months)
- Suicide
- Level of perceived social support
- Ability to perform valued rituals

2. What Is Abnormal Grief?

Abnormal grief is 'the intensification of grief to the level when the person is overwhelmed, resorts to maladaptive behaviour or remains in a state of grief without progression of the mourning process towards completion'.

Four types of abnormal grief reactions are described:

1. Chronic – the most common
2. Delayed – no grieving, followed by a later reaction
3. Exaggerated – perhaps leading to the development of phobias
4. Masked – such as by alcoholism

3. Staff Need Support Too

If it is alright for carers to grieve it should be acceptable for us to also. Any caring team must build in staff support such as debriefing sessions, to 'de-stress the distress'. What resources do we have to draw on ourselves and do we know our limits? In your meetings it can be helpful to undertake a Significant Event Analysis after a death, to reflect on the care provided but also to ensure that the staff involved have unloaded any baggage of residual feelings, especially if the death has been traumatic.

4. Stages Of Grief

	Common emotions and experiences	Task
Initial shock	Numbness, disbelief, heart and head in conflict	Accept the reality of the loss
Pangs of grief	Sadness, anxiety, vulnerability, anger, guilt, regret, hypersensitivity, preoccupation, social withdrawal, inertia, restlessness, transient hallucinations, nightmares	Experience the pain of grief
Despair	Loss of meaning and direction in life – lack of will to live	Adjust to a new environment in which the deceased is missing
Adjustment	Develop new interests, relationships and outlook – moving on	Emotionally relocate the deceased to an important but not central place

Home Work

Following on from Session 6 of the Domiciliary Care Training Programme we are asking you to complete the following tasks:

- Reflect on all that you have learnt since starting this programme
- How are you going to sustain what you have learnt? Meetings, reflective practice, changing /updating documentation
- What are your action plans going to be?

Take Home Message 6

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

This page is intentionally left blank.

Action Plan – Session 6

	To do		By when
1	How can you provide well coordinated cross boundary care?		
2	How can you provide spiritual care?		
3	How can you support carers?		
4	What are your next steps to sustain the work?		

This page is intentionally left blank.

Resources for Session 6

Activities

Activity 2 Significant Event Analysis

Activity 3 Looking After Carers

Evaluations - Post Training

Target exercise

Self assessment of confidence - on VLZ after session 6

Supportive care analysis - on VLZ after session 6

Training evaluation questionnaire - on VLZ after session 6

Case history - Eric - to be marked by trainer

This page is intentionally left blank.

Activity 2 SEA (Significant Event Analysis)

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

This page is intentionally left blank.

Session 6 - Activity 3 Looking After Carers

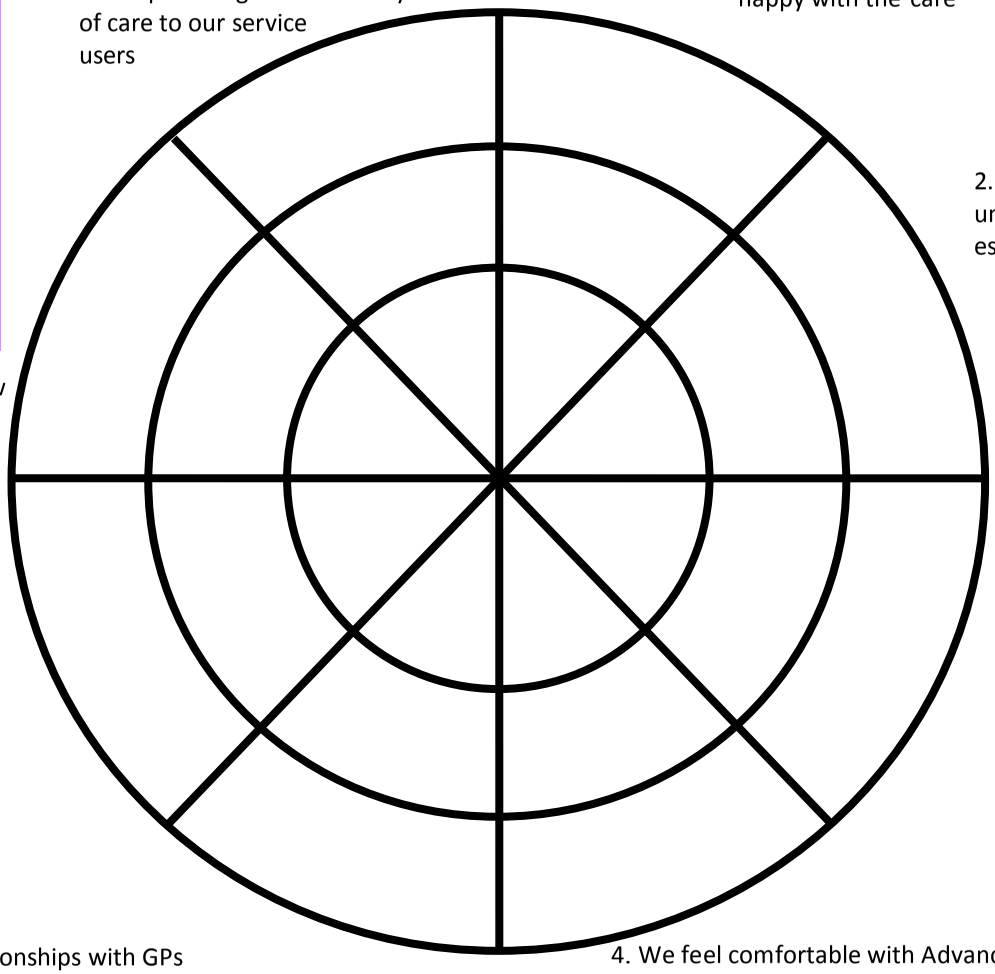
Consider the following questions:	**Reflections**
What resources are available in your area?	
If you were a family member, what would be most important to you?	

This page is intentionally left blank.

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

Target Exercise



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

4. We feel comfortable with Advance Care Planning discussions with our service users. These are discussions to find out the service users 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

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

6. We use an individual person centred plan of care for end of life in conjunction with district nurses.

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

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

This page is intentionally left blank.

Staff Follow Up Confidence Assessment Survey Questionnaire – After 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 e.g. NVQ		

I feel I need to know more about the following areas in End of Life Care?

1. Communication skills	Strongly disagree	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Strongly agree
2. Holistic assessment	Strongly disagree	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Strongly agree
3. Symptom management	Strongly disagree	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Strongly agree
4. Advance care planning	Strongly disagree	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Strongly agree
5. Care planning	Strongly disagree	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Strongly agree
6. Care of carers	Strongly disagree	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Strongly agree
7. Care of the dying	Strongly disagree	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Strongly agree

Comments: _____

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

8. Gold Standard Framework **Yes (aware of) ☐ Yes (have used) ☐ No ☐**

9. Preferred Priorities for Care **Yes (aware of) ☐ Yes (have used) ☐ No ☐**

10. Individual Plan of Care for End of Life **Yes (aware of) ☐ Yes (have used) ☐ No ☐**

11. Advance Care Planning **Yes (aware of) ☐ Yes (have used) ☐ No ☐**

Comments:_____

12. 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

13. 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

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

Please state:_____

15. 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

16. 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

17. 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

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

Comments:_____

19. Do you routinely discuss service users nearing the End of Life Care at regular Multi Disciplinary Team meetings? Yes ☐ No ☐

Comments:_____

Do you routinely transfer information regarding End of Life Care and patient's wishes (including Advance Care Planning discussions of needs and preferences) to?

20. GP Practice Yes ☐ No ☐

21. District Nursing Team Yes ☐ No ☐

22. Other, please specify Yes ☐ No ☐ _____

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

_____

_____

23. Any other comments or suggestions?

_____

Supportive Care Analysis - After

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 Green Amber Red None
Have you been involved in any planning discussions about key issues or concerns about the service user with other care providers e.g. 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? E.g.: better communication Earlier identification of deterioration	

This page is intentionally left blank.

Staged Assessment – Case History (Eric)

Introduction

Having completed the GSF Domiciliary Care Training Programme with the trainer from your Domiciliary Care agency we would like you to complete the following evaluation exercise. On successful completion you will receive a certificate of attendance and completion of the GSF Domiciliary Care Training Programme.

This evaluation is designed to assess the level of understanding that you have gained about GSF in Domiciliary Care and reinforce your knowledge of End of Life Care.

The evaluation will follow one service user and their family through the last few months of life.

Scenario – Introduction

Eric Smith is an 85 year old farmer who lives at home with his 90 year old wife who is his main carer. He lives on the family farm which is now run by his two sons who live close by. The farm also incorporates the local pub and Eric enjoys a pint, or two, in the evening with his friends.

He has chronic lung disease from years working with hay and straw etc. He is a heavy smoker, having smoked heavily all his life, and continues to do so enjoying a couple of cigarettes at night when he joins his friends in the bar even though he knows it's not good for him.

Past History

He has had several hospital admissions for chest infections and shortness of breath. He was last discharged a week ago. While he was in hospital he lost a lot of weight because he found it difficult to eat and there wasn't always someone to help him. He got frustrated and angry that he could not smoke.

He is increasingly short of breath when he tries to do anything and uses oxygen long term but this does not always help him breathe any easier and if he uses his oxygen he can't smoke. He gets very depressed that he cannot help in the day to day running of the farm anymore.

Coding

While Eric was in hospital his family expressed concerned about Eric's ability to cope at home and a case conference was held with his named Nurse, Social Worker, District Nurse and care agency manager and his family. Eric agreed to have help in the morning to get up and a care package was put in place.

You have been visiting Eric every day and have got to know him and his wife Vera very quickly. You have learnt a lot about him and his life and how things have changed for him since becoming older and in poor health. You have learnt how his health has deteriorated in the last year and in particular over the winter.

At your next team meeting you discuss Eric with your colleagues and how he should be coded for your GSF register.

Question

What would you take into consideration when coding Eric?

Question

How would you code Eric?

Question

Why would it be beneficial to code Eric?

Next Steps

As you have coded Eric as …….. what other things should you be considering?

ACP

While you have been caring for Eric he has commented that he does not want to go back into hospital as he found the whole experience quite distressing. Even though they had improved his chest infection he was still very short of breath and he knew that this was never really going to improve. His father had had severe lung disease before he died and he felt that he was following the same pattern. He had watched his father struggle for breath at the very end and he did not want same thing to happen to him when his time came.

Question

What is your response to Eric's concerns?

Question

What documents can be used to record Eric's wishes?

Question

What things do you have to take into consideration when having an Advance Care Planning discussion with a service user?

Eric has recorded his ACP and discussed it with Vera and his sons. His GP has visited and recorded in his practice notes that Eric does not want to go back to hospital and does not want to be resuscitated. He has reassured Eric and Vera that if Eric develops a chest infection again that he will arrange for the specialist community nurses to visit to provide necessary care such as intravenous drugs.

Carer Assessment

One day when you are visiting Vera answers the door and it is obvious to you that she has been crying.

Question

What do you do?

Vera tells you that Eric has become quite nasty towards her and she feels as if she can do nothing right. She feels very tired as he wakes her up several times in the night with his coughing. She hasn't been out for months as Eric does not like to be left on his own as he is frightened of not being able to get his breath. Her sons and their wives have been very helpful and do all her shopping for her but she feels very isolated now as she cannot get out to visit her friends.

Question

How can you help?

Eric has developed another chest infection. His GP visited 3 days ago and prescribed antibiotics but he isn't responding to them.

Question

What should you do?

The district nurse and GP have visited Eric and as he has not responded to the antibiotics they are of the opinion that Eric is dying. An individual person centred plan of care for end of life has been commenced.

Question

What are the benefits of using this type of documentation?

Eric has been on the individual person centred plan of care for end of life for three days now and you have noticed a further change today.

Question

How might you recognise that a person is dying? Decide for each symptom if they happen usually or sometimes and put each symptom into the correct column.

	Usually	Sometimes
Weak, thready pulse		
Unresponsive		
Unable to swallow		
Changes in colour		
Shallow breathing		
Chest secretions		
Restlessness		
Noisy breathing		
Sleeping more		

Question

How do you think Vera and her family are feeling?

Question

How can you support them?

Now hand your completed assessment to your trainer for marking.

Section B - Additional Resources

1. Glossary
2. Suggested Reading
3. Useful Website Links
4. NICE Quality Standards
5. Department of Health End of Life Care Strategy Quality Standards

1. Glossary

DNaCPR	Do Not attempt Cardio Pulmonary Resuscitation
AND	Allow a Natural Death
ADRT	Advance Decision to Refuse Treatment
OOH	Out of Hours Service (GPs, District Nurses)
DS 1500	(Benefit form that is completed by GP indicating that the person has a limited life expectancy and therefore is entitled to receive benefits such as attendance allowance without the usual delay)
Continuing Care Funding	Additional funding from the Primary Care Trust to allow for an increased package of care, if required, in cases of high need
DN	District Nurse
GP	General Practitioner
SPC	Specialist Palliative Care
ACP	Advance Care Planning
ADL	Activities of Daily Living
NSM	Needs Support Matrix
SEA	Significant Event Analysis
NICE	National Institute of Clinical Excellence
CQC	Care Quality Commission

Appendix 2 Suggested Reading

Caring for the Dying at Home **ISBN 185775946X**	Keri Thomas	Official textbook of the Gold Standards Framework.
ABC Palliative Care **ISBN 072790793X**	Marie Fallon and Bill O'Neil	A practical user-friendly guide to palliative care. Includes info on: common medical problems, pain relief, social and psychological issues and advice on communicating with a dying patient and their family. Written by both specialists and primary care workers.
Introducing Palliative Care **ISBN 185775915X**	Robert Twycross	An introductory text for palliative care covering symptom control, ethics and communication.
A-Z Pocketbook of Symptom Control **ISBN 0951989510**	Peter Kaye	A checklist of treatment options for symptom control, intended for palliative care professionals, GPs, District Nurses and hospital doctors.
Breaking Bad News **ISBN 0951989561**	Peter Kaye	10 step approach to breaking bad news plus case studies. (Not available in bookshops but can be ordered from EPL Publications, 41 Park Avenue North, Northampton NN3 2HT.)
Palliative Care in the Home **ISBN 0192632272**	Doyle & Jeffrey	A quick reference guide to palliative care in the home for health professionals covering symptom control, psycho-social, spiritual and ethical issues.
Palliative Care for Care Homes A Practical Handbook **ISBN-13:** 9781846192487 **10:** 184619248X	Christine Reddall	A clear and easy-to-read handbook primarily for workers caring for the dying in care homes, but which will also be of interest to family members caring for relatives with life-threatening conditions. This is a resource book to provide information on palliative care. It is designed primarily to help carers who work in care homes of all categories.
Advance Care in End of Life Care **ISBN 978-0-19-956163-6**	Keri Thomas	Takes a comprehensive and international look at ACP, frames the purpose, process and outcomes and includes contributions from experts across the world

LEARNING	wwwCancerNursing.org.uk	CancerNursing.org is an open learning site dedicated to the provision of free education that aims to enhance the understanding and the skills of health professionals and others concerned with the care of cancer patients. On line lectures from specialists in their field including spirituality, resuscitation and dysphagia and nutrition
	www.e-lfh.org.uk www.e-ELCA.org.uk	e-learning programme providing national, quality assured online training content for the healthcare profession.
	www.agedcarechannel.co.uk	This TV station broadcasts, via satellite, direct to your care home. You and your staff can watch live and record a comprehensive schedule of programmes, covering all aspects of training
	www.scie.org.uk/socialcaretv/	**Online training for health and social care providers of all types.**
	www.helpthehospices.org.uk/our-services/running-your-hospice/education-training/e-learning /	Free CLiP programme gives professionals, carers and teams from a variety of health and social care settings the knowledge and skills needed in their daily work.
	www.scils.co.uk	Social Care Information & Learning Services. A variety of learning and development resources available to help meet National Minimum Standards. Registration required
	www.ncpc.org.uk	The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. Subscription gives you free publications and attendance at regional conferences and workshops
	www.scie.org.uk	Good practice guides, resources and information specifically for social care service users, practitioners and providers
	www.macmillan.org.uk	Macmillan Foundations in Palliative Care available to download or order on this site
	GSF Clinical Skills Course for care home staff	Course designed to complement the work you are already doing in implementing the GSF in your care home Contact the National GSF Centre for details
	www.advancecareplanning	Advance Care Planning learning pack commissioned by the Department of health and the Social Care Institute for Excellence You can use this to give yourself a good grounding in ACP or to help train your colleagues.
	www.ukhca.co.uk	United Kingdom Homecare Association Ltd (UKHCA) is the professional association of home care providers from the independent, voluntary, not-for-profit and statutory sectors. Provides train the trainers and on line courses
	www.rcn.org.uk/development/practice/cpd_online_learning	several on line CPD courses, particularly dignity, available to members of the RCN
	www.mckinleymed.co.uk/online-training *www. vimeo.com/32919546 &search forMcKinley T34 syringe driver training*	There are several websites offering guidance and on line training for the McKinley syringe driver. Some of these are PCT guidance eg Glasgow, Norfolk, Lincolnshire so use the one pertinent to you particular area if available

END OF LIFE	www.endoflifecareforadults.nhs.uk	The National End of Life Care Programme works with health and social care services across all sectors in England to improve end of life care for adults by implementing the Department of Health's End of Life Care Strategy.
	www.mcpcilorg.uk	*The Marie Curie Palliative Care Institute Liverpool (MCPCIL) is dedicated to making a positive, sustained difference to how people are cared for at the end of life.*
	www.dyingmattersorg.uk/ Short film - "I didn't want that".	Dying Matters is a national coalition which aims to change public knowledge, attitudes and behaviours towards death, dying and bereavement, encouraging people to talk about their wishes towards the end of their lives, including where they want to die and their funeral plans with
DEMENTIA	www.alzheimers.org.uk	Alzheimer's Society produces a range of publications and resources, from guides to implementing good practice and planning quality care services to practical ideas for improving the lives of people with dementia. You can now order these resources online.
	www.dementiauk.org	Dementia UK Training specialises in the provision of high quality training courses for those who work with older people and people with dementia.
	http://youtu.be/CrZXz10FcVM Gladys Wilson and Naomi Feil	Naomi Feil, founder of Validation Therapy, shares a breakthrough moment of communication with Gladys Wilson, a woman who was diagnosed with Alzheimer's in 2000 and is virtually non-verbal.
	http://vimeo.com.80791217	Gerry Harris is 92 and has vascular dementia. A cautionary tale for a health service faced with an ever increasing ageing population many of whom will die with dementia.
	www.lifestorynetwork.org.uk/	Life story work enables us to see people as individuals in the context of their relationships with
DIGNITY	www.dignityincare.org.uk	Details of how to become a dignity champion and promote dignity in your place of work
	http://youtu.be/MTcopj6dYWQ	Extract from Amanda Warings' powerful film "What do you see"
RESUSCITATION	https://www.eoedeanery.nhs.uk/medical/page.php?page_id=2910	DNACPR Patient Information Leaflets produced by East of England or East Midlands
	https://www.resus.org.uk/pages/deccprmd.pdf	Model patient information leaflet from the Resus Council

VERIFICATION OF EXPECTED DEATH	www.endoflifecareforadults.nhs.uk RCN - Guidance for staff responsible for care after death	Developed by the National End of Life Care Programme and National Nurse Consultant Group (Palliative Care), this guidance sets out key principles and is intended as a guide for training, as well as for informing the development of organisational protocols for this area of care, it aims to provide a consistent view that accommodates England's diverse religious and multi-cultural beliefs
CARER SUPPORT	www.carersuk.org	Carers UK has years of expertise about caring. We produce a variety of resources that can help you better understand both the effects of caring on people's lives and the effects that policies have on the lives of carers.
SPIRTUALITY	www.queenscourt.org.uk/spirit	This website is the work of MCCN: Supportive Care: Spiritual Care Subgroup as a guide for individual spiritual and religious needs assessment, in supportive, palliative and end of life care
ASSESSMENT TOOLS	disdattool.wordpress.com/ www.britishpainsociety.org/pub_professional.htm	DiS-Dat distress assessment tool for people with severe communication problems and cognitive impairment The assessment of pain in older people: National Guidelines (2007) Further information re: geriatric depression scale

4. National Institute for Clinical Excellence (NICE) Quality Standards

End of Life Care for Adults Quality Standards

NHS
National Institute for
Health and Clinical Excellence

1	People approaching the end of life are identified in a timely way. Session 2
2	People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences. Session 4
3	People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment. Session 4
4	People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment. Session 3, Session 6
5	People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible. Session 4, Session 6
6	People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences. Session 4, Session 5
7	Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences. Session 3, Session 4, Session 6
8	People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person´s current medical condition, care plan and preferences. Sessions 1, Session 6
9	People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences. Session 2, Session 3, Session 6
10	People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night. Sessions 3, Session 6
11	People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication. Sessions 3, Session 4, Session 5, Session 6
12	The body of a person who has died is cared for in a culturally sensitive and dignified manner. Session 5, Session 6
13	Families and carers of people who have died receive timely verification and certification of the death. Session 5, Session 6
14	People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences. Session 6
15	Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers. All Sessions
16	Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and

5. Department of Health End of Life Care Strategy Quality Markers 2009

1. Have an action plan for delivery of high quality End of Life Care, which encompasses patients with all diagnoses, and is reviewed for impact and progress
2. Institute effective mechanisms to identify those who are approaching the end of life
3. Ensure that people approaching the end of life are offered a care plan
4. Ensure that individuals' preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals
5. Ensure that the needs of carers are appropriately assessed and recorded through a carer's assessment
6. Have mechanisms in place to ensure that care for individuals is co-ordinated across organisational boundaries 24/7
7. Have essential services available and accessible 24/7 to all those approaching the end of life who need them
8. Be aware of End of Life Care training opportunities and enable relevant workers to access or attend appropriate programmes dependent on their needs
9. Adopt a standardised approach to care for people in the last days of life
10. Monitor the quality and outputs of End of Life Care and submit relevant information for local and national audits