

Project Invicta – Improving End of Life Care in East Kent

My Wishes – East Kent's End of Life Register

TRAINING PACK

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1. Introduction

1.1. What is Project Invicta

Project Invicta was set up after listening to patients and staff about how to improve End of Life Care within the East Kent Locality. Although there were many examples of good practice in this area, it was reported that there were concerns about gaps in the service provided to patients and their carers over the 24-hour period, some repetition of care and difficulties in communicating all relevant information to all health professionals who cared for someone at the end of their life.

Project Invicta aims to improve end of life care by providing a care navigation centre which is available 24 hours a day, 7 days a week to co-ordinate and navigate care for a patient at the end of their life.

The Care Navigation Centre will work hard to put patients at the centre of their care and provide better-coordinated services by improving communication between GP, hospital, hospice and community teams. The service is supported by “My Wishes” an electronic network that allows all health care professionals involved in a patient’s care to share the record.

This training pack has been put together with reference and follows the same format to “coordinate my care”¹ the London service led by Royal Marsden Hospital who kindly shared their training pack with the project.

1.2 What is My Wishes – East Kent’s End of Life Register

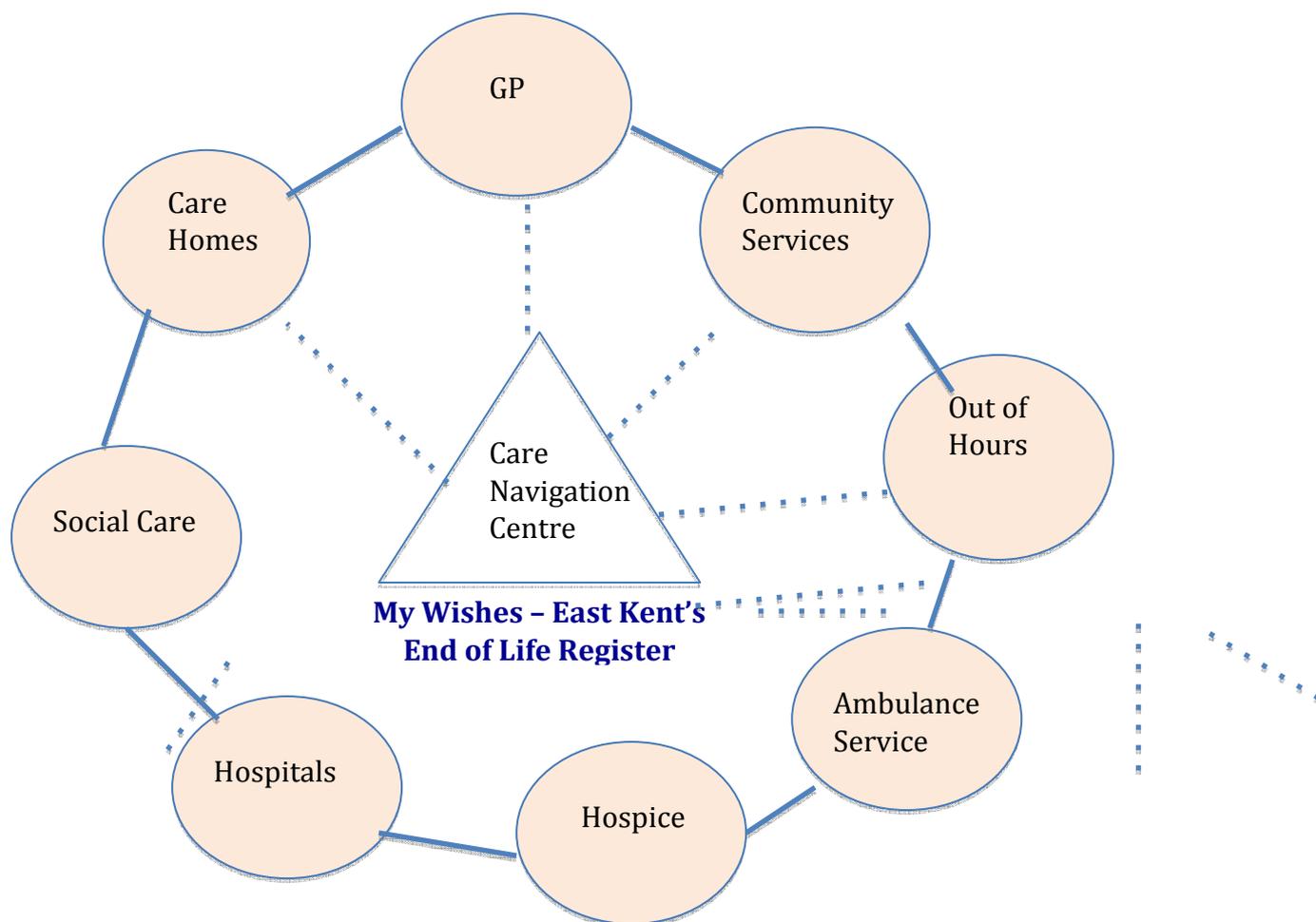
My Wishes – is an electronic end of life register which records details of patients who are nearing the end of life. Patients will be asked to give consent for some key information about their decisions, to be recorded on this system. These decisions and any needs identified are then shared appropriately to help provide the best care possible. The system will enable patient preferences and needs to be communicated among staff and organisations that are responsible for their care, either now, or in the future 24hours a day 7 days a week. Access to this information will help staff make every effort to follow patient’s wishes about their care at this stage of their life.

¹ Coordinate my Care, a clinical service that coordinates care, giving patients choice and improved quality of life. Training Pack. Nov 2011. The Royal Marsden

Evidence has reported that the benefits of an end of life register are:

- Reduction in unscheduled care
- Better communication of patient wishes
- More patients dying in their place of choice
- Register supports delivery of patient choice
- Positive experience for stakeholders as increased inter agency and partnership working
- More seamless care
- Less family distress

1.3 Approach



- The service integrates end of life care pathways across East Kent between health and social services:
 - GPs (in and out of hours)
 - Community nursing teams
 - Hospitals
 - Hospices
 - Social workers
 - South East coast ambulance services
 - Intermediate care
 - Care homes
- Is evolving and developing care pathways with local health and social care partners
- Is available for all patients on the “My Wishes “ East Kent’s End of life register
- Continues to Evaluate the project and service and supports the implementation of any learning

1.4 Teaching and Training includes:

1. How to identify patients who are at the end of life and appropriate to be added to My Wishes end of life register
2. How to gain informed consent from patients to include their record on the My wishes register.
3. How to have advanced care planning conversations with patients, their carers, exploring their preferences and wishes.
4. How to discuss and make treatment escalation plans and cardiopulmonary resuscitation (CPR) decisions.
5. How to input patients data on the My Wishes register and understanding of the significance of clinical data entry.

1.5 Aims of Project Invicta – Improving End of Life Care across East Kent

In England in July 2008, the Department of Health published an End of Life Care Strategy to “bring about a step change in access to high quality care for all people approaching the end of their life” in all care settings. This would improve co-ordination of services through the deployment of a whole system care pathway approach for the commissioning and provision of integrated services. Project Invicta was born from the national strategy and the need to provide integrated services and make more efficient use of existing health and social care services and resources at a time of increasing demand and reducing available budgets.

The proposed outcomes of Project Invicta are:

- To improve end of life care experience for individuals, carers, family and friends

- An increase in the number of patients dying in their place of choice
- A reduction in the number of acute emergency admissions , for patients at the end of life
- A reduction in the number of end of life care patients dying within an acute hospital setting
- A reduction in the number of fast track NHS continuing healthcare placements

An increase in the number of patients whose final days are managed on the LCP

- An increase in the number of patients with an updated DNACPR
- An increase in the number of patients held on an electronic end of life register

We are currently pulling together a baseline data set to ensure we can measure progress against the project.

1.6 The training pack

This training pack is a user guide to inform professionals as to how the care navigation centre and My Wishes end of life register can be optimally used.

2. Information for patients and their carers

2.1 Planning your healthcare at the end of your life

Most people want to have a say over the healthcare they receive at the end of their lives when the time comes. However, it is not always easy to discuss your thoughts and wishes with those around you. Just thinking about it can make those close to you very upset, but then when the time comes, the people who are caring for you won't have a clear idea of what you want. Where you want to be treated for instance, or the type of care you want or treatment you wish to refuse.

That is why in East Kent we have established a "My Wishes" register, where healthcare staff who are responsible for your care can find out the decisions you have made.

They will do their very best to ensure that your wishes are respected where possible.

2.2 What is the My Wishes register?

The My Wishes register is a record of your decisions about:

- The type of care you would like to receive as you approach the end of your life, including any cultural or religious wishes
- It may include any legal refusal of treatment you may have made in an Advance Decision to Refuse Treatment or through the appointment of Lasting Power of Attorney for personal welfare.
- Your preference of where you would like to die, whether at home, in a care home, in hospital or in a hospice

The register will also have key information about your diagnosis, your condition and the medical treatment you are receiving.

2.3 How will the My Wishes register be used?

The My Wishes register will be used by Health and Social Care professionals who are involved in your care who will be able to view your decisions.

The information is held securely online and can be accessed only by staff responsible for your care, such as your GP, the ambulance service, community nurses, social care and hospice services.

They can access it at any hour of the day or night, so you can be confident that everyone looking after you knows what care you want.

Data from the register may also be used to evaluate the services we offer to ensure that we provide the best possible care and meet patients' needs.

2.4 Who do I talk to about My Wishes register

Your GP, hospice staff or others providing your care will discuss your wishes with you and input the information. They will update it as they discuss your wishes with you during your care.

- You can change it at any time you want just by letting your GP, hospice staff or another health professional looking after you know.
- The information about your care and treatment will be updated by those providing your care.
- You may wish to write your wishes and preferences in an Advance Care Plan. You can discuss this further with your GP or health professional caring for you.
- You can call the Care Navigation Centre on 01233 504133 who will be able to deal with your call at any time day or night.

2.5 What if I don't want to use the My Wishes Register

It's your choice if you want to have your details on the register. If you're not on the register, the people who are caring for you won't know your wishes, which means you may not get the care that you want at the end of your life.

2.6 Can I access the information about me on My Wishes Register

My Wishes itself is not accessible to patients although, when your record is created you can ask for a paper copy of the information held about you.

The healthcare professionals involved in your care may need to update your My Wishes entry periodically to reflect any change in your circumstances. You may request an up-to-date copy of your entry from your GP or any professional who has access to My Wishes register at any time.

2.7 Will my preferences and wishes be met

Your preferences will always be taken into account when planning your care. However, sometimes things can change unexpectedly (like carers becoming over-tired or ill), or resources may not be available to meet a particular need.

2.8 What if I wish to refuse treatment

If you wish to refuse treatment you can discuss this further with your GP or health care professional. An Advance Decision to Refuse Treatment enables someone aged 18 and over, while still capable, to refuse specified medical

treatment for a time in the future when they may lack the capacity to consent to or refuse that treatment.

An advance decision to refuse treatment must be valid and applicable to current circumstances. If it is, it has the same effect as a decision that is made by a person with capacity: healthcare professionals must follow the decision.

2.9 What if I need urgent help or advice about my health

You may wish to contact your GP or if you need any urgent health advice or help, 24 hours a day, seven days a week, you can call the Care Navigation Centre on 01233 504133.

3. Information for health care professionals

3.1 Why should I use My Wishes – East Kent's End of Life Register

My Wishes aims to enable patient choice to improve patients' and carers' experience at a time when there is potential for significant distress.

Multiple care providers are often involved in the patients care at the end of their life and several professionals and organisation's known to the patient. It is really important that information is communicated and shared across geographical and organizational boundaries. This sharing of information about patient's wishes and anticipated problems enables professionals to make appropriate and timely clinical decisions particularly in an urgent or out-of-hours situation.

3.2 When should I use My Wishes – East Kent's End of Life Register

The register is aimed at those patients who are in the last year or phase of their life.

There may be patients who have a prognosis of more than one year who may also like to have their wishes recorded, perhaps due to anticipated loss of communication or mental capacity. These patients may also be appropriate for entering on the My Wishes register.

If a patient is known to different teams such as community, hospital and hospice. My Wishes, is a useful way of ensuring that clinicians in each setting can access up-to-date information.

Patients who have information recorded on the My Wishes register will be able to access the care navigation centre which has been set up to assist patients and their carers with problems and concerns 24hours a day seven days a week. Health professionals can also access this service for specialist palliative care advice and to contact other services. Care navigators will have all relevant information available from the My Wishes register to support patients and health professionals.

3.3 How do I get the most of Wishes – East Kent's End of Life Register

For professionals to access up-to-date information patient information, the clinical record is dependent upon relevant information being entered accurately and in a timely fashion.

The record is comprehensive but there is no expectation that all fields should be completed when the patient initially provides consent. The record will develop as more fields are completed. The timing should be based on the patient's readiness to have the discussions.

Pilgrims Hospice will check the records regularly as part of a governance process and will administer the register. The software provider Adastra will host the register. If you have entered information you may be contacted if there is a query about a patient's record.

3.4 How do I use My Wishes – East Kent's End of Life Register

My Wishes Register is an easy tool allowing you access to information held for end of life care patients relevant to your area of work.

Users will need a secure N3 internet connection as the register is accessed via URL link. A new user form can be downloaded from the link. Once completed a user name and password will be allocated to you and you can start using My Wishes register.

3.5 How does My Wishes become integrated into primary care practice

Following training and the availability of the My Wishes register, it may be useful to review which of your patients are appropriate for the register.

GP practice meetings including GSFs can be a prompt to highlight patients who are appropriate for the inclusion on the My Wishes register. An appropriate clinician will need to have discussions with any patients identified to ensure they consent to the record. Progress can then be reviewed regularly.

A full list of all patients entered on the register can be easily displayed or generated at each practice, which can be used as the basis for multidisciplinary team discussions. Regular caseload review by specialist and community nurses can be an opportunity to review the care records of their patients.

Any new patient can be entered onto the register at any time. These can be identified by the GP or by community staff or local palliative care teams. Information can be entered onto the system after any significant interaction with the patient, such as discussion about preferences and wishes, unstable clinical condition change in medication and hospital discharge.

It is suggested that any patient on My Wishes register be reviewed by their GP every 3 months to ensure that the information is in keeping with the clinical situation.

3.6 How will Health Professionals work with the Care Navigation Centre

The Care Navigation Center will be a resource and service that is available for patients, carers and health professionals to ensure patients and carers get the right care at the right time and are available 24 hours a day, 7 days a week. Any patient who has been entered onto the My Wishes register can access this service and should be given the details of how to access this service.

4. Identification of patients

Identification of patients appropriate for entry onto the My Wishes Register can be undertaken by using a variety of tools that are available these include:

- The Supportive and Palliative Care Indicator Tool (SPICT™) ² Used in collaboration with NHS Scotland and with kind permission by DrKirsty Boyd and Prof Scott Murray. This tool is also used by Coordinate my Care in London.
- GSF prognostic Indicator Guidance

The Supportive and Palliative Care Indicator Tool (SPICT™) aims to identify patients with one or more advanced, progressive illnesses and a limited prognosis to enable more people to benefit from pro-active care and support in the last year of life. Identifying patients with one or more advanced, progressive illnesses is essential if more people are to benefit from pro-active care and support in the last year of life

The SPICT is a clinical tool initially developed following a literature review of key clinical indicators suggesting advanced illness³

The SPICT can be used to identify patients with advanced, progressive, incurable conditions or who are at risk of dying of a sudden acute deterioration who may have unmet supportive or palliative care needs

Patients identified using the SPICT, and their families, should be considered for holistic needs assessment and care planning.

The tool has been evaluated in clinical practice by an NHS Lothian Health Service Research funded project of patients with advanced kidney, lung, cardiac or liver disease following an unplanned hospital admission - this study has been extended to other patient groups and clinical areas. Peer review and collaborative working with partner projects and colleagues from across the UK to help refine the SPICT and evaluate its use in routine clinical practice.

The tool has been revised (July 2012) following data and results from this work.

² Boyd K, Murray SA, Recognizing and managing key transitions in end of life care BMJ 2010;314:c4863

<http://www.palliativecareguidelines.scot.nhs.uk/careplanning/spict.asp>

³ Boyd K, Murray SA, Recognizing and managing key transitions in end of life care BMJ 2010;314:c4863

<http://www.palliativecareguidelines.scot.nhs.uk/careplanning/spict.asp>

Figure 2. Supportive and Palliative Care Indicator Tool (SPICT™) used with kind permission given by Dr Kirsty Boyd and Prof Scot Murray (and Gill Highet, lead researcher)



Supportive and Palliative Care Indicators Tool (SPICT™)



The SPICT™ is a guide to identifying people at risk of dying within the next 12 months.

Look for two or more general indicators of deteriorating health.

- Performance status poor or deteriorating, with limited reversibility. (needs help with personal care, in bed or chair for 50% or more of the day).
- Two or more unplanned hospital admissions in the past 6 months.
- Weight loss (5 - 10%) over the past 3 - 6 months and/or body mass index < 20.
- Persistent, troublesome symptoms despite optimal treatment of any underlying condition(s).
- Lives in a nursing care home or NHS continuing care unit, or needs care to remain at home.
- Patient requests supportive and palliative care, or treatment withdrawal.

Look for any clinical indicators of advanced conditions

Cancer	Heart/ vascular disease	Kidney disease
Functional ability deteriorating due to progressive metastatic cancer.	NYHA Class III/IV heart failure, or extensive coronary artery disease: <ul style="list-style-type: none"> breathlessness or chest pain at rest or on minimal exertion. 	Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.
Too frail for oncology treatment or treatment is for symptom control.	Severe, inoperable peripheral vascular disease.	Kidney failure due to another life limiting condition or its treatment.
		Stopping dialysis.
Dementia/ frailty	Respiratory disease	Liver disease
Unable to dress, walk or eat without help.	Severe chronic obstructive pulmonary disease or severe pulmonary fibrosis <ul style="list-style-type: none"> breathless at rest or on minimal exertion between exacerbations. 	Advanced cirrhosis with one or more complications in past year: <ul style="list-style-type: none"> diuretic resistant ascites hepatic encephalopathy hepatorenal syndrome bacterial peritonitis recurrent variceal bleeds
Eating less; difficulty maintaining nutrition.	Needs long term oxygen therapy.	
Urinary and faecal incontinence.	Has needed ventilation for respiratory failure.	Liver transplant is contraindicated.
Unable to communicate meaningfully; little social interaction.		
Fractured femur; multiple falls.		
Recurrent febrile episodes or infections; aspiration pneumonia.		
Neurological disease	Assess and plan supportive & palliative care	
Progressive deterioration in physical and/or cognitive function despite optimal therapy.	<ul style="list-style-type: none"> 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/ plan with the patient and family. Plan ahead if the patient is at risk of loss of capacity. Handover: care plan, agreed levels of intervention, CPR status. Coordinate care using the GP/ primary care register. 	
Speech problems with increasing difficulty communicating and/or progressive dysphagia.		
Recurrent aspiration pneumonia; breathless or respiratory failure.		

SPICT™, July 2012

5. Communicating Information

Good communication skills are vital in ensuring the needs of people nearing end of life, their families and carers are identified, responded to and met – respectfully and compassionately.

Communications skills training boosts the confidence and competences of staff responsible for helping identify and meet these needs.

There are many tools available; The National End of Life Programme in association with Connected funded 12 pilot sites to explore training need, provision, strategy and sustainability.



These tools can be found by following the following link

<http://www.endoflifecareforadults.nhs.uk/education-and-training/communication-skills/tools>

Tools include:

- Finding the words, communication skills workbook;
- Benchmarking tool;
- Improvement wheel; and
- Tools to support assessment and planning

5.1 Gaining consent from patients for entry onto the My Wishes Register

A critical step in the initiation of My Wishes register is gaining consent from a patient to enter their information. Informed consent requires a patient to be able to understand the information being imparted to them, be able to retain it, use and weigh it up and finally to communicate a decision back. The need to gain consent to share information between healthcare professionals is at the heart of information governance. It will have been a common occurrence for patients during management of their underlying disease. Gaining consent to share information on end of life care (EoLC) should, therefore, not come as a surprise but is likely to be a more sensitive topic for both patient and the healthcare professional conducting the consultation.

The London Pilot suggested some useful phrases to introduce the register

Useful phrases to introduce My Wishes⁴

Leader statement	Follow on statements
Thank you for your time. There is a new communication tool available to us and I would like to explain to you what it is, why it is important and to obtain your consent for its use.	It is called My Wishes. It is a secure electronic record that allows legitimate health and social care providers such as the ambulance services, community nursing and hospitals to be informed and updated about patients' diagnoses, wishes and preferences. It was specifically designed for patients facing a life-limiting illness. Only people who directly care for you will be able to see your details.
	If you should need any emergency medical care in future, My Wishes can help your healthcare team provide the type of care you want. If you change your mind about your wishes and preferences, My Wishes can be updated at any time because it is a communication tool for us to capture these changes in a timely manner.
	May I capture your wishes and preferences of care on this record system?

⁴ Modified from Coordinate my care, A clinical service that coordinates care, giving patients choice and improved quality of life. Training pack. The Royal Marsden. Nov 2011

5.2 Advance Care Planning

Once a patient has given informed consent for their information to be entered onto My Wishes, there are further points that the patient should be made aware of that might be phrased in the following ways:

- If for any reason you were unable to make your own decisions, who would you want to make those for you?
- Where would you most like to be cared for now that the focus is on symptom control? Home, hospice, hospital, care home?

At the first discussion on End of Life Care it may or may not be appropriate to determine preferred place of death but if this is appropriate questions such as

- Have you thought about where you would prefer to die? Home, hospice, hospital, care home?
- Have you discussed with your family where you would prefer to die? Home, hospice, hospital, care home?

If not addressed at initial discussions, it is important to address preferred place of death at a subsequent time. Advance care planning is the process for discussing and planning ahead for when a patients' condition deteriorates so that their wishes can be met. To facilitate this discussion there are several tools available.

The gold standards framework has further information on Advance Care Planning

<http://www.goldstandardsframework.org.uk/AdvanceCarePlanning>

The definition of Advance Care Planning (ACP) is taken from the National End of Life Care Programme (NEoLCP) (2011) Capacity, care planning and advance care planning in life limiting illness – A guide for health and social care

(<http://www.endoflifecareforadults.nhs.uk/publications/pubacpguide>).

Advance care planning is a voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future and, if they wish, set on record: choices about their care and treatment and / or an advance decision to refuse a treatment in specific circumstances, so that these can be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide once their illness progresses.

Under the terms of the Mental Capacity Act 2005 formalised outcomes of the ACP may include one or more of the following:

- Advance statements to inform subsequent best interests decisions
- Advance decisions to refuse treatment (ADTR) which are legally binding if valid and applicable in the circumstances at hand
- Appointment of Lasting Powers of Attorneys (LPA) for health and welfare and/or property and affairs

It all ADSE up

There are several key elements to consider when working alongside the individual and their family. Those elements are captured within the acronym ADSE – ‘its all ADSE up’

A = Ask

D= Document

S= Share

E= Evaluate

Project Invicta aims to support these processes by supporting GPs and health care professionals to ask the right questions, to document the patients wishes and undertake advance care planning and by providing the register to help share the information and to evaluate its success.

ACP is a pivotal part of the care planning process, ensuring that individuals wishes and preferences remains at the heart of care planning and service provision.

Why do it?

We know that most people when asked express a wish to die at home, currently over 50% of deaths take place in acute hospitals and about 25% of all hospital beds are occupied by someone who is in the last year of their life. By implementing ACP within your local area potential outcomes include:

- Improve the experience and quality of care received
- Enable more people to die in the place of their choice
- Deliver a reduction in the number of inappropriate admissions and interventions
- Open and transparent communication that benefits both the individual and those important to them
- Improved care planning and co-ordination of care
- Supports anticipatory care planning

5.3 Preferred Priorities of Care

The Preferred Priorities for Care (PPC) document is designed to help people prepare for the future. It gives them an opportunity to think about, talk about and write down their preferences and priorities for care at the end of life. It is a simple and short tool that may be very useful for patients. The PPC essentially serves three purposes:

- It facilitates discussion/s around end of life care wishes and preferences and from these discussions
- The PPC can enable communication for care planning and decisions across care providers
- Should the person lose capacity to make a decision about issues discussed, a previously completed PPC acts as an advance statement. This means that the information included within the PPC can be used as part of an assessment of a person's best interests when making decisions about their care.

It is available from the National End of Life Care Programme.



<http://www.endoflifecareforadults.nhs.uk/publications/ppcform>

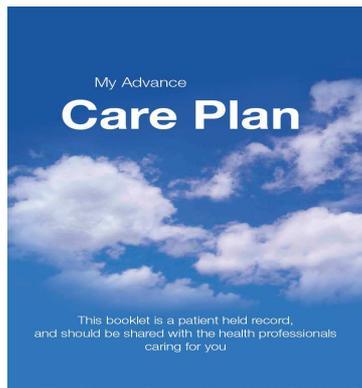
<http://www.endoflifecareforadults.nhs.uk/publications/support-sheet-18-preferred-priorities-for-care>

There is an easy read version available and a support sheet.

Project Invicta had also explored Advance Care Plans used within Kent and there is an advance care plan available on the Pilgrims Hospices website which is used in West Kent.

<http://www.pilgrimshospices.org/wp-content/uploads/My-advance-care-plan.pdf>

This will be modified slightly and available for use in East Kent.



5.3 Advance Decisions to Refuse Treatment

When having discussions with individuals about their wishes and preferences for their care at the end of life - the conversation may include thoughts and wishes around Advance Decisions to Refuse Treatment (ADRT).

For further information

Support sheet 4 – Advance decision to refuse treatment

<http://www.endoflifecareforadults.nhs.uk/publications/rtssupportsheet4>

Advance decision to refuse treatment- A guide for health and social care

<http://www.endoflifecareforadults.nhs.uk/publications/pubadrtguide>

Advance decision to refuse treatment website

<http://www.endoflifecareforadults.nhs.uk/news/all/new-web-address-for-adrt-website>

6. Cardiopulmonary resuscitation (CPR) decisions

CPR is undertaken in an attempt to restore breathing and spontaneous circulation in a patient in cardiac and/or respiratory arrest.⁵

Survival rates after cardio respiratory arrest and CPR are low. There is limited evidence of survival rates for patients approaching the end of life but effective CPR in the community for this population is very unlikely.

The decision as to whether CPR should commence is an important aspect of Advance Care Planning in patients with a limited prognosis.

- The responsibility for making the decision as to whether CPR should commence rests with the most senior clinician currently in charge of the patient's care. In the patient's home this is the GP.
- Decisions about CPR must be made on the basis of an individual assessment of each patient's case and should be agreed by the multidisciplinary team.
- Decisions should be reviewed regularly
- Where there is no advance decision regarding CPR then, in the event of cardiopulmonary arrest, CPR should be initiated and the appropriateness then evaluated.
- To avoid inappropriate CPR, decisions regarding CPR should be made in a timely manner.
- The decision not to commence CPR is known as 'do not attempt resuscitation' decision often abbreviated to DNAR.
- If the MDT believes that CPR will not re-start the heart and maintain breathing, it should not commence. A DNAR decision should be made and documented. This decision is a clinical one. It is not the patient's. The MDT need to then decide if it is in the patient's best interest to know that a DNAR order has been made.
- If the MDT believes there may be a realistic chance of successful CPR, the benefits of prolonged life must be weighed against the potential burdens to the patient. In this circumstance this is not solely a clinical decision and must involve consideration of the patient's known or likely wishes. Where possible, the subject of CPR should be discussed with the patient where possible.
- To make an informed choice regarding CPR, the patient should be sensitively made aware of the likely success and outcomes of CPR in their individual circumstances.
- If the patient lacks capacity, those closest to the patient should be included in discussions to explore what might have been the patient's wishes, feelings, beliefs and values.

⁵ Decisions regarding CPR. A joint statement from the Resuscitation Council (UK), BMA and Royal College of Nursing Oct 2007.

- If after discussion a competent patient refuses CPR, this should be respected.
- All decisions and the discussion surrounding the final decision should be clearly documented on the My Wishes register.

6.1 CPR decision and discussion

Resuscitation is a sensitive topic to discuss, however communication and the provision of information are essential parts of good quality care. It should never be discussed in isolation and, therefore, should form one part of the detailed ongoing discussions with patients and families about end of life issues. It is essential to follow the guidance on communication with terminally ill patients when initiating discussions around CPR to avoid unnecessary patient/family distress.

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION

Adults aged 16 years and over

DNARadult.1(March 2009)

Name _____
Address _____
Date of birth _____
NHS or hospital number _____

Date of DNACPR order:

____ / ____ / ____

DO NOT PHOTOCOPY

In the event of cardiac or respiratory arrest no attempts at cardiopulmonary resuscitation (CPR) will be made. All other appropriate treatment and care will be provided.

1 Does the patient have capacity to make and communicate decisions about CPR? YES / NO
If "YES" go to box 2

If "NO", are you aware of a valid advance decision refusing CPR which is relevant to the current condition? If "YES" go to box 6 YES / NO

If "NO", has the patient appointed a Welfare Attorney to make decisions on their behalf? If "YES" they must be consulted. YES / NO

All other decisions must be made in the patient's best interests and comply with current law. Go to box 2

2 Summary of the main clinical problems and reasons why CPR would be inappropriate, unsuccessful or not in the patient's best interests:

3 Summary of communication with patient (or Welfare Attorney). If this decision has not been discussed with the patient or Welfare Attorney state the reason why:

4 Summary of communication with patient's relatives or friends:

5 Names of members of multidisciplinary team contributing to this decision:

6 Healthcare professional completing this DNAR order:

Name _____ Position _____
Signature _____ Date _____ Time _____

7 Review and endorsement by most senior health professional:

Signature _____ Name _____ Date _____
Review date (if appropriate) _____

Signature _____ Name _____ Date _____
Signature _____ Name _____ Date _____

DNA CPR form

7. Care Navigation Centre

The care navigation centre is hosted by Pilgrims Hospices and is staffed 24 hours a day, 7 days a week. The service is available to any patient or their carers and family who have been added to the My Wishes register. The aim of the service is to ensure that the patient has access to the right service, delivered by the right person at the right time. Care navigators have been trained to navigate care for the patient to ensure that their needs are met. The care navigator will be responsible for ensuring the patient has access to the service they need to support them with their choices. They will have access to the information on the My Wishes register. Please remember that the Care Navigators are not clinicians but have undertaken training to support their role.

This service can also be used by health care professionals who would like to access specialist advice, co-ordinate services for their patient or to arrange hospice admission. For example the ambulance service may call the care navigation centre if they have been called to a patient who is on the end of life register and would discuss with the navigator how best to manage the patient if their wish is to remain at home. The care navigator would assess what other services would be needed to support the patient and prevent the patient being admitted to A&E.

The telephone number for the Care Navigation Centre is 01233 504133.

This number should be given to patients and their carers when they are entered onto the My Wishes register

The Fax number for the Care Navigation Centre is 01233 504108

8. How to use My Wishes Register

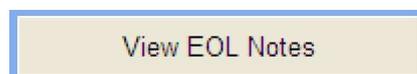
The 'My Wishes Register' has been designed to enable healthcare professionals to record and share information relating to end of life care patients; including details of their carers, next of kin, power of attorney holders, diagnosis, resuscitation preferences and other key information

8.2 How to access My Wishes Register

Access to the My Wishes register - <https://www.mywisheseastkent.org>

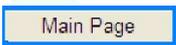
Viewing an EOL register entry

When logging in to the End of Life Care Register select **View EOL Notes**



Carry out a patient search by entering information into the search criteria fields—click **Search**

A blue-bordered form titled "Search Criteria". It contains five input fields with labels: "DOB:", "Forename:", "Surname:", "Postcode:", and "NHS Number:". Each label is followed by a white rectangular input box.

To view more details of an entry click [View](#) to the left of the appropriate entry. After viewing the entry click  button to return to search screen

Editing or Adding to a Register Entry for an Existing Patient

When logging in to the End of Life Care Register select **Edit All EOL Notes**

Carry out a patient search —from the list of returned notes—click **Edit** to the left of the entry—the patient note entry will be displayed

Edit the patient and/or register details as appropriate—click **Update** to save the information

Adding a Register Entry for a New Patient

Carry out a patient search to ensure patient has not previously been added to the Register—click the **Add New Note** button and complete the Search Criteria box—click **Add Patient**

To include any hidden register entries place a tick the **Show Hidden Patients** box

Show hidden patients

A message will be displayed under the search criteria box if no matches have been found. To add a new patient to the database click **Add Patient**

The '**Note Edit**' screen is broken down into six main sections and can be completed in any order:

Patient Demographics **Note Settings**
Contact Details **Note Questions**
Home Address **Notes**

Continue to complete the register — The search will identify if they are already on the register. If the patient is not found, the demographics will have to be completed.

Any field marked with a * is mandatory and **must** be completed

Home Address: use the '**Address Lookup**' field to search for a patient address—enter the postcode and click '**Lookup**' - double click the correct entry



Home Address

Address Lookup:

Note Settings: The review date will automatically set to six months from the current date—this can be changed to a more suitable date if required.

Mark this Note as Hidden:

This will hide the note but the patient can still be found on the register

Completing the End of Life Register

Until the patient consent has been recorded the questions will be disabled. Once clicked the questions will load and will appear in the lower half of the screen.



Has patient given consent for information sharing? Yes

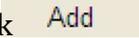
The information is divided into three tabs:



CORE INFORMATION ADVANCE CARE PLANNING CONTACTS

- **Core Information**
- **Advance Care Planning**
- **Contacts**

Continue to answer any questions you know about the patient

To save a new patient entry click 

TIP:

The NHS number and telephone contact numbers **must** be valid—if an incorrect number or incorrect number of digits is entered the system will **not** accept the entry and a warning will be displayed.

Care Navigation Centre - Single Point of Access

This dedicated contact number is available to patients on the register who may need urgent health advice 24 hours a day, 7 days a week. This number aims to improve access to timely and effective integrated services for individuals in their last days of life.

TEL: 01233 504133

FAX: 01233 504108

For more information please contact:

mavis.williams@pilgrimshospices.org - Project Invicta

Project Manager or

Faye.Hames@nhs.net - End of Life Commissioner, East Kent