Patient Identification Strategy at End of Life - Everybody's business.

Alliance Vision - Alliance Approach

"Voluntary, independent, health and social care services working together to provide the best care possible having been discussed and decided with the individual"

Version	Date	Name	Comment
V1.0	July 2018	Dr Julie Barker	Out to Project Group for comments
V2.0	Nov 2018	Dr Julie Barker	with adjustments after consultation

Contents.

Introduction.

In order to benefit from advance care planning, tailored to individual needs and priorities, it is essential that all clinicians and workers caring for people who have life limiting conditions or are becoming frail and old are recognised formally and care planning undertaken. Failure to act pro-actively and holis-

tically and failure to communicate effectively with other key people are the key reasons why the NHS is less effective and sustainable than it could be and patients are not cared for in the way that they would wish. If these were consistently addressed within a changing culture staff morale and patient satisfaction would all improve.

For the purposes of this document and associated services, 'End of Life' is defined as being approximately within the last 12 months of life. Prognosis is notoriously tricky as all clinicians are well aware and those who are identified and offered advance care planning are recognised to live long than they would if not identified by virtue to the individualised care they are given. The risk of not identifying people who may be approaching the last year of life is that their care is reactive and not focussed on their personal wishes which may not be known. In Mid Notts, those people who have been registered on EPaCCS (Electronic Palliative Care Co-ordination System) are 70%+ likely to achieve their priorities for care as opposed to <40% for those who haven't. Admissions and death on an acute hospital ward are significantly less likely for those who have been identified.

End of Life Together, the integrated approach to end of life care for all services supporting patients who may be within their last 12 months of life, needs to improve its identification and EPaCCS registration rates with associated care planning and co-ordination, in order to improve outcomes for patients and reduce unnecessary and intrusive interventions. This strategy is written to formalise the responsibility for all workers and to support local and national strategy for End of Life Care (see references).

General Principles - all services.

Whilst pre-knowledge of the patient and ***continuity of care*** have been shown to result in more accurate prognostication, reduction of admission rates and death, even with no prior contact with the patient it is still possible to reasonably accurate identify if someone may be in the last 12 months of life by ***asking the surprise question***: 'Would I be surprised if this person died within the next 12 months?' If the answer to the question is no then advance care planning should be commenced where this has not already and the person should be offered a key worker and care co-ordination (with EPaCCS registration).

Outside this question there are also a number of more objective indicators pertinent to different types of conditions that can be used in the assessment. Various tools have been developed and validated to help with this. ***The GSF Pro-active identification Guide (PIG)*** is one of the most intuitive and appropriate to use (see Appendix A). This has been selected for use in Nottinghamshire.

As per the EOL Together Service model, once identified, the patient will be registered on EPaCCS (electronic database) and a live telephone introductory conversation will be pro-actively made by Patient Call (the Care Co-ordination service within Mid Notts) in order to familiarise the patient and their carers with the service and what it offers. This should pre-empt the need to call 111 or 999 at times of need in most situations.

Organisations must ensure they ***communicate prognosis*** not only to the patient (where they wish to know) and key family or carers but also to their GP and other clinicians caring for that person. An NHS that does not communicate with others also caring for a person is not acceptable. Also, see the comments about carers (in the section on Domiciliary care). Professionals sometimes are reluctant to communicate prognosis to a person for fear of upsetting them or causing them to give up on life. However, most patients are grateful to have an honest and compassionate communication of their condition and often are aware of it even if it has not been discussed.

Using **language** such as 'becoming more unwell' or 'more frail' 'reaching the last phase of life' or 'dying' should not be avoided and should be coupled with offers of care and support. Use of the Nottinghamshire Advance Care Plan (which refers to a 'Gold' patient) and the associated Clinician guidance which has a suggested script is encouraged (appendix 3&4).

Opportunities: General practice.

Primary care staff are very well placed to identify patients by virtue of their unparalleled long-term relationship with the person concerned and the amount of information available to them. For this reason, primary care is likely to be the most frequent sector of the services to identify and register patients. They are also best placed to have the sensitive conversations about prognosis that needs to occur. All staff should be trained to a level where they can recognise general decline and know how to respond in order to ensure the person is able to be fully assessed.

Key opportunities of relevance:

- Chronic disease clinics - deterioration (refer to GSF PIG)
- General functional decline
- New diagnosis e.g. severe frailty* , terminal cancer, dementia
- MDT meetings using GPRCC data, e-healthscope.
- Recent admission/discharge
- failure to attend booked hospital appointments and self removal from follow-up
- Recurrent falls/general decline.
- Patient initiated e.g. advice on setting up a power of attorney.

* 60%+ of patient diagnosed with severe frailty will die within 12 months.

Opportunities: Community Nursing and the community LICT (local integrated care team)

District nurses may encounter patients in support of their long term condition (insulin administration, anticoagulation injection, dressing leg ulcers) and should feel confident to recognise when a person's condition has deteriorated such that EOL registration is triggered. The nursing team is very well placed to recognise general decline (physical and cognitive) and be informed about falls. Likewise, the community MDT/LICT/PRISM team is well placed to identify EOL patients who present in similar ways to the list above. ***Where not already registered, such patients should be flagged at the MDT meetings or via a task to the patients' usual doctor.***

Opportunities: Voluntary Community Services & Organisations

Community organisations such as luncheon clubs, churches and day centres may recognise a person is becoming frail and possibly in need of more help and support. The key alerting event may be stopping attending at a regular event. It is appropriate for them to be able to signpost the person they are concerned about to their GP or to Patient Call or other support services. They may need to enhance their supportive role for the person.

Opportunities: Residential and Nursing Homes

As our population grows older, increasing numbers will spend their last years or months in residential care. Care homes should be supported to identify and care plan with all their residents, most of whom will regard the home as their home. Hospital admissions and discharge to a care home should trigger offer of or review of an advance care plan.

Nursing homes will often look after people with more complex needs and for a shorter duration (average time from admission to death is less than 6 months). For this reason ***all nursing home patients*** should be registered on EPaCCS and offered pro-active advance care planning, including treatment escalation plans where appropriate. The Respect Process document is especially useful for this purpose and should also be used to record patient priorities as part of more general advance care planning for both residential and nursing home residents.

Opportunities: Domiciliary Care

Carers supporting people in their own homes are well placed to observe deteriorating function but may not know how to use this information in a way that promotes care planning. GPs and nurses who attend people who are housebound often do not routinely make a point of interacting with their carers or close family and may miss critical information about direction of travel in health, especially if that clinician isn't familiar with the patient.

Ensuring that carers have an opportunity to interact directly with clinician in person or by phone should be routine for all organisations. Hospital wards and GP surgeries should ensure that they do not allow patient confidentiality to act as a barrier for good communication. This is simply dealt with by asking patients who have capacity permission to communicate and taking best interest decisions when they don't.

Opportunities: Hospital Outpatient Departments

Hospital outpatient clinicians currently care for people who are likely to be in the last 12 months of life and where the PIG would flag this. Currently it is unusual for GPs to be informed by letter that a person should be on a palliative care or End of Life register. This means it is often a lottery as to whether the Primary Care team will pick up the right cures from a patient condition e.g. an MRC score of 4+ in a COPD or heart failure patient.

Oncology departments often continue to promote use of chemotherapy regimes in the context of a very sick and deteriorating patient whose last weeks of life can be thus blighted by toxic side effects. Recognising when a person is not responding well to treatments needs to be honestly and compassionately shared and instead of discharging a person 'because we cant do anything else for you', asking the primary care team or palliative care team to support the person to live the rest of their life with as good a quality as possible is the right thing to do.

The acute trusts are recommended to have copies of the GSF PIG visible in all relevant outpatient departments and clinicians routinely considering whether their patient may be reaching the last 12 months by reference to the appropriate indicators. This must then be communicated with their GP even if it is not communicated at that time with the person concerned (patient understanding of their condition should also be communicated).

Hospital staff training should ensure that patient End of Life identification and communication to them (where appropriate) and to their GP surgery (in all cases) should be mandated by hospital trusts.

Opportunities: Hospital MIU/A&E departments

Frail patients and those with advanced long term conditions will often be seen in emergency departments with falls, infections or exacerbations. Such episodes should be viewed in a holistic way to determine whether it is part of a pattern of decline that warrants not only complete assessment and review of care plan including de-prescribing where appropriate but whether restoration onto EPaCCS and care co-ordination referral is appropriate.

The ICS (Integrated Care System) needs to move towards pro-actively seeking information (is this person already on the EOL register?) as well as sharing information which promotes a holistic care plan rather than just dealing with the presenting problem and its treatment.

Opportunities: Hospital Wards

Recurrent emergency admission to hospital is a key indicator. Recurrent admissions with exacerbations of a LTC or an infection or fall should trigger consideration of EOL registration. Local and National data indicates that 3 or more emergency admissions is highly predictive of death within the next 6-12 months. Most patients are never flagged as being end of life and never of-

fered advance care planning which enables them to exercise some choice and control over this most important part of their life. Satisfaction with patient care in hospitals for those who die is lowest in acute hospital wards and highest in hospices, largely because of their patient-centredness. A busy acute ward is a difficult place to bring a sense of peace and personal control and most patients would not choose to die there. However where hospitals have a pro-active policy of identifying dying patients and changing gear from 'cure' and discharge to comfort care with some sort of flagging system to ensure recognition and good communication, quality of care and satisfaction rates can be very high (examples include the Swan system at NUH). likewise, hospitals with very good links to palliative care services have higher patient and relative experience. Once identified, patient priorities for care should be sought and every effort made to respect and act on them.

Opportunities: Ambulance paramedics and other emergency response services including GP out of hours services.

Emergency response vehicles are regularly despatched to EOL patients both identified and with pre-existing care plans and not yet identified. This may be for many reasons:

- a 111 call for advice triggers a 999 ambulance e.g. for breathing difficulties
- help after a fall
- carer crisis
- deterioration due to infection
- exacerbation of a long term condition
- uncontrolled symptoms

Whilst GP services usually have access to flagged notes where there are care plans, EMAS often fail to pass on the flags to their vehicles in transit. Recognising a person who should be on an EOL register should be routinely in scope for all professionals attending patients and training programmes for that organisation should reflect this.

Safeguarding alerts have become much more frequently shared by EMAS. In the same way, information that would potentially trigger an end of life registration should be routinely shared with the person's GP.

Training.

1. Online modules e-LFH
2. Gold Standards Framework -specific to GP, Care Homes, Domiciliary Care, Community Hospitals, Acute Hospitals, Hospices, prisons.
3. Dying to communicate courses run at regular intervals from John Eastwood Hospice (Mansfield) and Haywood House (Nottingham).
4. Respect process website with app training and CPD accreditation.
5. Locally run training, in house and multi-agency.

The Gold Standards Framework Proactive Identification Guidance (PIG)

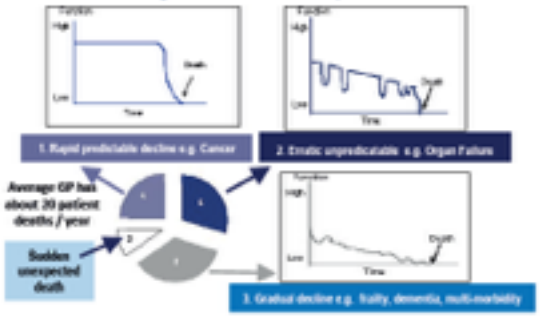
The National GSF Centre's guidance for clinicians to support earlier identification of patients nearing the end of life leading to improved proactive person-centred care

GSF PIG 6th Edition Dec 2016 K Thomas, Julie Armstrong Wilson and GSF Team, National Gold Standards Framework Centre in End of Life Care
http://www.goldstandardsframework.org.uk for more details see GSF PIG

Proactive Identification Guidance – proactively identifying patients earlier.

This updated 6th edition of the GSF PIG, renamed as Proactive Identification Guidance and formally known as Prognostic Indicator Guidance, aims to enable the earlier identification of people nearing the end of their life who may need additional supportive care. This includes people who are nearing the end of their life following the three main trajectories of illness for expected deaths – rapid predictable decline e.g. cancer, erratic decline e.g. organ failure and gradual decline e.g. frailty and dementia. Additional contributing factors when considering prediction of likely needs include current mental health, co-morbidities and social care provision.

Three trajectories of illness (Lynn et al)
reflecting the three main causes of expected death



Why is it important to identify patients early?

Earlier identification of people who may be in their final stage of life leads to more proactive person-centred care. About 1% of the population die each year, with about 30% hospital patients and 80% of care homes residents in their last year of life. Most deaths can be anticipated though a minority are unexpected (estimated about 10%). Earlier recognition of decline leads to earlier anticipation of likely needs, better planning, fewer crisis hospital admissions and care tailored to peoples' wishes. This in turn results in better outcomes with more people living and dying in the place and manner of their choice. Once identified, people are included on a register and where available the locality/electronic register, triggering specific active supportive care, as used in all GSF programmes and in GSF cross boundary care sites.

The 3 key steps of GSF

PIG and GSF – Early proactive identification of patients is the crucial first step of GSF, used by many thousands of doctors and nurses in the community and hospitals. For more information on GSF, how it is used in practice to help identify patients early, assess needs and wishes through advance care planning discussions and plan care tailored to patient choices, see the GSF website.

National Policy support for earlier identification.

General Medical Council – 2010

www.gmc-uk.org/static/documents/content/End_of_life.pdf

The GMC definition of End of Life Care; '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:

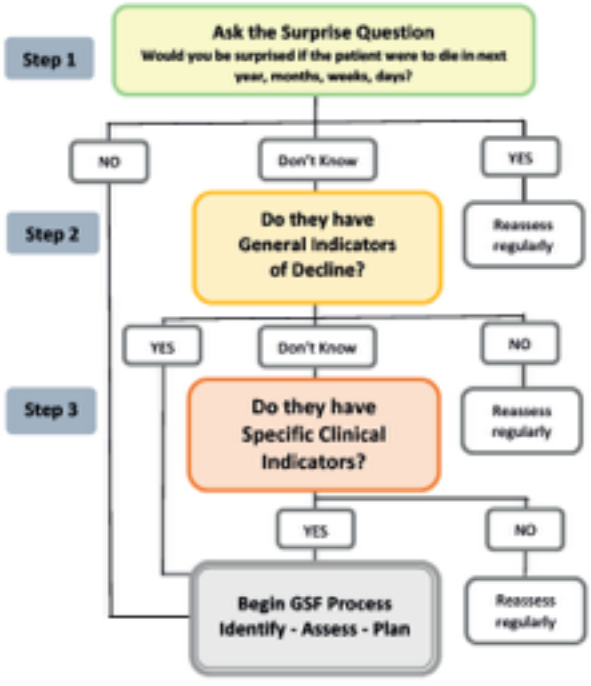
- Advanced, progressive, incurable conditions.
- General frailty and co-existing conditions that mean they are expected to die within 12 months.
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition.
- Life threatening acute conditions caused by sudden catastrophic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

NICE Guidance in End of life care 2011 Quality statement 1

https://www.nice.org.uk/guidance/qs13/chapter/Quality-statement-1-Identification

- 'Identification – People approaching the end of life are identified in a timely way.
- Systems – Evidence of local systems in place to document identification of people approaching the end of life.'

Proactive Identification Guidance – GSF PIG Flow-chart



The GSF PIG 2016 – Proactive Identification Guidance

Step 1 The Surprise Question

For patients with advanced disease or progressive life limiting conditions, would you be surprised if the patient were to die in the next year, months, weeks, days?

The answer to this question should be an intuitive one, pulling together a range of clinical, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient's quality of life now and in preparation for possible further decline?

Step 2 General indicators of decline and increasing needs?

- General physical decline, increasing dependence and need for support.
- Repeated unplanned hospital admissions.
- Advanced disease – unstable, deteriorating, complex symptom burden.
- Presence of significant multi-morbidities.
- 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.
- Decreasing response to treatments, decreasing reversibility.
- Patient choice for no further active treatment and focus on quality of life.
- Progressive weight loss (>10%) in past six months.
- Sentinel Event e.g. serious fall, bereavement, transfer to nursing home.
- Serum albumin <25g/l.
- Considered eligible for DS1500 payment.

Step 3 Specific Clinical Indicators related to 3 trajectories

1. Cancer

- Deteriorating performance status and functional ability due to metastatic cancer, multi-morbidities or not amenable to treatment – if spending more than 50% of time in bed/lying down, prognosis estimated in months.
- Persistent symptoms despite optimal palliative oncology. More specific prognostic predictors for cancer are available, e.g. PPS.

2. Organ Failure

Heart Disease

At least two of the indicators below:

- Patient for whom the surprise question is applicable.
- CHF NYHA Stage 3 or 4 with ongoing symptoms despite optimal HF therapy – shortness of breath at rest on minimal exertion.
- Repeated admissions with heart failure – 3 admissions in 6 months or a single admission aged over 75 (50% 1yr mortality).
- Difficult ongoing physical or psychological symptoms despite optimal tolerated therapy.
- Additional features include hyponatraemia <135mmol/l, high BP, declining renal function, anaemia, etc.

Chronic Obstructive Pulmonary Disease (COPD)

At least two of the indicators below:

- Recurrent hospital admissions (at least 3 in last year due to COPD)
- MRC grade 4/5 – shortness of breath after 100 metres on level
- Disease assessed to be very severe (e.g. FEV1 <30% predicted), persistent symptoms despite optimal therapy, too unwell for surgery or pulm rehab.
- Fulfils long term oxygen therapy criteria (PaO2<7.3kPa).
- Required ITU/NIV during hospital admission.
- Other factors e.g., right heart failure, anorexia, cachexia, >6 weeks steroids in preceding 6 months, requires palliative medication for breathlessness still smoking.

Kidney Disease

Stage 4 or 5 Chronic Kidney Disease (CKD) whose condition is deteriorating with at least two of the indicators below:

- Patient for whom the surprise question is applicable.
- Repeated unplanned admissions (more than 3/year).
- Patients with poor tolerance of dialysis with change of modality.
- Patients choosing the 'no dialysis' option (conservative), dialysis withdrawal or not opting for dialysis if transplant has failed.
- Difficult physical or psychological symptoms that have not responded to specific treatments.
- Symptomatic Renal Failure in patients who have chosen not to dialyse – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload.

Liver Disease

Hepatocellular carcinoma.

Liver transplant contra indicated.

Advanced cirrhosis with complications including:

Liver Disease *continued*

- Refractory ascites
- Encephalopathy
- Other adverse factors including malnutrition, severe comorbidities, Hepatorenal syndrome
- Bacterial infection current bleeds, raised INR, hyponatraemia, unless they are a candidate for liver transplantation or amenable to treatment of underlying condition.

General Neurological Diseases

- Progressive deterioration in physical and/or cognitive function despite optimal therapy.
- Symptoms which are complex and too difficult to control.
- Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis, breathlessness or respiratory failure.
- Speech problems: increasing difficulty in communications and progressive dysphasia.

Parkinson's Disease

- Drug treatment less effective or increasingly complex regime of drug treatments.
- Reduced independence, needs ADL help.
- The condition is less well controlled with increasing "off" periods.
- Dyskinesias, mobility problems and falls.
- Psychiatric signs (depression, anxiety, hallucinations, psychosis).
- Similar pattern to frailty – see below.

Motor Neurone Disease

- Marked rapid decline in physical status.
- First episode of aspirational pneumonia.
- Increased cognitive difficulties.
- Weight Loss.
- Significant complex symptoms and medical complications.
- Low vital capacity (below 70% predicted spirometry), or initiation of NIV.
- Mobility problems and falls.
- Communication difficulties.

Multiple Sclerosis

- Significant complex symptoms and medical complications.
- Dysphagia + poor nutritional status.
- Communication difficulties e.g., Dysarthria + fatigue.
- Cognitive impairment notably the onset of dementia.

3. Frailty, dementia, multi-morbidity

Frailty

For older people with complexity and multiple comorbidities, the surprise question must triangulate with a tier of indicators, e.g. through Comprehensive Geriatric Assessment (CGA).

- Multiple morbidities.
- Deteriorating performance score.
- Weakness, weight loss exhaustion.
- Slow Walking Speed – takes more than 5 seconds to walk 4 m.
- TUGT – time to stand up from chair, walk 3 m, turn and walk back.
- PRISMA – at least 3 of the following:

Aged over 85, Male, Any health problems that limit activity?, Do you need someone to help you on a regular basis?, Do you have health problems that cause require you to stay at home?, In case of need can you count on someone close to you?, Do you regularly use a stick, walker or wheelchair to get about?

Dementia

Identification of moderate/severe stage dementia using a validated staging tool e.g., Functional Assessment Staging has utility in identifying the final year of life in dementia. (BGS) Triggers to consider that indicate that someone is entering a later stage are:

- Unable to walk without assistance and
- Urinary and faecal incontinence, and
- No consistently meaningful conversation and
- Unable to do Activities of Daily Living (ADL)
- Barthel score >3

Plus any of the following: Weight loss, Urinary tract Infection, Severe pressures sores – stage three or four, Recurrent fever, Reduced oral intake, Aspiration pneumonia.

NB Advance Care Planning discussions should be started early at diagnosis.

Stroke

- Use of validated scale such as NIHSS recommended.
- Persistent vegetative, minimal conscious state or dense paralysis.
- Medical complications, or lack of improvement within 3 months of onset.
- Cognitive impairment / Post-stroke dementia.
- Other factors e.g. old age, male, heart disease, stroke sub-type, hyperglycaemia, dementia, renal failure.