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, 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 users 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)

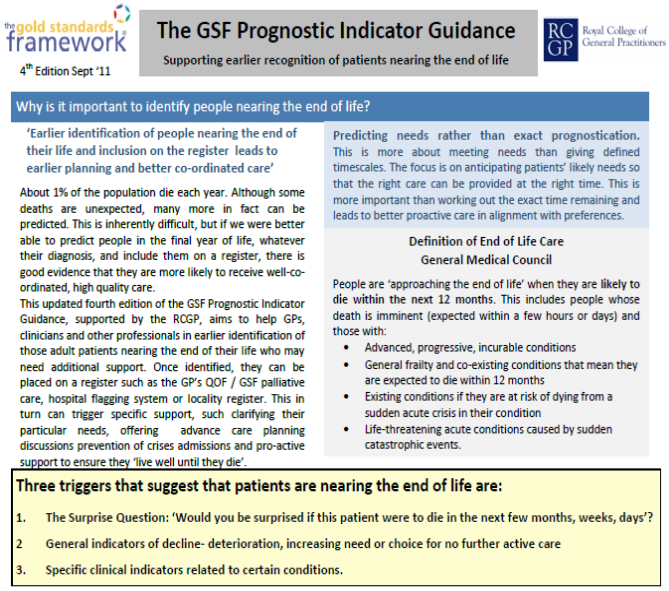
Identification was found to be one of the key bottlenecks and weak areas. This showed that we need to:

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 GSF Prognostic Indicator Guidance

Supporting earlier recognition of patients nearing the end of life

4th Edition Sept '11

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 practices 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

Uses 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 (workbook folder session 2) 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.....

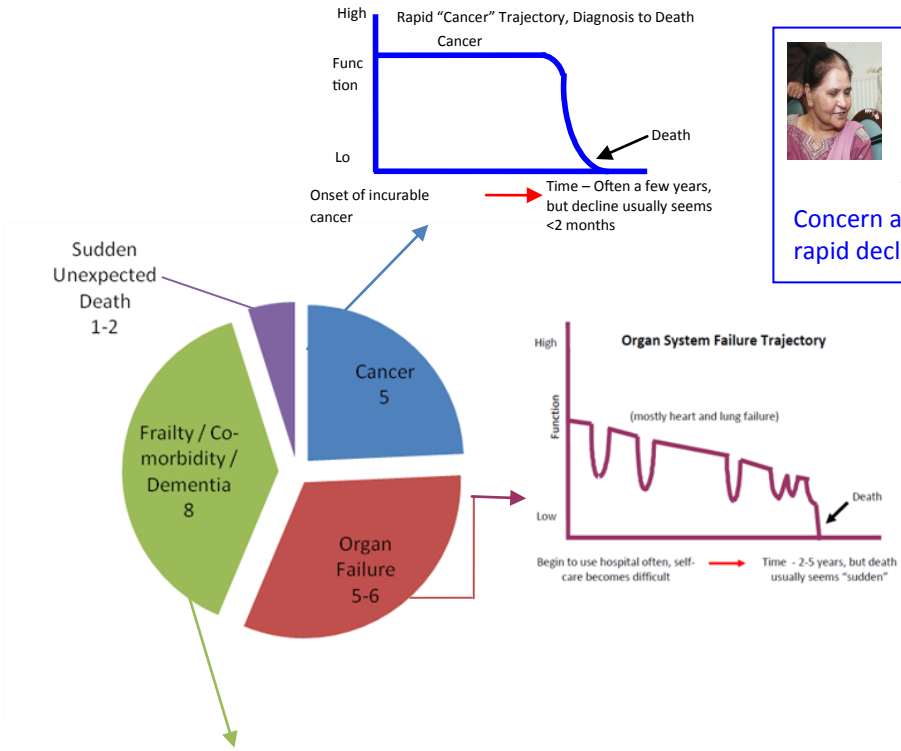
Guidance on Coding and Identification likely prognostic stage of service users

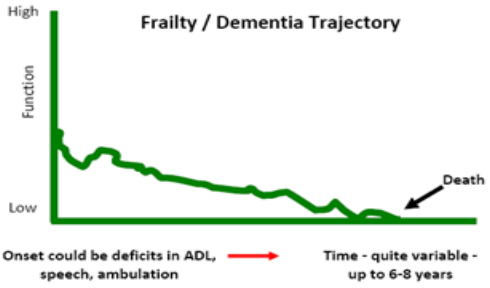
We are aware that there are different illness trajectories in the final years and months of life. People have differing needs at different times during the course of their illness, and yet some of these follow a similar pattern that becomes apparent to healthcare providers. It is inherently difficult to accurately predict the exact stage that someone has reached in their illness trajectory, and 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 were 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 patients 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

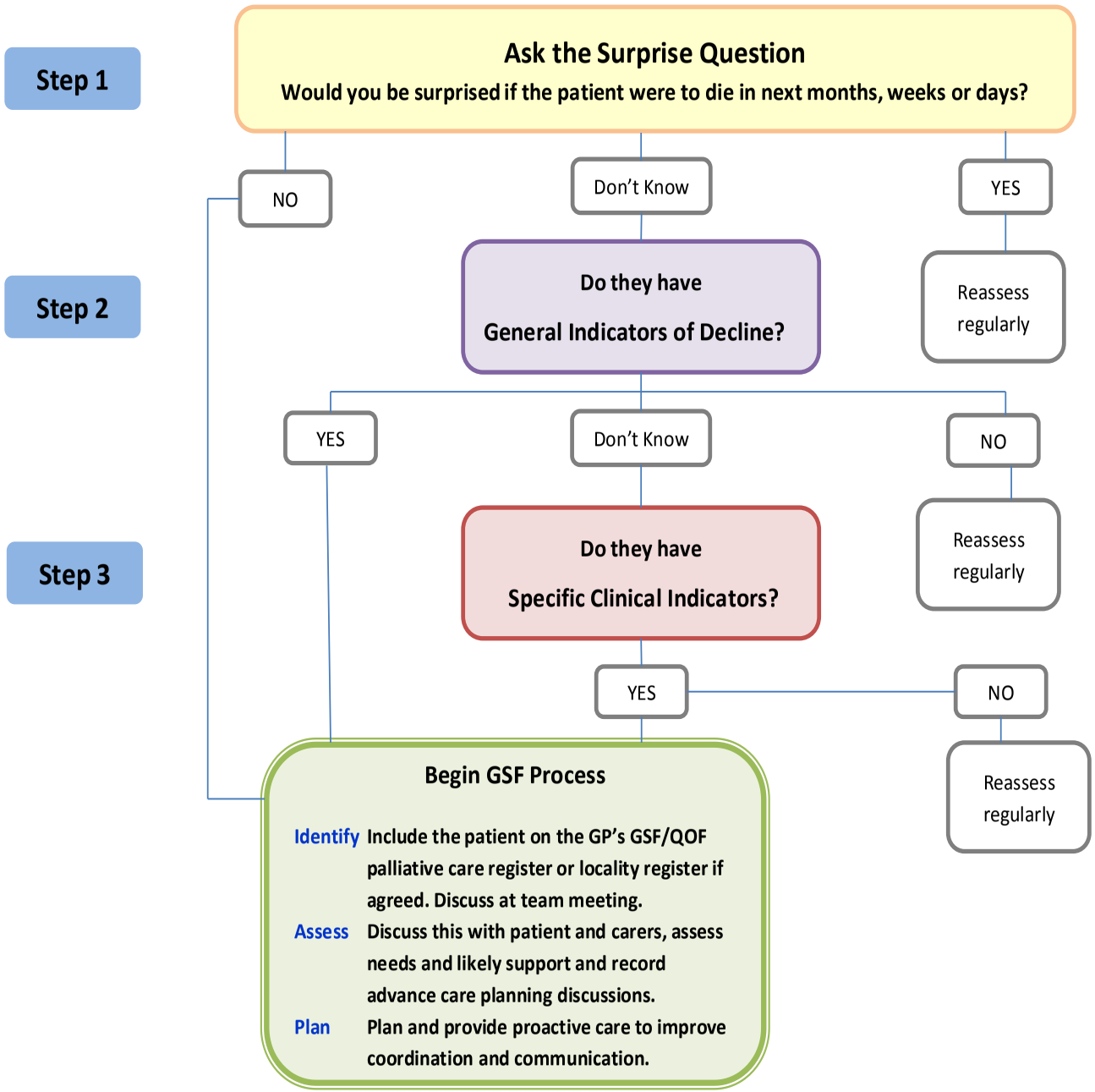
Barthel Index describes basic Activities of Daily Living (ADL) as 'core' to the functional assessment. E.g. feeding, bathing, grooming, dressing, continence, toileting, transfers, mobility, coping with stairs etc.

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

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?		

Resources for session 2

Activities

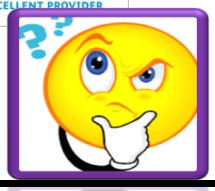
Activity 1 –indicators

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



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**	

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				

SCR 1 TO BE INSERTED HERE

Name	NHS Number Key GP
DOB Address	
Tel No	Current Code A-D Date A=Years A B=Months B C= Weeks C D=Days D
Main Diagnosis	Family/carer contacts + Tel No Contact at night Y/N Comments
Other Conditions	

Personnel involved Health/Social Professionals Domiciliary Care Agency	Advance Care Plan Discussion (Thinking Ahead) Y/N
Hospital Specialists District Nurse team Others (OT, Physio, priest) Macmillan/Nurse/SPC ¨ Hospice ¨ Social Services ¨	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:

/cont over.....

Date	Initials	Notes/important events	Needs based code **(refer to matrix for action)**