END OF LIFE CARE

A proactive approach to Palliative and End of Life Care for all Diagnoses

Lincolnshire

www.eolc.co.uk

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How to use this guide

This guide is meant to be a quick and easy to use resource. The idea is that it can be a tool to support patients at different stages on their journey. This means that information is repeated in different sections. This is done deliberately to help users of the guide to find the information they need as quickly as possible.

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Introduction

End of life care is the responsibility of all health and many social care providers caring for:

- People suspected of having a prognosis of less than one year to live
- People with chronic, progressive illness who have supportive needs
- People diagnosed with a condition for which there is no cure. These include neurological conditions such as motor neurone disease; organ failure; respiratory illness such as chronic obstructive pulmonary disease; some cancers; cerebral-vascular illness, and dementia. The aim is to anticipate need and then plan to prevent crisis, rather than considering only prognosis.

Care throughout the patient journey

For patients aged 18 and over reaching the end of their life, this brochure helps describe their journey across health and social care settings, ensuring they are identified and that they and their families receive the right care, support and care planning. The aim is to anticipate the possible problems that the person may have, plan to prevent them and react proactively in a coordinated way if need arises.

The End of Life Care Strategy (2008), Nice (2013) and One Chance to Get it Right (2014) set out consistent messages:

- Identification of people approaching end of life
- Care planning, assessing needs and preferences for end of life care and agreeing a care plan to reflect these, then reviewing these regularly
- Co-ordination of care (which can be done in a phased approach)
- Sensitive communication between staff and the person who is dying and those important to them
- The dying person and those identified as important to them are involved in decisions about treatment and care
- The people important to the dying person are listened to and their needs are respected
- Care is tailored to the individual and delivered with compassion, with an individual care plan in place
- The patient's family and loved ones are supported throughout this journey and after death

This guide has been produced by a collaborative partnership which fully encourages everyone to work with this guidance.

See Appendix 1 for the end of life care process.

Palliative and end of life care

Palliative care is not limited to those with cancer or those in the last days or weeks of life. Palliative care is for everyone with a life-limiting illness, including neurological conditions and dementia, and offers a range of symptom management and other interventions and support to improve quality of life. It can include advance care planning, in discussion with the patient and those important to them, and integrated working by health and social care professionals.

Palliative and end of life care

For many years, palliative care largely meant the terminal care of those with cancer. Patients with progressive end-stage disorders were not offered access to palliative services despite their poor prognosis and symptoms comparable to or worse than many cancers. It was used as the only option for a patient when active treatment had failed and generally concentrated on end of life.

It is now appreciated that supportive and palliative care is applicable from much earlier in the patient's illness and can be used in combination with disease-modifying or curative treatments. Supportive and palliative care may be relevant at any or all points along the disease continuum – from pre-diagnosis, through diagnosis and treatment, to recovery or death. The aim is to optimise quality of life for patients and their families by promoting wellbeing, psychological and spiritual support, symptom management and bereavement support (NCPC, 2015).

Good palliative care demands teamwork, providing support wherever the patient is. A combination of professionals from medical, nursing and allied health and social care, along with informal carers, can provide this.

Patients with palliative care needs should be identified early and management plans instituted with referrals for appropriate support. However, recent research has shown that patients are either not identified or are identified too late. Seventy-five per cent of cancer patients and only 20 per cent of non-cancer patients receive palliative care. The absence of Advance Care Plans leads to patients dying in the wrong place and receiving the wrong care, especially for those with a non-cancer diagnosis. Lincolnshire consistently performs badly in the national VOICES survey (Office of National Statistics, 2013).

The purpose of this guidance is to support the early identification of patients who may require palliative care and to direct clinicians in the decision-making process, concerning those aspects that contribute to quality of life and death for patients, regardless of diagnosis. It has also been developed to signpost clinicians to the palliative services available to patients and their carers.

Palliative care is patient centred rather than disease focused; death accepting but life enhancing; a partnership between patients and carers; concerned with healing rather than curing.

Right patient	Identify patients and carers (Up to 70 percent go unidentified in Lincolnshire)
Right care	Patient centred, delivering the right services by the right people in an integrated and coordinated way
Right place	Most patients want to die at home but most die in hospital (more than half)
Right time	Responsive
Every time	High quality

Prognosis of less than one year

Identifying patients who may be in the last year of life allows for planning on how to support patients and those important to them. One tool to use to identify these patients is the Gold Standards Framework 'surprise' question ("Would you be surprised if this patient died in the next 12 months?"). Patient needs can be anticipated and support planned, in discussion with patients and those important to them.

The following information should be considered at the point – whatever the care setting and diagnosis – when the patient is believed to be in the last year of life. Individuals may be considered for NHS Continuing Healthcare (CHC) funding using the checklist tool. Some elements of care including CHC funding, Advance Care Planning (ACP) and supportive care planning may have already been started i.e. for people with dementia or those in residential care.

Other elements of care include palliative rehabilitation which aims to maximise independence, quality of life and self management within the confines of the illness.

Identifying the point when people may have a life expectancy of one year is complex, especially for those with a non-cancer diagnosis. For those with a cancer diagnosis, there is often a clear point at which the person moves from curative to palliative care. This is a trigger for the primary healthcare team to consider use of the Gold Standards Framework for community palliative care in managing the person's care (see Appendix 2).

The focus is on the seven principles of:

- Communication
- Co-ordination of the person's care
- Control of symptoms
- Continuity of care
- Continued learning
- Carer support
- Care of the dying

For those with a non-cancer diagnosis, it is not unusual for there to be periods of deterioration which respond well to specific interventions. Thus the primary health care team should also consider general indicators of decline and functionality and ability to self-care as triggers to suggest that a non-cancer patient may have a prognosis of 12 months or less. The prognostic indicators (see Appendix 2) also include specific clinical indicators for non-cancer conditions as guidance.

Rather than predicting timescales, however, thinking ahead allows consideration of patient needs and how to meet them. Anticipating possible deterioration will allow and encourage discussions around preferences and needs at an earlier stage, which in turn should ensure appropriate care and support can be mobilised.

It may be important to consider the completion of a full holistic patient assessment and physical examination to identify any unmet needs. The outcome of these assessments will determine appropriate action, including referral to other services such as specialist palliative care or long-term conditions management teams, signposting on to social support and assisting patients and their carers to learn new skills to self manage and improve the quality of their lives in their last year.

Carer fatigue is a major contributory factor in crisis hospital admissions. Two of the factors are lack of appropriate and timely support and lack of appropriate equipment. A rigorous assessment of carer needs should be considered to ascertain the full range of support needed as well as the provision of supportive equipment.

Communicating information to the patient about the prognosis of their condition should also be considered at this time. East Midlands Cancer Network has developed guidance for communicating bad news with their patients and their families (Appendix 3, breaking bad news flowchart). The professional having these

discussions ideally should have good communication skills. Dying to Communicate (advanced communication skills) training is available in Lincolnshire.

In acknowledging the sensitive nature of these discussions, the role and concept of a named key worker should be introduced. The key worker has been defined as "a named professional who is 'best placed' to ensure that the person receives holistic and timely end of life care" (ADRT Project Team, 2012). In primary care this is likely to be the GP initially, who alongside the wider team of community nurses, long-term conditions or social services team and palliative care specialists, should use a fully integrated approach around the patient and their family to ensure the best possible outcome for them.

Neighbourhood Teams, where they exist, have a role in assisting general practice as do specialist nurses, community hospitals and secondary care professionals, in identifying when patients enter the palliative or end of life stage of their lives. Updating the GSF palliative care register and reviewing patient care regularly, then recording the nationally agreed codes on the clinical system is essential. In this way, communicating decisions to the wider health community is facilitated via the Electronic Palliative Care Co-ordination System (EPaCCS).

Neighbourhood Teams are being developed across the county as part of the Lincolnshire Health and Care programme. They are a new way of working across health and social care organisations, designed to meet the needs of an ageing population and transform the way that care is provided for people with long-term conditions, by enabling those with complex needs to lead more healthy, fulfilling and independent lives. They provide an opportunity to recognise those people in the last year of their lives. See Appendix 4 for more information about Neighbourhood Teams.

Patients should be referred by the key worker to Marie Curie Rapid Response, and patients and carers should be given the phone number for the service **(Tel: 0845 055 0709).** The service operates from 4pm to 8am Monday to Friday, and 24 hours a day at weekends and bank holidays. Patients and carers may refer themselves to the service as well.

Prognosis of less than six months

Planning ahead continues to be the key to good patient outcomes as the patient's condition deteriorates. Patients may be eligible for funding to support their care. Carer needs should be considered, and plans made, in conjunction with the patient and those important to them, about what will happen as the disease progresses. Communicating patient wishes to out of hours, EPaCCS and other health and social care providers can help patients achieve their preferred place of care and death.

Planning continues to be important to support patients and those important to them.

It is at this stage of their illness that the person may apply for Attendance Allowance or Personal Independence Payment, under special rules using a DS1500 form. This will ensure that applications are processed quickly.

There should also be further assessment regarding the continuing care needs of the person and consideration of application for support according to eligibility criteria for Continuing Healthcare funding. These initiatives along with other potential benefits provide support for the person and those involved in their care.

Communicating information via the EPaCCS template will enable other clinical members of the wider team to access and share information about the patient's wishes. The template synchronises with My Right Care and enables 111, ambulance trusts, out of hours and hospital accident and emergency teams to access this information. It is important to communicate DNACPR status, following review of this, in accordance with the local DNACPR policy, as well as any other Advance Care Plans and/or other Advance Decisions to Refuse Treatment.

The most appropriate type of respite support should be discussed where this is available and agreed with the patient, carer and health professionals, including a statutory carer's assessment, if this has not been done already.

A fast-track process exists locally for carers of people who have been identified in the last year of life using Gold Standard Framework prognostic indicators (see Appendix 3). A fast-track process should be used for people who are in the last few months of their lives. This may necessitate discussion between health and social care providers.

At this stage, patients should be referred to the out of hours service. The referral is made usually by the key worker and includes information about patient choices such as DNACPR, ACP, ADRT and preferred place of care and death (where known), as well as diagnosis and prognosis. This referral can help out of hours teams respond appropriately to the needs and wishes of palliative patients and can avoid unplanned admissions to acute hospitals.

The Lincolnshire Palliative Care Co-ordination Centre (PCCC) is an administrative centre which matches care needs with care providers for patients who have palliative care requirements. Care is provided for days and/or nights, using Hospice at Home, Marie Curie night service and generalist care agencies (depending on Continuing Healthcare funding). Referrals are taken by telephone and via nhs.net accounts from community case managers, community nursing staff, clinical nurse specialists and other key workers for patients who have a palliative care diagnosis, are aged 18 or older and are registered with a Lincolnshire GP. The SystmOne palliative care template will need to be completed prior to referral to the PCCC. A prioritisation tool is used for all referrals (see Appendix 6). The PCCC is open every day of the year **(Tel: 0845 055 0708)** from 9am to 6pm, Monday to Friday, and 9am to 5pm at weekends and bank holidays.

Email: sbh.pccc@nhs.net

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Prognosis of a few weeks

Reviewing care and support for patients with a prognosis of a few weeks can ensure that they are able to achieve their preferred place of care and death. Symptom management should be considered, including the prescribing and provision of pre-emptive drugs, as should putting in place or increasing any existing care the patient is receiving. Support for those caring for the patient also should be reviewed.

If an individual has a rapidly deteriorating condition that may be entering the terminal phase, consideration should be given to applying for NHS Continuing Healthcare funding. This will enable their needs to be met urgently, allowing them either to go home to die or for appropriate end of life support to be put in place to allow the patient to remain at home. This would be a primary health need because of the rate of deterioration, and in all cases where the individual has such needs, consideration should be given to apply for funding via the Fast Track tool. This helps provide care to the individual at the end of their life.

Pre-emptive prescribing of a palliative care pack ('just in case' box) should be considered at this stage after discussion with the patient and carer. This ensures that there is an emergency supply of PRN (as required) subcutaneous medication in the patient's home in advance of any deterioration in the patient's ability to take medication orally. These can then be administered during out of hours periods and may avoid unnecessary medical visits and delays. See local policy for the anticipatory supply of palliative care medication signpost. For information about prescribing, the Palliative Adult Network Guidelines are available online (www.pallcare.info).

GPs are advised to report a death to the coroner if the patient has not been seen two weeks before death. The calls are usually handled by a Coroner's Officer, usually a senior policeman with extensive experience, who will exercise judgement on whether a coroner's case has to be opened or whether the GP can issue a death certificate. This decision depends on the coroner and their coroner's officer. There have been some unfortunate cases where a post mortem for an expected death has been arranged which may have been avoided if the patient had been seen before death by a doctor.

Most GPs welcome a call from a nurse to alert them that an expected death will occur soon, to give them an opportunity to decide whether a visit is necessary. An experienced GP who knows the patient will have the local knowledge to make an accurate judgement.

The carer's needs should be reviewed to ensure that the appropriate type and level of support is in place to enable them to cope, especially if the patient has chosen to die at home. Information should be provided on how to access advice and support if a crisis arises.

Communicating information to the provider of out of hours care and the ambulance service is essential at this time. Entering information into relevant clinical templates can allow this information to be shared through My Right Care as it is introduced throughout Lincolnshire. These templates can also act as prompts to ensure nothing is missed.

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Prognosis of less than one week

A way of caring for all dying patients in England – no matter where they want to be cared for and die – has been developed, to replace the Liverpool Care Pathway (which went out of use in 2014). This approach to caring was developed by the Leadership Alliance of Dying People (2014).

Priority One – Recognise

The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, these are reviewed regularly and decisions revised accordingly.

Priority Two – Communicate

Clear and sensitive communication needs to take place between staff and the person who is dying and those identified as important to them. This includes identifying the extent of the person's need for information and allowing them to decline discussions regarding the possibility that they may be dying.

Priority Three – Involve

The dying person and those identified as important to them are involved in decisions about treatment and care to the extent that the dying person wishes.

Priority Four – Support

The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

Priority Five – Do

An individual plan of care is agreed, co-ordinated and delivered with compassion. (Including: food and drink, symptom control, psychological, social and spiritual support).

- Ensure unnecessary interventions are minimised
- Daily review of the person's condition and agreed decisions/wishes
- Evaluate and update those decisions as needed to ensure appropriateness and effectiveness

The Five Priorities for Care should be considered for all patients whether it is a short, acute illness that leads to death or an expected death due to terminal illness where the patient is already receiving end of life care.

Once a person's health has deteriorated to the stage where their death is likely within the next days and hours, the care and information being provided must be reviewed according to the person's needs and wishes and includes involvement of those important to them.
An experienced clinician should be involved in these multi-disciplinary decisions.

An individualised care plan should be created for the person that includes all Five Priorities for Care e.g. the Care of the Dying Person documentation and care planning (for use in hospital and the community as per universal standard operating procedure). A hospital patient who expresses a wish to be cared for at home should be referred to the specialist discharge team.

Information should be provided to those important to the person about what to expect and what to do when they die. As a minimum they should be provided with a leaflet such as Coping with Dying (St Christopher's Hospice, 2014) or End of Life – A Guide (Marie Curie, 2014).

Assessment of current medication, the discontinuation of non-essential drugs and the prescribing of PRN sub-cutaneous medication for potential development of adverse symptoms are part of creating an individualised care plan and should be considered at this stage and prescribing palliative care medications in anticipation of need according to local policy and guidelines.

It is essential that there is clear communication between the organisations involved. In particular, providers of out of hours care, Marie Curie Rapid Response, Palliative Care Co-ordination Centre (if involved) and the ambulance service should be notified of the patient's status at this time using the relevant notification forms or referral systems.

EPaCCS can be a useful tool to improve communication. The system allows rapid access to key details about a patient at end of life, helping to prevent inappropriate admissions to hospitals.

More details for Lincolnshire visit www.eolc.co.uk

Care after death

> There is only one opportunity to ensure good care after death and it is not easy to co-ordinate everything that needs to happen. The person who provides this care takes part in a significant process. It requires sensitive and skilled communication to address the needs of family members and communication needs to be empathetic and clear.

Clinicians need to be aware of local resources to support the family after a bereavement. Co-ordinated working between the many individuals involved in the process is vital.

The latest multi-professional guidance for staff responsible for care after death can be found here:

www.hospiceuk.org/what-we-offer publications?cat=72e54312-4ccd-608d-ad24ff0000fd3330

After death, most primary care teams develop their own processes and systems. For example the team may decide who will make initial contact with the family and at six to 12 weeks and in 12 months. An administrator will inform other local health professionals involved with their care. The use of the Gold Standard Framework after death analysis tool is helpful for teams to improve their GSF meetings and processes. For more information about the after death analysis tool, access: www.goldstandardsframework.org.uk.

A useful and practical leaflet for families after a death can be downloaded here: www.gov.uk/government/publications/support-after-a-death-leaflet

Health and social care will recognise that end of life care does not stop at the point of death. Other considerations include:

- The timely verification and certification of death or referral to the coroner is important. Marie Curie Rapid Response nurses are qualified to verify expected deaths. Rapid Response service is available from 3pm to 7am, Monday to Friday, and 24hrs/day at weekends and bank holidays (Tel: 0845 055 0709). Out of hours, the ambulance service and out of hours doctors also can verify death. During working hours, the patient's GP should be informed for further information and support. Case managers and Macmillan nurses can verify death as well.
- Care and support of carer and family including emotional and practical bereavement are also very important
- Signposting to other care and support available
- Deaths should be registered within five days. To make an appointment to register a death, please contact the registrar at Lincolnshire County Council **(Tel: 01522 782244).** Further information is available at www.lincolnshire.gov.uk
- For more information on what to do after death, please speak to the patient's key worker or contact the Department of Work and Pensions website: www.direct.gov.uk/en/Governmentcitizensandrights/Death/ index.htm
- Those registering a death at the local Register Office can request the Tell Us Once service, where a range of government organisations is informed about a death. This is a free and confidential service

Most grief resolves in a normal manner. However, there are times when extra support is required. When caring responsibilities come to an end, carers can feel an acute sense of loss not only of the person who has died but also in terms of their own role for the future.

Social networks are the main source of support for most people and many report that they do not need formal bereavement services. However, bereavement services are available to support carers and families/friends to come to terms with their loss and move on with their lives. Services include one-to-one or group support sessions where people can talk about any concerns or anxieties caused by a death. In this way, they can understand their grief and come to terms with their loss. There are also more informal events designed to help them remember their loved ones.

Bereavement Advice Centre www.bereavementadvice.org/ is a free helpline and web-based information service offering practical information on what to do after the death of someone close.

Cruse Bereavement Care www.cruse.org.uk, **(Tel: 0844 477 9400)** and **St Barnabas Lincolnshire Hospice (Tel: 01522 518200)** also offer bereavement support.

Services to meet individual needs

Here is a list of services that may enhance a person's care. Information is included about what the service can offer and how to refer. People approaching the end of life who may benefit from these services must be offered this care in a timely way appropriate to their needs and preferences.

Specialist palliative care support

Specialist palliative care (SPC) is care delivered by specialist multidisciplinary teams.

It encompasses hospice care (inpatient, day therapy and hospice at home) as well as a range of other specialist advice, support and care including the hospital palliative care teams, Palliative Discharge Liaison Nurses and Macmillan Nurses. Specialist Palliative Care should be available on the basis of need and for ALL diagnoses.

Examples of when a team would refer include:

- Complex pain and symptom management
- Psychological support for patients and families who are experiencing difficulty in accepting and coming to terms with the disease process
- Need for palliative rehabilitation
- Discharge planning (in hospitals) where specialist support is considered a requirement to help promote the quality of life for the patient and family
- Terminal care where specialist advice is required to enhance the comfort of the patient and family
- Staff support and education

Welfare benefits service

Welfare community service at St Barnabas Hospice offers confidential advice and support with any aspect of benefits and grants that may be appropriate for individuals and their families.

Contact via central referral point Tel: 01476 513544

Macmillan Clinical Nurse Specialists

Community Macmillan CNS are experienced nurses who have undergone additional training in cancer and palliative care. As part of the Specialist palliative care team, they provide specialist advice on complex aspects of care that have not responded to first line management. This can include, physical symptoms, psychological support and bereavement support. If not directly involved with the patient, the Macmillan CNS can offer support and advice to staff. They are also involved in teaching either on a formal or informal basis. The Macmillan CNS works within Community Integrated Teams across the County.

Specialist palliative care clinics

Referral to specialist palliative care outpatient clinics is by healthcare professionals only.

Palliative care consultants:

Lincoln	Dr Georgina Keenleyside
Boston	Dr Adam Brown

Tel: 01522 511566

Grantham	Dr Kat Collett

Tel: 01476 513545

Specialist palliative care physician

Louth	Dr Lawrence Pike

Tel: 01507 351508

These specialists work across St Barnabas Lincolnshire Hospice and United Lincolnshire Hospitals.

Hospital staff have access to these specialists via the same contact numbers.

In addition, Thorpe Hall (Sue Ryder Hospice at Peterborough) **(Tel: 01733 225900)** holds clinics at Stamford Hospital, and Queen Elizabeth Hospital in King's Lynn **(Tel: 01553 613613)** holds palliative care clinics at North Cambridgeshire Hospital in Wisbech.

Day Therapy

St Barnabas Hospice Day Therapy promotes wellbeing, gives welfare advice, information, and supports choices and decisions about ongoing care to assist independent living. Care is provided by a team of specialist nurses, occupational therapists, physiotherapists, health rehabilitation support workers, chaplains and volunteers. Day Therapy staff work closely with community teams. An initial assessment is offered in a relaxed, informal setting and individualised care is agreed. A wide range of therapies are available. Patients can self refer and drop-in sessions are available. Day Therapy also includes access to nurse-led and consultant-led outpatient clinics, supporting patients with complex needs. The Day Therapy service is delivered by two teams.

Day Therapy South (Grantham, Spalding, Boston) Tel: 01476 513545.

Day Therapy North (Lincoln, Gainsborough, Louth, Skegness, Mablethorpe) Tel: 01522 518219

Hospice at Home (H@H)

Hospice at Home is a countywide service operating seven days a week. Care is provided by a team of specialist nurses and support workers. Care is person centred and individualised. The amount of care is dependant on assessed need and circumstances. H@H, part of St Barnabas Hospice, works closely alongside other community teams. H@H provides personal care, holistic assessment, support and advice on symptom management, psychological, social and spiritual aspects of care. Patients are supported to develop an Advance Care Plan (ACP) if this is appropriate.

Refer via the PCCC Tel: 0845 055 0708

Community nurses

District Nurse-Case Managers are highly skilled community specialist practitioners who have expertise in delivering and co-ordinating care with other agencies such as social services, St Barnabas and Marie Curie, to people in the community with complex health care needs. They lead and manage a skill-mixed team to ensure that individuals, families and carers are supported to be cared for in their own homes, through illness and disability, including palliative and end of life care.

Marie Curie Rapid Response

Marie Curie Rapid Response is a community based nursing service providing specialist palliative care to support patients and carers at home. The teams provide assistance out of hours and can respond to unscheduled need. The teams work from 4pm to 8am, Monday to Friday, and 24 hours a day at weekend and bank holidays. There are three teams in the county, based at Boston, Grantham and Lincoln. Each team includes a registered nurse and a healthcare assistant.

An information leaflet and card are given to the patient when they are referred to the service, to allow direct access. Healthcare professionals should register the patient with the service, but patients and carers can refer directly.

Tel: 0845 055 0709

Specialist Support in Hospital

The acute hospitals at Lincoln, Boston and Grantham, have Specialist Palliative Care Teams that may consist of Macmillan Clinical Nurse Specialists, Palliative Care Consultants and Discharge Liaison Nurses for Palliative and End of life care. Using holistic assessments, they support staff to manage patient complex needs including symptom management, psychological, social and spiritual care.

Specialist inpatient beds

Specialist inpatient beds are provided in Lincoln at St Barnabas Hospice on Nettleham Road in Lincoln. The 11 beds are offered to patients with complex palliative needs that community or hospital teams are struggling to manage. The unit is led by palliative care consultants, doctors and senior nurses and embraces a multidisciplinary team approach. The unit can support and care for patients with any palliative diagnosis and at any point from diagnosis, dependant on need. The average length of stay in the inpatient unit is approximately 16 days and patients can be discharged once their care needs can be met by community teams.

Referral from healthcare professionals via
Tel: 01522 511566.

Hospice in a Hospital

Hospice in a Hospital is based in Grantham Hospital and is a working collaboration between St Barnabas Lincolnshire Hospice and United Lincolnshire Hospitals Trust. It provides six beds in a specially designed part of the hospital. Care is provided by GPs and specialist nurses with advice and support from a palliative care consultant.

Referral from healthcare professionals via
Tel: 01476 464989.

Hospices out of area

Hospices out of area may be more appropriate for patients who live near county boundaries:
Thorpe Hall Hospice, run by Sue Ryder Care, is in Peterborough Tel: 01733 225900
St Andrews is in Grimsby Tel: 01472 350908
Beaumond House is in Newark Tel: 01636 610556

Community Inpatient Palliative Care Beds

Inpatient palliative care beds are provided in community hospitals across the county. Supported by local GP's, and Macmillan Clinical Nurse Specialists, patients are admitted for symptom management, holistic support, respite and rehabilitation as well as end of life care.

The Butterfly Hospice in Boston
has 6 palliative care beds
Tel : 01205 311222.

Scarborough Ward in Skegness Hospital
has 3 palliative care beds
Tel: 01754 613503

The Tulip Suite, Welland Ward, Johnson Hospital, Spalding
has 4 palliative care beds
Tel: 01775 652003

Referrals can be made directly to each Unit or contact PCCC for further information on
Tel: 0845 0550708

Information centres

Macmillan cancer information and support centres are present in Lincoln County, Pilgrim and Grantham hospitals. They offer free, confidential, drop-in advice, support and information about anything to do with cancer for patients and carers. Resources also are available for healthcare professionals.

Lincoln County Hospital Tel: 01522 573799
Pilgrim Hospital Tel: 01205 446392
Grantham Hospital Tel: 01476 464978

Non-cancer support

Hospice services are available to patients with any life-limiting diagnosis.

In addition, specialist disease-specific nurses offer direct support. There are community-based nurses caring for patients with Parkinson's Disease, heart disease and respiratory disease, among others.

The Palliative Care Co-ordination Centre (Tel: 0845 055 0708), GPs and community nursing teams can signpost to these specialists.

Charities also exist – for example British Heart Foundation **www.bhf.org.uk,** Parkinson's Society **www.parkinsons.org.uk,** Alzheimer's Society **www.alzheimers.org.uk,** and the Motor Neurone Disease Association **www.mndassociation.org** – which can offer support and signposting to local services.

Carer support

The Lincolnshire Carers and Young Carers Partnership

The Lincolnshire Carers and Young Carers Partnership can provide support and advice to carers in Lincolnshire.

www.lincolnshire.gov.uk/lcycp

Tel 01522 846911

Carers Connect

Carers Connect provides support for unpaid carers. The service offers information, advice, emotional and practical support, benefits checks, and carer support groups. It also offers education, employment and learning schemes, group grants scheme, and a Macmillan carer support service.

Tel: 01522 696000

Support for patients, families and carers

Neighbourhood Teams

Neighbourhood Teams are being developed across the county as part of the Lincolnshire Health and Care programme. They are a new way of working across health and social are organisations, designed to meet the needs of an ageing population and transform the way that care is provided for people with long-term conditions, enabling those with complex needs to lead more healthy, fulfilling and independent lives.
They provide an opportunity to recognise those people in the last year of their lives. See appendix 4 for more information about Neighbourhood Teams.

Family support services

Family support services provide emotional and psychological support to patients, families and carers. The service is provided by trained staff and volunteers. The type and frequency of support is agreed on an individual basis and may include group therapies. Bereavement support groups are offered across the county by St Barnabas Hospice and may lead into friendship groups and companion groups.

Contact via Tel: 01522 518225

Key worker role

Care works most effectively when there is one key worker co-ordinating everything for the patient. This key worker usually is community based, such as a GP or Health Care Professional, from the Community integrated team. Whatever the professional role, the key worker should have a set of skills and knowledge to support the patient and those important to them.

A key worker is defined as: **"A named professional who is 'best placed' to ensure the person receives co-ordinated, holistic and timely end of life care"** Advance Decision to Refuse Treatment Project Team (2012). Accessed via **www.adrt.nhs.uk/module-3-2-6-supporting.htm**

Best placed person

- Is preferably one person with ongoing responsibilities from this stage of the patient's journey
- Would usually be community based. It is acknowledged that there may be a key worker identified within secondary care. This would lead to close partnership working across primary/secondary care
- The key worker is usually obvious to the person and would be identified at the time the person meets the criteria for the Gold Standards Framework
- The key worker will have the appropriate knowledge, skills and attitude to fulfil the role including encouraging self-care, supporting diversity and advocacy

Proactive co-ordination of holistic care

- Explaining the role of the key worker
- Advance care planning
- Maintaining continuity of care
- Assessment of care / needs
- Treatment / intervention
- Co-ordination of care
- Procuring of health, social and voluntary services
- Offering carer / family support
- Available and accessible

Communication

- Central to role
- Networks / signposting
- Documentation / patient-held record including My Right Care and EPaCCs document
- Utilisation of information technology (and potential technology) to maximise Inter-agency communication (My Right Care)

Knowledge and skills

- Understand and implement the philosophy of palliative care underpinned by the guiding principles, local and national guidance
- Case management
- Local service provision including benefits, housing
- Knowing when to relinquish/ transfer the role if necessary

Supporting person-centred care, choice and autonomy

- Advanced communicator
- Advocate
- Negotiator
- Delegation
- Sign-poster
- Listener
- Choice
- Physical, spiritual, emotional needs
- Supporting diversity
- Empowerment

Ongoing patient assessment is imperative to ensure effective and appropriate management of care and support needs. It is therefore important to understand that, as such, the key worker role may change through the patient journey, but continuity must also be maintained.

For further information about the key worker role, see Appendix 5.

Welfare benefits

A free welfare benefits advice service is available to support patients in Lincolnshire. Referrals can be made by phone or fax. A brief summary of different types of financial support is listed below. Some benefits have changed, in name and acceptance criteria. The service also can signpost to other organisations which may be of assistance.

Welfare benefits

St Barnabas Lincolnshire Hospice offers a free welfare benefits advice service throughout Lincolnshire. Referrals can be made via a central referral line (Tel: 01476 513544 or fax 01476 513 543). Help is available to patients and their carers to assist with claiming all welfare benefits and access various charitable grants if appropriate. The welfare benefits team can also signpost to other agencies such as Age UK and The Citizens Advice Bureau.

Disability Living Allowance (DLA) is no longer available for new claims for people over the age of 16. However, it is still available for children under 16. DLA has a care component and a mobility component. There are three rates for the care component, low, middle or high with two rates for the mobility component, low or high.

Personal Independence Payment (PIP) is a benefit for people who have a physical or mental disability and need help participating in everyday life or find it difficult to get around. It replaced Disability Living Allowance (DLA) for people aged 16 or over and under 65 when applying. PIP has two components, a daily living component for help participating in everyday life and a mobility component for help with getting around. Both components have a standard or an enhanced rate.

Eligibility

There are certain conditions that must be met before help with care and mobility may be considered.

Living alone

Entitlement is based on the amount of help needed, not the amount actually received, so it is not affected by whether a person lives alone or has someone on the premises.

When benefit can be claimed

Neither component is payable until a person has needed help for three months (qualifying period) and the person must be expected to need help for a further nine months (prospective test) unless claiming under the special rules.

Attendance Allowance (AA) is a benefit for people over 65 who have a physical or mental disability and need help or supervision to remain safe. It only has the one component which is for care needs but can be awarded at either the low or high rate.

AA is not normally payable until a person has needed help for six months (qualifying period) unless claiming under the special rules.

Special rules

Special rules apply to those who are not expected to live longer than six months because of a terminal illness. The special rules mean that the person will qualify for help with personal care at the highest rate automatically, even if no help is needed.

DS1500 special rules

This form DS1500 should be issued by GPs if requested by a patient, or their representative, if it is considered that the patient may be suffering from a potential terminal illness. The DS1500 asks for factual information and does not require a prognosis.

The report should contain details of:

- The diagnosis
- Whether the patient is aware of their condition and, if unaware, the name and address of the patient's representative requesting the DS1500
- Relevant current and proposed treatment
- Clinical findings

EPaCCS and coordination of care

A new system to share information about patients in their last year of life is being developed across Lincolnshire. In pilot sites, this system has increased significantly the number of patients being cared for and dying in the place of their choice. The system allows rapid access to key details about a patient at end of life, helping to prevent inappropriate admissions to acute hospitals.

Having a difficult conversation with patients about their wishes in the last year of life is something all healthcare professionals do. It is not easy for patients when they have to do this repeatedly with new people from different organisations and it is not efficient for healthcare staff. It is even more frustrating when they have done this five times (the average for Lincolnshire) but that the professional making a judgement about them in a crisis at any time of day or night does not have access to those decisions.

The 2008 National End of Life Care Strategy recommended locality registers as a way to enable effective communication among professionals. From this experience grew the Electronic Palliative Care Co-ordination Systems (EPaCCS), which are now being implemented across the country. EPaCCS provide a shared locality record for health and social care professionals. They allow rapid access, across care boundaries, to key information about an individual approaching the end of life, including their expressed preferences for care.

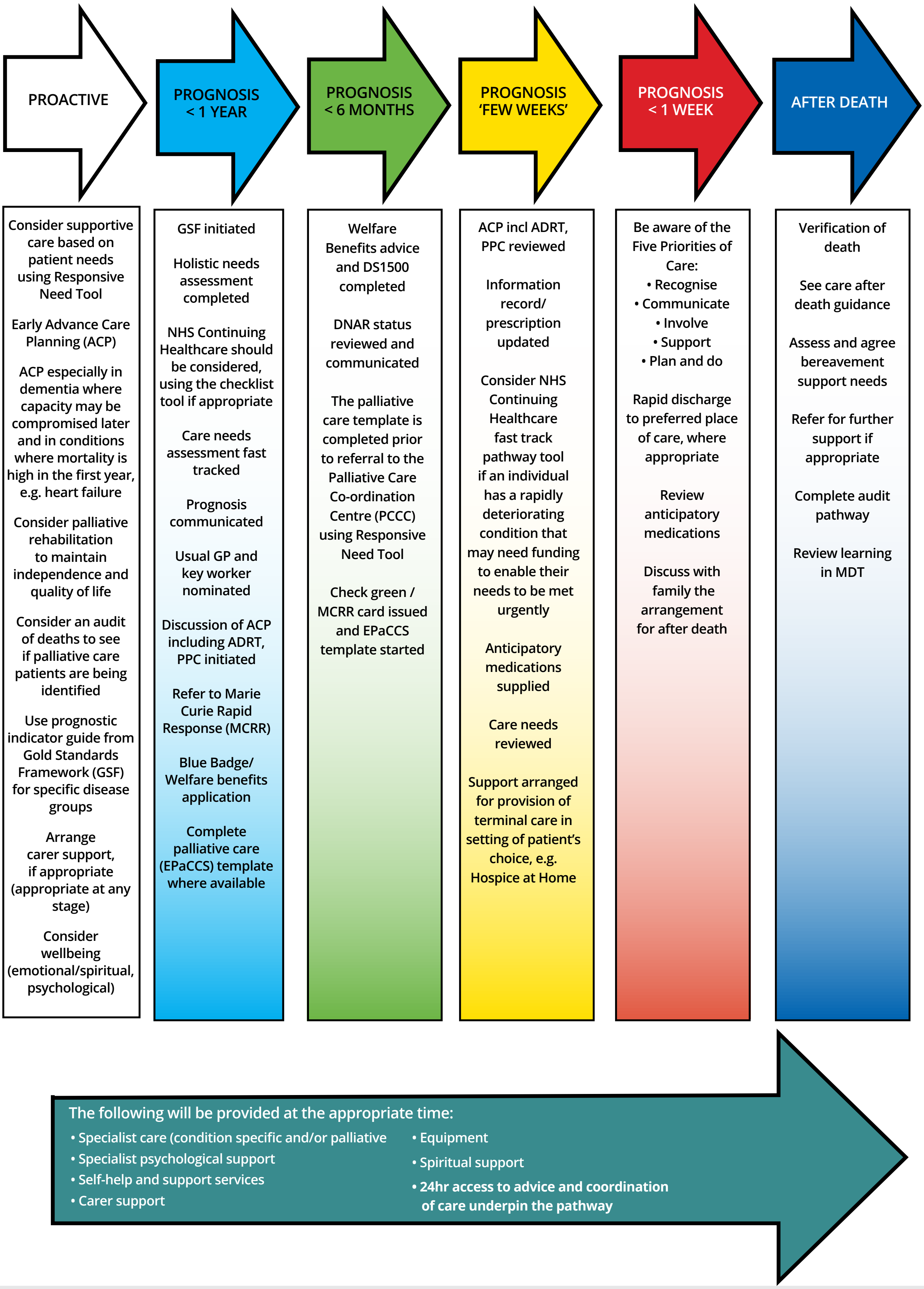
In Lincolnshire, the Electronic Palliative Care Co-ordination System (EPaCCS) is being introduced to resolve this dilemma. GPs and community and hospice staff are recording information about patient decisions and choices regarding their care on their clinical systems. Through EPaCCS and My Right Care, this information is shared widely with clinicians and care staff, including ambulance staff, with the patient's consent. (My Right Care is the interface between different IT systems and EPaCCS.) This allows decisions to be made that are appropriate for the patient, especially in emergency situations.

Survey data elsewhere already suggest more patients die in their place of choice with effective co-ordination of care from EPaCCS. Trials have shown a reduction in unnecessary hospital admissions and empowerment of patients and their carers in self management.

Appendix 1

Details of care provision

End of life care – Details of care provision



PROACTIVE

Consider supportive care based on patient needs using Responsive Need Tool

Early Advance Care Planning (ACP)

ACP especially in dementia where capacity may be compromised later and in conditions where mortality is high in the first year, e.g. heart failure

Consider palliative rehabilitation to maintain independence and quality of life

Consider an audit of deaths to see if palliative care patients are being identified

Use prognostic indicator guide from Gold Standards Framework (GSF) for specific disease groups

Arrange carer support, if appropriate (appropriate at any stage)

Consider wellbeing (emotional/spiritual, psychological)

PROGNOSIS < 1 YEAR

GSF initiated

Holistic needs assessment completed

NHS Continuing Healthcare should be considered, using the checklist tool if appropriate

Care needs assessment fast tracked

Prognosis communicated

Usual GP and key worker nominated

Discussion of ACP including ADRT, PPC initiated

Refer to Marie Curie Rapid Response (MCRR)

Blue Badge/ Welfare benefits application

Complete palliative care (EPaCCS) template where available

PROGNOSIS < 6 MONTHS

Welfare Benefits advice and DS1500 completed

DNAR status reviewed and communicated

The palliative care template is completed prior to referral to the Palliative Care Co-ordination Centre (PCCC) using Responsive Need Tool

Check green / MCRR card issued and EPaCCS template started

PROGNOSIS 'FEW WEEKS'

ACP incl ADRT, PPC reviewed

Information record/ prescription updated

Consider NHS Continuing Healthcare fast track pathway tool if an individual has a rapidly deteriorating condition that may need funding to enable their needs to be met urgently

Anticipatory medications supplied

Care needs reviewed

Support arranged for provision of terminal care in setting of patient's choice, e.g. Hospice at Home

PROGNOSIS < 1 WEEK

Be aware of the Five Priorities of Care:
- Recognise
- Communicate
- Involve
- Support
- Plan and do

Rapid discharge to preferred place of care, where appropriate

Review anticipatory medications

Discuss with family the arrangement for after death

AFTER DEATH

Verification of death

See care after death guidance

Assess and agree bereavement support needs

Refer for further support if appropriate

Complete audit pathway

Review learning in MDT

The following will be provided at the appropriate time:
- Specialist care (condition specific and/or palliative
- Specialist psychological support
- Self-help and support services
- Carer support
- Equipment
- Spiritual support
- **24hr access to advice and coordination of care underpin the pathway**

Appendix 2

Gold Standards Framework

The GSF Prognostic Indicator Guidance

The National GSF Centre's guidance for clinicians to support earlier recognition of patients nearing the end of life

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'

(GSF National Primary Care Snapshot Audit 2010)

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 as 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, UK 2010

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:

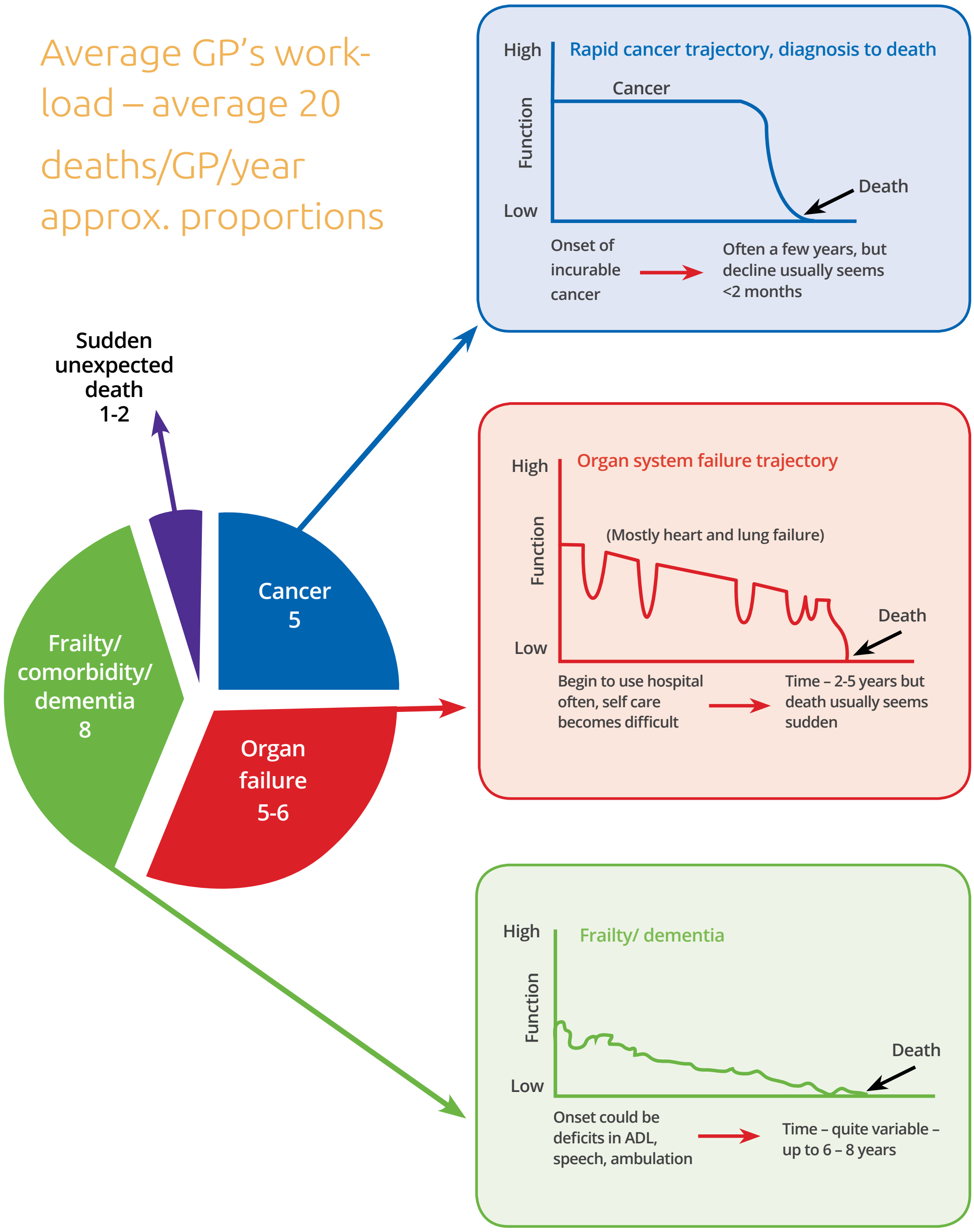
- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions that mean they are expected to die within 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic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

Appendix 2

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.

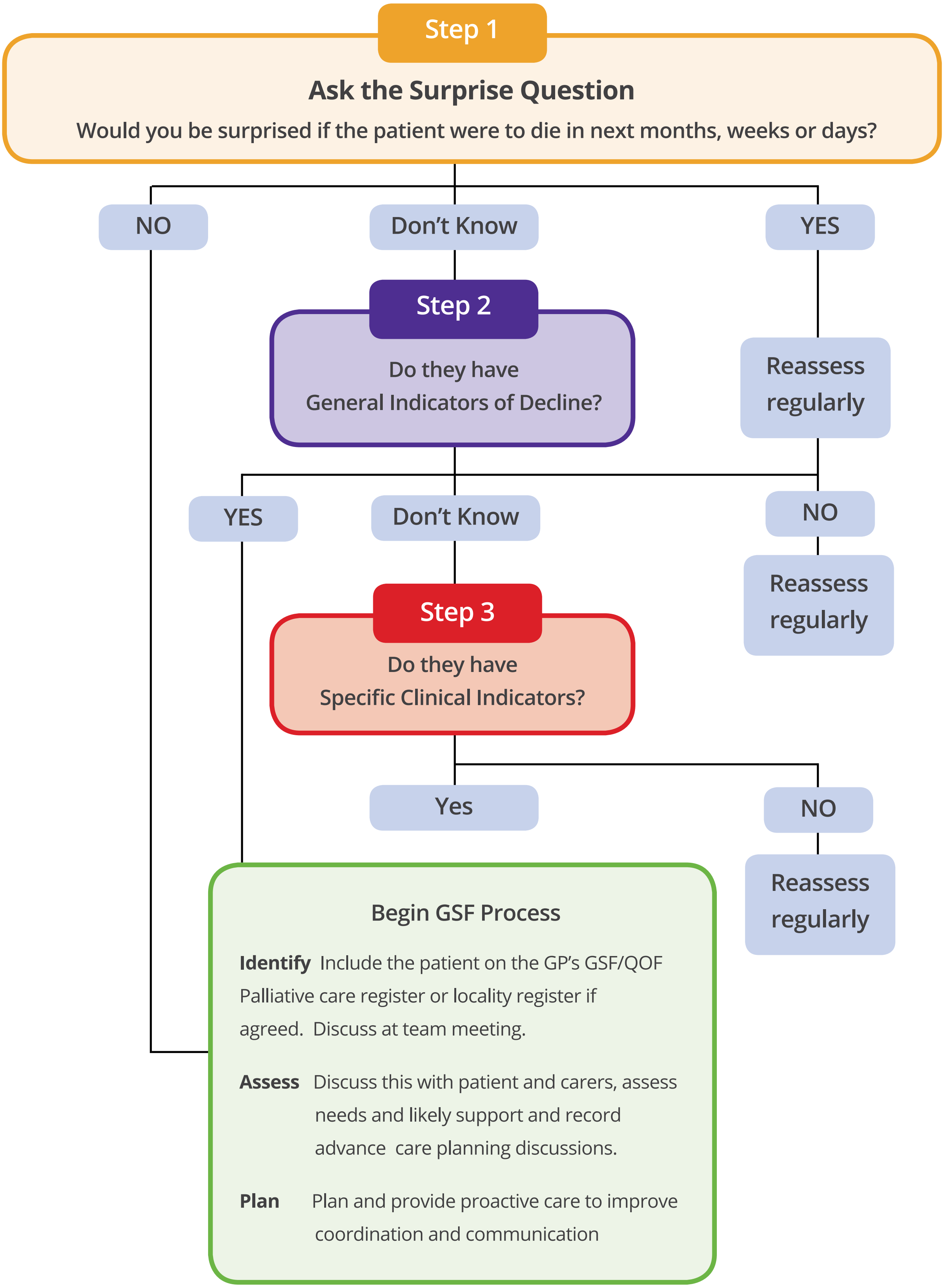
Average GP's work-load – average 20 deaths/GP/year approx. proportions



Prognostic Indicator Guidance (PIG) 4 Edition Oct 2011 © The Gold Standards Framework Centre In End of Life Care CIC, Thomas.K et al

Appendix 2

Summary of suggested three steps for earlier identification



Begin GSF Process

Identify Include the patient on the GP's GSF/QOF Palliative care register or locality register if agreed. Discuss at team meeting.

Assess Discuss this with patient and carers, assess needs and likely support and record advance care planning discussions.

Plan Plan and provide proactive care to improve coordination and communication

Appendix 2

More details of Indicators – the intuitive surprise question , general and specific clinical

Step 1

The Surprise Question

For patients with advanced disease of progressive life limiting conditions - Would you be surprised if the patient were to die in the next few months, weeks, days?

- The answer to this question should be an intuitive one, pulling together a range of clinical, co-morbidity, 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

Are there general indicators of decline and increasing needs?

- Decreasing activity – functional performance status declining (e.g.n 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 E (environment).
- Repeated unplanned/crisis admissions
- Sentinel Event e.g. serious fall, bereavement, transfer to nursing home
- Serum albumen <25g/l
- Considered eligible for DS1500 payment

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.

Appendix 2

Gold Standards Framework

Step 3 **Specific Clinical Indicators -** flexible criteria with some overlaps, especially with those with frailty and other co-morbidities

a) Cancer – rapid or predictable decline

Cancer

- Metastatic cancer
- More exact predictors for cancer patients are available e.g. PiPS (UK validated Prognosis in Palliative care Study). PPI, PPS etc.

  'Prognosis tools can help but should not be applied blindly'
- 'The single most important predictive factor in cancer is performance status and functional ability' - if patients are spending more than 50% of their time in bed/lying down, prognosis is estimated to be about 3 months or less.

b) Organ Failure – erratic decline

Chronic Obstructive Pulmonary Disease (COPD)

At least two of the indicators below:

- Disease assessed to be severe (e.g. FEV1 <30% predicted)
- Recurrent hospital admissions (at least 3 in last 12 months due to COPD)
- Fulfils long term oxygen therapy criteria
- MRC grade 4/5 – shortness of breath after 100 metres on the level or confined to house
- Signs and symptoms of right heart failure
- Combination of other factors – i.e. anorexia, previous ITU/NIV resistant organisms
- More than 6 weeks of systemic steroids for COPD in preceding 6 months.

Heart Disease

At least two of the indicators below:

- CHF NYHA Stage 3 or 4 - shortness of breath at rest on minimal exertion
- Patient thought to be in the last year of life by the care team - The 'surprise question'
- Repeated hospital admissions with heart failure symptoms
- Difficult physical or psychological symptoms despite optimal tolerated therapy.

Summary of suggested three steps for earlier identification

GSF Needs Based Coding

A - Blue 'All'
from diagnosis Stable
Year plus prognosis

B - Green 'Benefits' - DS1500
Unstable / Advaced disease
Months prognosis

C - Yellow 'Continuing Care'
Deteriorating
Weeks prognosis

D - Red 'Days'
Final days / terminal care
Days prognosis

Navy
'After Care'

This guidance aims to clarify the triggers that help to identify patients who might be eligible for inclusion on the register (supportive/palliative care/ GSF/ locality registers). Once identified and included on the register, such patients may be able to receive additional proactive support, leading to better co-ordinated care making processes and the importance of integrating advance care planning discussions into delivery of care. It is based on consideration of people's needs rather than exact timescales, acknowledging that people need different things at different times. Earlier recognition of possible illness trajectories means their needs can be better anticipated and addressed.

Identify
patients who may be in the last year of life

assess
current and future, clinical and personal needs

plan
plan cross boundary care and care in final days

Renal Disease

Stage 4 or 5 Chronic Kidney Disease (CKD) whose condition is deteriorating with at least 2 of the indicators below:

- Patient for whom the surprise question is applicable
- Patients choosing the 'no dialysis' option, discontinuing dialysis or not opting for dialysis if their transplant has failed
- Patients with difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy
- Symptomatic Renal Failure – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload.

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. Plus the following:

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% of predicted using standard spirometry)
- Dyskinesia, mobility problems and falls
- Communication difficulties.

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

Multiple Sclerosis

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

c) Frailty / Dementia – gradual decline

Frailty

Individuals who present with Multiple co-morbidity 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
- low physical activity
- depression.

Stroke

- Persistent vegetative or minimal conscious state or dense paralysis
- Medical complications
- Lack of improvement within 3 months of onset
- Cognitive impairment / Post-stroke dementia.

Dementia

There are many underlying conditions which may lead to degrees of dementia and these should be taken into account. 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.

It is vital that discussions with individuals living with dementia are started at an early stage to ensure that whilst they have mental capacity so that they can discuss how they would like the later stages managed.

Use of needs based coding

Prognostication or prediction of need.

Prognostication is inherently difficult and inaccurate, even when informed by objective clinical indicators. Most people tend to give undue weight to prognosis and too little to the importance of planning for possible need, especially for those with non-cancer illnesses, frailty and co-morbidities. In order to identify more accurately those patients who need additional pro-active supportive care, the focus should be on a pragmatic, even instinctive, prediction of the rate and course of decline. Some specific tools can help to predict accurately the time remaining for cancer patients but they should be used with caution (BMJ .2011; 343:d5171)

We suggest a move towards earlier consideration and more 'rainy day thinking' – bringing an umbrella just in case it rains. This instinctive, anticipatory and 'insurance-type' thinking relates more to meeting likely needs and planning ahead, rather than focusing on trying to predict likely timescales, and should ensure appropriate support and care can be mobilised.

If you can anticipate possible deterioration, then you can begin discussions about preferences and needs at an earlier stage. The aim of such advance care planning discussions is to establish patients' sometimes unvoiced concerns, needs and preferences, enabling more people to live out the final stage of life as they choose (see ACP Guidance on GSF/ EOLC web-sites. This also means you can introduce practical measures to prevent crises and make referrals for extra help or advice.

Needs Based Coding - the right care at the right time

Patients have differing requirements at varying stages of their illness. The use of needs-based or colour coding can be very helpful in prioritising need. Some clinicians in care homes, GP practices and hospitals use this system to identify their patients' stage of decline and so predict at an earlier stage their future needs. Although only a rough guide, this helps us focus on giving the right care at the right time, with regular reviews built in to trigger actions at each stage. As a result a needs/support care plan can be developed for each individual.

Needs Based Coding and Needs Support Matrices

Identifying the stage of illness and anticipating needs and support– to deliver the right care at the right time for the right patient.

- A – All stable, to read diagnosis - years
- B – Unstable, advanced, to read disease - months
- C – Deteriorating, to read exacerbations - weeks
- D – Last days of life, to read pathway - days

For further details of use of Needs / Support Coding and Matrices as part of the GSF Programmes contact the GSF Centre.

Needs Based Coding - the right care at the right time

Long term conditions. There is a strong correlation between care for patients with long-term conditions and those with advanced disease nearing the end of life. This is especially true for patients with organ failure (heart failure, COPD). Close collaboration with case managers can reduce unplanned admissions and support good end of life care.

Use of this guidance by different teams

Primary care teams. Identifying patients, the first step of GSF, is key to developing a Palliative Care Register, which forms part of the QOF palliative care points in the GMS contract.

The National Primary Care Snapshot Audit (2010) in England demonstrated 3 key findings:

- Only about 25% of patients who died were included on the GP's Palliative Care/ GSF register
- Only 25% of these had non-cancer conditions
- Most importantly, those patients identified early and included on the register received better care. The focus should be on a pragmatic, even instinctive, prediction of quality co-ordinated care

Therefore this affirms the need for earlier recognition and identification of people nearing the end of life where possible, i.e. the 1% of the population who die each year, greater representation of patients with non-cancer, organ failure, and those with frailty and dementia is recommended, including those from care homes.

Two helpful questions for practice teams to ask:

1. **What is your register ratio?**
   The number of patients on your palliative care register over the number who died in your practice (using the 1% rule as an approximation e.g. 5000 population = about 50 deaths/ year).
2. **What is your non-cancer/cancer ratio on register?**
   What percentage of patients on the register have cancer or non-cancer conditions as their main cause of death?

For more details on the QOF points and guidance on Next Stage GSF in Primary care, see the GSF website.

Care homes. Use of the surprise question and this guidance has been found to help identify residents who are most in need in care homes. This can help focus care and trigger key pro-active support, thereby leading to reduced hospital deaths (e.g. halving of death rate in care homes using GSF in Care Homes Programme).

Acute hospital teams. About 25% of all hospital beds are occupied by someone who is dying. The National Audit Office estimates that at least 40% of those people have no medical need to be there. Improved early identification of people in the final year of life helps reduce hospitalisation and accessing supportive and palliative care services. It is extremely helpful if hospital teams notify GPs that a particular patient has advanced disease and might be included on their register.

Specialist teams. Specialist palliative care teams play a vital role especially with cancer patients, but there is a need for collaboration with other specialist teams for non-cancer patients to provide optimal care. These include those with dementia, care of the elderly, heart failure, etc. and this guidance may help clarify referrals.

Commissioners/managers. This guidance could be used as part of an end of life care strategic plan, with improved provision of services for all patients nearing the end of life and introduction of a locality register.

Appendix 2

Gold Standards Framework

"It should be possible therefore to predict the majority of deaths, however, this is difficult and errors occur 30 per cent of the time... However, the considerable benefits of identifying these patients include providing the best health and social care to both patients and families and avoiding crises, by prioritising them and anticipating need.

Identifying patients in need of palliative care, assessing their needs and preferences and proactively planning their care, are the key steps in the provision of high quality care at the end of life in general practice."

Quality and Outcomes Framework (QOF Guidance) 2011/12 Guidance

"It is recommended that people approaching the end of life are identified in a timely way".

(Draft Recommendation NICE Guidance in End of life Care 2001)

This is not attempting to answer the question that doctors often hear - 'how long have I got?' Rather, it responds to the underlying sometimes unspoken questions from people facing a new reality 'If I haven't got long, then what should I do and how can you help?'

(Thomas K GSF Centre 2008)

"For many people suffering from a chronic illness, a point is reached where it is clear that the person will die from their condition. Despite this, for many conditions it may be difficult, if not impossible and potentially unhelpful, to estimate prognosis accurately.The Prognostic Indicator Guidance developed as part of the Gold Standards Framework (GSF) provides useful prompts or triggers to a healthcare professional that discussions about the end of life should be initiated, if this has not already happened".

(DH End of Life care Strategy 2008 England)

Identification of people with a life-limiting illness when they are starting to need a change in their goals of care contributes to end of life care planning and can aid communication with patients and families. It depends on clinical judgement and weighing up a complex mix of pathology, clinical findings, therapeutic response, co-morbidities, psychosocial factors, and rate of decline.

(Glare P J Palliat Med 2008)

"Using the GSF 'PIG' has helped us to identify these patients earlier than we previously did, especially those with non-cancer, thereby giving them earlier support as they face the end of their lives, leading to fewer crises and hospital admissions."

(GP using Next Stage GSF Training Programme 'Going for Gold')

Development of this guidance paper. This guidance was originally commissioned from the GSF Centre in June 2006 to support GPs include appropriate patients on their QOF Palliative Care Registers i.e. those considered to be in the final 12 months of life. It is regularly revised following extensive consultation with clinical and disease specialist groups, palliative care specialists and GPs in the Royal College of General Practitioners. Particular thanks go to the NHS End of Life Care Programme and University of Edinburgh team for their help. Since publication, this Guidance has been widely used by clinicians in many sectors in the UK and internationally. A list of detailed references is available on request. This is one of several tools available to support improvements in End of Life Care, and further details on best use, IT support and further developments can be obtained from the GSF Centre.

Resources and Further Reading :

National Gold Standards Framework Centre for End od Life Care- Primary care, care homes and other areas **www.goldstandardsframework.org.uk**

National Primary care Snapshot Audit (2009/2010) DH report + Next Stage GSF Primary Care Training **www.goldstandardsframework.org.uk/GSFInPrimary+Care**

NHS End of life care Programme **www.endoflifecareforadults.nhs.uk**

NHS Department of Health. End of Life Care Strategy (2008) P51, 3.22 **http://www.endoflifecareforadults.nhs.uk/strategy/strategy**

GMC End of Life Care **www.gmc-uk.org/static/documents/content/End_of_life.pdf3**

QOF Palliative Care - **www.nhsemployers.org/SiteCollectionDocuments/QOFguidanceGMScontract_2011_12_FL%2013042011.pdf**

NICE Draft Quality standards in End of Life Care (for consultation- due Nov 2011) **www.nice.org.uk/guidance/qualitystandards/indevelopment/endoflifecare.jsp**

National Audit Office End of Life care Report Nov 08 **www.nao.org.uk/publications/0708/end_of_life_care.aspx**

British Geriatrics Society. **www.bgs.org.uk/index.php?option=com_content...id**

The 'Surprise question': Lynn J 2005 Altarum Institute Center for Elder Care and Advanced Illness **www.thehastingscenter.org/pdf/living-long-in-fragile-health.pdf**

Dying Matters- and the QIPP Find the 1% campaign – **www.dyingmatters.org.uk** or National Council for Palliative Care **www.ncpc.org.uk**

Liverpool Care Pathway for the Dying Patient. **http://www.mcpcil.org.uk/liverpool-care-pathway/**

QIPP Department of Health **www.endoflifecareforadults.nhs.uk/strategy/policy/quality-innovation-productivity-prevention**

Frameworks for Implementation (2010) from the End of Life Care Programmes - **www.endoflifecareforadults.nhs.uk/publications/end-of-life-care-for-heart-failure-a-framework, www.kidneycare.nhs.uk/Library/EndofLifeCareFINAL.pdf, www.endoflifecareforadults.nhs.uk/publications/care-towards-the-end-of-life-for-people-with-dementia,**

www.endoflifecareforadults.nhs.uk/publications/end-of-life-care-in-long-term-neurological-conditions-a-framework

Renal advisory group of the NSF, British Renal Society, and British Transplant Society. **www.britishrenal.org**

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Appendix 3

Breaking Bad News Flowchart

Step 1	**Preparation** Check the patient's notes and talk to the team Check who should be present Set time aside Set the scene and ensure privacy
Step 2	**What does the patient know?** 'It would help me to know what you understand about your illness.'
Step 3	**Is more information wanted?** 'I have your results, would you like me to discuss them with you?'
Step 4	**Give a warning shot** 'I'm afraid it looks more serious than we had hoped'
Step 5	**Allow patient to refuse information at this time** 'It must be difficult for you to talk about this today'
Step 6	**Explain (if requested)** A narrative of events can be useful
Step 7	**Elicit and listen to concerns** 'I know that this is bad news but is there anything that is particularly distressing you?'
Step 8	**Encourage ventilation of feelings** 'How does that news leave you feeling?'
Step 9	**Summarise and plan** 'Your main concerns at the moment seem to be...'
Step 10	**Offer availability and support** Follow-up appointment 'We will work on this together'
Step 11	**Communicate with the team** Document in notes and letters, inform patient's GP

From Guidelines for communicating bad news with patients and their families (2010) East Midlands Cancer Network (p14)

Identifying Patients Who Require Supportive and Palliative Care

Neighbourhood Team Tool

‘Predicting needs rather than exact prognostication’

This may include patients with:

- Advanced, progressive incurable conditions
- General frailty and co-existing conditions that indicate they could be expected to die within 12 months
- Existing conditions, where they are at risk of dying from a sudden acute crisis in their disease pathway
- Life threatening acute conditions caused by sudden catastrophic events

Triggers:

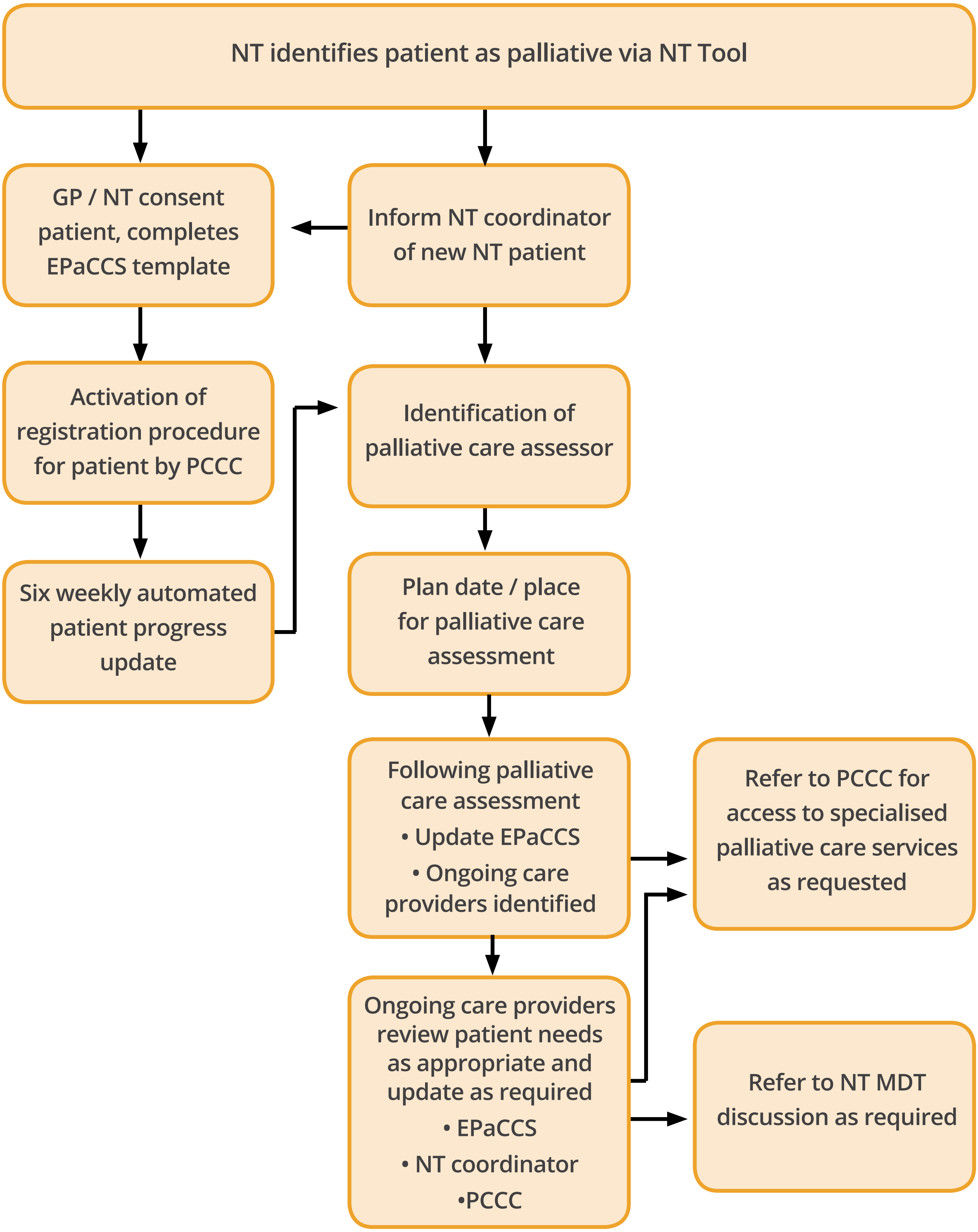
- General indicators of deterioration identified, including decline in functionality and ability to self care
- Specific clinical indicators of disease deterioration identified, including decisions for no further curative treatment
- Diagnosis of two or more existing, progressive co-morbidities
- Repeated unplanned admissions or increased and/or unexpected contact with health or social care professionals
- Despite best medical interventions; you would not be surprised if the patient were to die in the next 6-12 months?

Two or more triggers suggest the patient is palliative and indicate the requirement for a palliative care needs assessment

Please refer to flowchart on next page.

Appendix 4

Neighbourhood Team flowchart for access to palliative assessment and support



NT identifies patient as palliative via NT Tool

GP / NT consent patient, completes EPaCCS template

Inform NT coordinator of new NT patient

Activation of registration procedure for patient by PCCC

Identification of palliative care assessor

Six weekly automated patient progress update

Plan date / place for palliative care assessment

Following palliative care assessment
- Update EPaCCS
- Ongoing care providers identified

Refer to PCCC for access to specialised palliative care services as requested

Ongoing care providers review patient needs as appropriate and update as required
- EPaCCS
- NT coordinator
- PCCC

Refer to NT MDT discussion as required

Supportive and Palliative Care Indicators Tool (SPICT™).

- The SPICT™ is used to identify people with one or more advanced conditions for assessment of supportive and palliative care needs, and care planning.
- The SPICT™ has 6 general indicators of deteriorating health, and clinical signs of advanced underlying conditions.
- SPICT™ helps **identify people at risk of deteriorating and dying.** It does not give a 'prognosis' or indicate when a person's health might decline.

Assess and plan care for people identified using SPICT™

Poor or deteriorating performance status
Increasing need for personal care
Arrange additional support/care for people at home to avoid hospital admission, if possible.

Unplanned hospital admissions: review treatment/ medication and care.

Poorly controlled symptoms: optimise treatment of underlying conditions; minimise polypharmacy; stop medicines no longer of benefit; use palliative symptom control measures.

- Identify people in the community, or when discharged home, with complex or increasing needs for coordinated care, from the primary care team and other community services.
- Consider assessment by a specialist palliative care service or another appropriate specialist or service for people with complex symptoms or other needs.
- Agree, record and share an **Anticipatory Care Plan**

Conversations with people whose health is deteriorating.

- Include close family/ friends and any registered 'Power of Attorney' (POA).
- Involve them in shared decision-making if the person's capacity is impaired.

Talk about:

- What do you know about your health problems and what might happen in future.
- 'What matters' to you and what are your concerns? What would help with those things?
- Who should be contacted and how urgently if this person's health deteriorates?

Consider discussing:

- The outcomes and risks/benefits of hospital care and treatments (eg. IV antibiotics; surgery; acute stroke, vascular or cardiac interventions; tube/IV feeding; ventilation).
- Treatments that will not work or have a poor outcome in this situation. (eg. CPR)

Agreeing an 'Emergency treatment care plan' in case the person deteriorates rapidly.

Appointing a 'POA' in case the person's decision-making capacity is lost in the future.

I wish we had treatment for....could we talk about what we can do if that's not possible?

I hope you will stay well for a long time, but I am worried you could get less well again...

Can we talk about how we might cope with not knowing exactly what will happen and when?

If you were to get less well again, what would be important for us to think about?

Sometimes people want to talk about whether they would want treatments only available in hospital....

Appendix 5

SPICT Guide and Tool

Supportive and Palliative Care Indicators Tool (SPICT™)

The SPICT™ is a guide to identifying people at risk of deteriorating health and dying. Assess these people for unmet supportive and palliative care needs.

Look for two or more general indicators of deteriorating health.

- Performance status is poor or deteriorating (the person is in bed or a chair for 50% or more of the day); reversibility is limited.
- Dependent on others for most care needs due to physical and/or mental health problems.
- Two or more unplanned hospital admissions in the past 6 months.
- Significant weight loss (5-10%) over the past 3-6 months, and/ or a low body mass index.
- Persistent, troublesome symptoms despite optimal treatment of underlying condition(s).
- Patient asks for supportive and palliative care, or treatment withdrawal.

Look for any clinical indicators of one or more advanced conditions

Cancer

Functional ability deteriorating due to progressive metastatic cancer.

Too frail for oncology treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; swallowing difficulties.

Urinary and faecal incontinence.

No longer able to communicate using verbal language; little social interaction.

Fractured femur; multiple falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/ or progressive swallowing difficulties.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Heart/ vascular disease

NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:

- breathlessness or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe chronic lung disease with:

- breathlessness at rest or on minimal exertion between exacerbations.

Needs long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping dialysis.

Liver disease

Advanced cirrhosis with one or more complications in past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.

Review supportive and palliative care and care planning

- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals, and a care plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Record, communicate and coordinate the care plan.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™, April 2015

Appendix 6

Responsive Need Tool (RNT) – to be used in conjunction with RNT scoring aid

Level and score	Description of level	Care requirements/plan
Level 4 **Score 31 - 44**	• Patient's condition is deteriorating rapidly towards the end of life with frequent changes in condition noted • Without intervention, admission to hospital or crisis is inevitable • Intervention will enable preferred place of care/death	• Care delivered by specialists and generalists • In addition to care provided by key worker / community team, up to three visits/contacts a day from specialist palliative care providers • Registered professional / key worker uses the scoring tool to reassess the patient weekly, or in the event of significant change, and informs PCCC so care package can be arranged • Consider EPaCCS
Level 3 **Score 26 - 30**	• Patient's condition is deteriorating with weekly changes to condition noted • Without intervention, admission or crisis is probable or possible • Patient is at risk of worsening quickly • Intervention will enable preferred place of care/death	• Care delivered by specialists and generalists • In addition to care provided by key worker / community team from three visits/contacts a week up to daily contact by specialist palliative care providers • Registered professional / key worker uses the scoring tool to reassess the patient weekly, or in the event of significant change, and informs PCCC so care package can be arranged • Consider EPaCCS
Level 2 **Score 21- 25**	• Patients condition is deteriorating with changes to condition noted over several weeks/ monthly • Intervention is required to support patient in preferred place of care and anticipate and address future changing care needs (e.g. Advance Care Plan)	• Consider referral to St Barnabas Day Therapy Services / or Hospice at Home services via PCCC Tel: 08450 550708 • Care delivered by specialists and generalists. In addition to care provided by key worker/ community team up to two visits/contacts a week by specialist palliative care providers • Registered professional / key worker uses the scoring tool to reassess the patient weekly, or in the event of significant change, and informs PCCC so care package can be arranged • Consider referral for carer's assessment • Consider EPaCCS
Level 1 **Score less than 21**	• Patient is asymptomatic or symptoms are well managed and stable • Patient and carer are coping and aware of how to access support in case of change	• Care delivered by generalists if required in patient home • Referral to St Barnabas Hospice Day Therapy on Tel: 01476 513545 • Consider referral for carer's assessment • Consider EPaCCS

If your professional judgement is that patient is of a higher/lower level and you can justify this please alter level indicated by the scores and inform PCCC of this professional judgement.

Appendix 6

Responsive Need Tool (RNT) – to be used in conjunction with RNT scoring aid

Prognostic indication	More than six months	1
	Less than six months	2
	Less than two months	3
	Within two weeks	4
Age	74 + under	0
	75 + over	1
Co-morbidities	Long-term illness	0
	More than one long-term illness/long-term co-morbidity	1
Deterioration status	Stable	0
	Monthly changes	1
	Weekly changes	2
	Daily changes	3
Hospital admissions	No unplanned admissions in the last three months	0
	One or two unplanned admissions in last three months	1
	One or two unplanned admissions in last month	2
	More than two unplanned admissions in last month	3
Symptoms (physical)	Asymptomatic or well controlled	0
	Generally well controlled/needs weekly monitoring /one symptom	1
	Two or more symptoms needing daily monitoring	2
	Two or more symptoms not controlled or requiring s/c meds	3
Psychological needs	Coping well, no psychological needs	0
	Generally coping, mood changes consistent with illness, needs met by current support network	1
	Psychological symptoms that requires intervention. Psychological distress is impacting on patient wellbeing	2
	Psychological problems requiring continuous support and/or specialist input to address distress/anguish	3
Fatigue/Conscious level	Conscious, but tires easily	1
	Conscious, but spends less than half the day sleeping/resting	2
	Conscious, but spends more than half the day sleeping/resting	3
	Semi-conscious/unconscious	4
Personal hygiene	Fully independent	0
	Partially Independent/has established social care package to support patient/ needs assistance of one carer for personal care (any of these)	1
	Needs assistance of two to meet personal care needs	2
	Needs full assistance/hygiene needs met while patient in bed	3
Eating and drinking	Appetite unaffected	0
	Still eats three meals a day, although quantity of intake may be reduced	1
	Reduced eating and drinking where nutrition an issue: e.g. snacking only/may be on supplements	2
	Minimal intake, sips/nil by mouth	3

Appendix 6

Responsive Need Tool (RNT) – to be used in conjunction with RNT scoring aid

Mobility	Independent, still able to get outdoors	0
	Independent, but generally housebound	1
	Needs assistance/support/able to transfer only e.g. bed-chair	2
	Bed bound	3
Performance score Karnofsky Performance Scale (AKPS) – see scoring guidelines below	Score 90 – 100 relatively fit/well	1
	Score 60 – 80 not regularly active/symptoms limit activity, not dependent on others all of the time	2
	Score 40 – 50 Mildly-moderately frail, frailty progressing, requires considerable assistance with ADLs or in bed some of the time	3
	Score 0 – 30 – Severely frail/bed bound/ terminally ill/ completely dependent for personal care	4
Cognition	Full mental capacity/no memory problems	0
	Mild cognitive impairment/memory problems/potentially reversible	1
	Moderate cognitive impairment/memory problems/fluctuating mental capacity	2
	No mental capacity/severe cognitive impairment	3
Carer/Next of Kin (NOK) (relates to carers coping)	Carer/NOK has as good informal support/long established care package	1
	Carer/NOK able to cope but needs weekly professional support	2
	Carer/NOK needing increased professional support/limited informal support available	3
	Carer/NOK unable to cope without professional support/high risk carer breakdown requires carers assessment	4
Spirituality / Future planning (Advance Care Planning)	Future preferences and wishes/spiritual needs addressed	1
	Future preferences and wishes/spiritual needs assessment/review	2
	Future preferences and wishes/spiritual needs require planned intervention	3
	Requires urgent intervention for unresolved issues	4
Total score	Total	

Australia-modified Karnofsky Performance Scale (AKPS) assessment criteria	
Normal; no complaints; no evidence of disease	100
Able to carry on normal activity; minor sign of symptoms of disease	90
Normal activity with effort; some signs or symptoms of disease	80
Cares for self; unable to carry on normal activity or to do active work	70
Able to care for most needs; but requires occasional assistance	60
Considerable assistance and frequent medical care required	50
In bed more than 50 per cent of the time	40
Almost completely bedfast	30
Totally bedfast and requiring extensive nursing care by professionals and/or family	20
Comatose or barely rousable	10
Dead	0

Function as per Karnofsky score

High Function

Moderate Function

Low Function

June 2015

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