Appendix 3

Southern Derbyshire Clinical Commissioning Group End of Life Resource Kit

The Action Learning Set and training sessions will guide you in the production of an End of Life Care Resource Kit.

The examples included will support development of End of Life Care in line with the Derbyshire End of Life Care Guidance.

1. After Death Analysis
2. Guidance for developing a Supportive/Palliative Care Register
3. Supportive / Palliative Care Register
4. Guidelines for staff helping patients to complete an advanced statement of wishes
5. Planning for your Future Care (statement of wishes)
6. Best Interest End of Life Care Plan
7. Guidance for Best interest end of life care plan
8. Allowing a natural Death’ DNA CPR Information for relatives
9. Prompts for Palliative Care meeting
10. Significant event analysis
11. RightCare information Derbyshire example
12. Pain assessment tool
13. Liverpool Care Pathway information
14. Derbyshire End of Life Quality Award
15. Information and support for family and other Carers
16. Useful web sites
17. Route to Success for Care Homes (National End of Life Care Programme)
1. **After Death Analysis**

**Please review last 5 deaths**

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<td>Age/ gender</td>
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<td>Date of death</td>
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<td>Diagnosis/ es</td>
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<td>Was an ACP completed?</td>
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<td>Was a RightCare management plan completed?</td>
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<td>Place of death</td>
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<tr>
<td>Preferred place of death [when recorded]</td>
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<tr>
<td>If not in preferred place of death . Why?</td>
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<td>If died in hospital. Length of stay</td>
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<td>Number of crisis admissions in last 6 months of life</td>
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<td>Was LCP/ End of Life Care Pathway used?</td>
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<td>If not why?</td>
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<tr>
<td>Bereavement support given to family</td>
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2. Guidance for Developing a Supportive / Palliative Care Register in Care Homes

Why a Supportive Care Register?

A Supportive Care Register identifies residents thought to be approaching the end of life.

A code is then applied according to where we think they may be in the end of life journey.

The benefits:

- As a prompt to explore resident’s wishes and preferences e.g. Advance Care Plan, Best Interest End of Life Care Plan,

- A focus for monthly palliative care meetings, which give time for staff to explore holistic care planning i.e. looking at physical, emotional, social and spiritual needs.

- Encourages staff to think ahead e.g. requesting out of hours plans, anticipatory drugs

- Encourages staff to review how they are achieving residents preferred place of care and whether they felt the resident had a “good death”.

How to set up your Register

- See an example register Appendix 2— Care Homes have found having 1 resident per page easier.

- Discuss what you are planning to do with your GPs. Many practices use the Gold Standards Framework and have a Supportive Care Register for patients in their practice,

- Discuss with GPs which residents are on their Supportive / Palliative Care register, some GPs may be happy for you to attend their Palliative Care Meeting when they discuss your residents.

Adapted from the Pan Birmingham Palliative Care Network Guidance and “A quick guide to identifying patients for supportive and palliative care” by Dr P McDaid
Discuss which residents should be included on the Supportive Care Register with all the staff and visiting health professionals eg Respiratory Nurses, Macmillan Nurses where relevant.

Use information in Appendix 1 to help you decide who to include on the register.

Start with a small number of residents e.g. 3-5

Code the residents using either the colour code or letter code as below

**Health Warning:** Coding residents is not an exact science. Residents tend to have multiple health problems and their recovery from illnesses can be unpredictable.

**Colour Code**
- **Red** – Days / week
- **Amber** – Requiring active symptom management [physical / emotional / social / spiritual]
- **Green** – identified as end of life, as far as possible to assess in the last year of life

**Letter Code**
- **A** – Days / week
- **B** – Requiring active symptom control
- **C** – Identified as end of life

**Family Aware**
This column is to say the family are aware that the resident is thought to be at end of life, and staff are using the Gold Standards Framework approach to plan the best possible care of the resident working with the GP and other health professionals as needed.

**Health Warning:** Remember you can only share information with families if the resident gives permission, or has given permission.

**Reviewing the Register**

**Update Register**
As each resident’s condition changes, you need to build in a regular review of the Supportive/Palliative Care Register, at least 1 monthly, this can be done during your Palliative Care Meeting. At that point you can update your register.

**Achieving Residents Preferred Place of Care**

Adapted from the Pan Birmingham Palliative Care Network Guidance and “A quick guide to identifying patients for supportive and palliative care” by Dr P McDaid
The Palliative Care meeting is also a good opportunity to review how patients have died, using the significant events analysis. Part of this review will be seeing whether they died in their preferred place of care, and if not then why not?

This is not about blame but using the reflection to develop the service. Hopefully in the vast majority of cases it will be positive and rewarding experience for staff.

## Share Information / Storage of Information

When considering where to store the Supportive/ Palliative Care Register It is important to ensure that all care staff have easy access to it, so they are up to date with changes made.

### Appendix 1

The following triggers, provide some guidance to assist in making predictions of life expectancy. They are derived from a number of sources to assist in compiling your Supportive Care Register:

<table>
<thead>
<tr>
<th>General Triggers</th>
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<tbody>
<tr>
<td><strong>Surprise questions</strong></td>
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<td></td>
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<tr>
<td><strong>Choice</strong></td>
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<tr>
<td><strong>Need</strong></td>
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</table>

<table>
<thead>
<tr>
<th>General decline –symptoms with low level activity</th>
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<td><strong>General</strong></td>
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### Condition:

<table>
<thead>
<tr>
<th>Clinical indicators of disease severity</th>
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</table>

Adapted from the Pan Birmingham Palliative Care Network Guidance and “A quick guide to identifying patients for supportive and palliative care” by Dr P McDaid
| Dementia | Unable to walk without assistance **and**  
|         | Urinary and faecal incontinence **and**  
|         | No consistently meaningful verbal communication **and**  
|         | Unable to dress without assistance  
| Plus any of: | 10% weight loss in previous 6 months without other cause  
|         | Urinary Tract infection  
|         | Severe pressure sores – grade 3 or 4  
|         | Recurrent fevers  
|         | Reduced oral intake despite all efforts of staff /weight loss  
|         | Aspiration pneumonia  
| Stroke | Minimal consciousness state/dense paralysis/incontinence  
|         | Medical complications  
|         | Lack of improvement within 3 months of stroke  
|         | Cognitive impairment/post stroke dementia  

Adapted from the Pan Birmingham Palliative Care Network Guidance and “A quick guide to identifying patients for supportive and palliative care” by Dr P McDaid
### 3. Supportive /Palliative Care Register

<table>
<thead>
<tr>
<th>Date started:</th>
<th>Name of Resident</th>
<th>GP</th>
<th>Resident summary</th>
<th>Post death notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Review date</td>
<td>Diagnosis</td>
<td>Code</td>
<td>Advance care plan in place?</td>
<td>Preferred place of care stated?</td>
</tr>
</tbody>
</table>

**Key:**

- **A** = Days/week to live,
- **B** = requiring active symptom management, for physical, emotional, social or spiritual issues
- **C** = identified as end of life

Adapted from the Gold Standards Framework   April 2012
Guidelines for staff helping patients to complete an advanced statement of wishes

- This document is an Advance statement of wishes and is part of the advance care planning (ACP) process. The ACP process may also include advance decisions, advance decisions to refuse treatments (ADRT), ‘Do not attempt resuscitation’ (DNAR) orders and Lasting Power of Attorney (LPA) orders (these should be documented on separate forms).

- This advance statement is concerned with patients own wishes and preferences.

- Patients are to be offered the choice as to whether they want to complete the document and take part in the discussions, some may not to do this and this should be respected.

- It is best completed by the patient but can be recorded by family members or staff using the patients own words if the patients is unable to write.

- If appropriate, family or people close to the patient should be encouraged to engage in the process, thereby acknowledging and respecting the patients wishes should the need arise, hopefully avoiding any disagreements regarding care that can occur. Patients consent must be obtained before any confidential information is shared or discussion held with other people.

- It is essential that sufficient time is allowed for completing and reviewing the form.

- Always explain that, whilst every effort will be made, preferences and wishes cannot always be guaranteed as circumstances change and resources may not be available

- It is anticipated that the content of the form is shared with health and social care staff to enable future care provision offering individuals choice, therefore, permission should be sought to allow the sharing of the information, whilst maintaining confidentiality

- Discussion regarding DNAR, AD & ADRT should be addressed sensitively and the necessary documents completed in line with current policy.

- Advance statements should be introduced as early as possible for patients on the supportive care register and those with long term conditions.

- The document is to be kept with the patient who should be encouraged to take it with them if the place of care changes
This document is for you to help you think about your wishes or preferences for your care

It will help you plan and express your wishes to those providing that care

It will also give your doctors, nurses and social carers information so that they can try to deliver that care

This document does not constitute an Advanced Decision to Refuse Treatment (ADRT), a Do Not Attempt Resuscitation (DNAR) or a Lasting Power of Attorney (LPA) Order. Whilst you can use this document to express your wishes in respect to these things there are separate forms to complete if you wish to make a ADRT, DNAR or LPA order.

You can discuss with your family and friends, if you wish, what things are important to you. This might include whether you want to be admitted to hospital or if you prefer to receive as much care as possible at home

These wishes can be discussed with your doctor, nurse etc and options explored, if your condition or views were to change

It will enable you to have more choice in how you want to be treated, giving you the opportunity to ask questions and discuss things that are important to you

Please note you are encouraged to review this document regularly and if necessary change or withdraw your views or statements. Any changes should be recorded on this form and discussed with your Doctor, healthcare professional and family. The information in this document is to help ensure you receive the right care but circumstances can change unexpectedly potentially requiring alternative options to be considered and discussed with you
This document is my advance statement where I have recorded my preferences for the type of care I would like to receive to help maintain the best quality of my life. This includes what things are important to me and where I would like to receive that care.

Please note this plan supports other aspects of my care and along with other documents forms my overall advance care plan.

| My NAME: | _______________________________________________________________ |
| ADDRESS: | ______________________________________________________________|
| D.O.B | ______________________________________________________________|
| Name of my G.P. | ____________________________________________________________ |

**My Key Contact**

(This could be a family member or friend who has been involved with this plan and can be contacted about future discussions)

| Their NAME: | ____________________________________________________________ |
| Their Relationship to me (ie partner, son / daughter/ Lasting Power of Attorney): | ____________________________________________________________ |

The person / healthcare professional who assisted me in completing this plan (if applicable).

| Their NAME: | ____________________________________________________________ |
| Their relationship to me: | ____________________________________________________________ |
| Their Contact Details | ____________________________________________________________ |
The person / healthcare professional who assisted me in completing this plan (if applicable).

**Their NAME**: __________________________________________________________

**Their relationship to me**: ________________________________________________

---

**My illness or current condition is**: _______________________________________

__________________________________________________________________________

These are the things that are important to me regarding how I want to be cared for:

---

I understand whilst it may not always be possible to make arrangements to meet my preferences, when the time comes, the place I would like to die is:

---

These are my concerns and fears:

---

The following are what I would **not** want to happen to me:

---

**Advance Decisions to Refuse Treatment**: 

I understand that I can refuse specific, even life sustaining, treatments, in the future. This will be only relevant if I cannot make the decision for myself then and will be in anticipation of my circumstances. I am aware I can discuss this with my doctor or healthcare professional.

I have described below how any advance decision to refuse treatment can be found (e.g. a copy attached to this document or who to contact).

---

By signing this form any information which I have given can be used with my consent to help to plan and deliver my care. It can only be shared with people / professionals relevant to my care. It can not be used for any other reason without permission. I have the right to change my mind at any stage.
My Signature __________________________________________________________

Date completed: ______________________________________________________

Review Dates: ________________________________________________________

_______________________________________________________________

Below is a list of people / services that have been told about my plan:

_______________________________________________________________

_______________________________________________________________

_______________________________________________________________
6. **Best Interests End of Life Care Plan**

For residents in Derbyshire Care Homes who have been assessed as lacking mental capacity to make these decisions at this time.

- Family, and those involved in the care of the resident need to meet and discuss together what they think the resident would have wished or preferred.
- Plan for what may happen, all the “what ifs”, even though we hope for the best.
- Ask the family to bring any related documents e.g. Lasting Power of Attorney or Advance Decision to Refuse Treatment / Living Will/ Advance Directive.

<table>
<thead>
<tr>
<th>Name of Resident</th>
<th>Date of Birth</th>
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</thead>
<tbody>
<tr>
<td>Name of Care Home</td>
<td>NHS Number</td>
</tr>
</tbody>
</table>

### Reason for making a Best Interest Decision

An Advance Care Plan [ACP] gives people an opportunity to discuss their wishes and preferences before they lose the ability through illness to express their ideas.

However despite every effort being made to optimise ability to make a decision around his / her future care he / she has been assessed as unable to make this decision and this is considered to be a permanent impairment.

Date of Mental Capacity Assessment [MCA]?

Who completed the MCA?

### Who was involved in making the plan?

Name & role

### Has the resident appointed a Lasting Power of Attorney [LPoA] for Health and welfare?

Yes / No

**If Yes**
- Name & contact details of LPoA
- Ask to take a copy of document

### Does the resident have an Advanced Directive /Living will or Advanced Decision to Refuse Treatment

- Where is it stored?
- What does it cover?
- Ask to take a copy of document

### These are the things that we think the resident would say are important to how they are cared for.
These are the things that we think the resident would be worried about happening. Discuss any interventions that may be needed.

Has the resident expressed any views about allowing a natural death?

Use information sheet to discuss whether it is in resident’s best interest to be resuscitated if heart and/or breathing stops

Please ring whether the relatives think it would be best for the resident to:

Allow a Natural Death

Or

Attempt Cardio Pulmonary Resuscitation

This will need to be agreed by the GP & documented in resident’s record

Preferred place of care.

Preferred place of death

Any particular religious or spiritual arrangements they may have wanted

Names and signatures of those people involved in best interest discussion

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<thead>
<tr>
<th>Name</th>
<th>Signature</th>
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</table>

Check list of people who need to be aware of End of Life care plan.

<table>
<thead>
<tr>
<th>Person/Organisation</th>
<th>Date Informed</th>
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</thead>
<tbody>
<tr>
<td>Family Members</td>
<td></td>
</tr>
<tr>
<td>GP</td>
<td></td>
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<tr>
<td>EMAS</td>
<td></td>
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<tr>
<td>Out of Hours</td>
<td></td>
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<tr>
<td>Social Services</td>
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</tbody>
</table>

Date Plan to be reviewed.

Date reviewed

Date Plan to be reviewed.

Date reviewed
7. Guidance for Use of Best Interest End of Life Care Plan

- This form can be completed by any Registered Nurse, who has attended Mental Capacity Act training and has the necessary communication and end of life skills. [please contact numbers below if you feel you need more support or training]

- Only use the Best Interest End of Life Care Plan if a mental capacity assessment has recognised that the resident has been assessed as lacking capacity to decide how they would like to be cared for at the end of their life. The Mental Capacity Assessment should be documented (example form is below).

- If the resident is able to understand the issues and express their wishes they should be supported to use “My Future Care” or whatever Advance Care Plan document you use in your Care Home. If you assess the resident as lacking mental capacity to complete My Future Care and believe this is not a temporary situation e.g. a urinary tract then the Best Interests End of Life Care Plan should be used.

- It is best practice to get close family, and those involved in the care of the resident to meet and discuss together what they think the resident would have wished or preferred.

- This may not always be practical so you may need to talk to different people at different times. You may be able to use a care review to include the assessment nurse and care manager and family together.

- It is important that family understand that the decision will be made in the best interest of the resident and many factors will be taken into account including their views of what the resident would have wished and the residents health at the time the decision is being made.

- When asking about Lasting Power of Attorney make sure it is for Health and Welfare. Some people will have Lasting Power of Attorney for finance and others will have an Enduring Power of Attorney neither of these are relevant to these decisions.

- Before having a discussion with resident’s family think about the possible interventions the resident may need given their condition eg PEG, IV antibiotics, ensure you can discuss the benefits and burdens of any likely interventions.

- It is good practice to give the relatives an information sheet about Allowing a Natural Death/DNAR.

If you would like more support using this form please contact:

Jane Carr, End of Life Programme Facilitator
07795 617305

Kathy Gorman, Assistant Head of Clinical Quality, Southern Derbyshire CCG
07900 820735 or 01332 868738
Mental Capacity Assessment

Start by assuming that the patient has capacity if there is doubt, proceed to the two stage test of capacity Always do your best to optimise the person’s functioning eg pick their best time of day, reduce distractions.

The result of each step of the assessment should be documented, ideally by quoting the person.

<table>
<thead>
<tr>
<th>Name of Resident</th>
<th>Date of birth</th>
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<tbody>
<tr>
<td>Name of Nursing Home</td>
<td>NHS Number</td>
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</tbody>
</table>

**Stage 1**

Does the person have an impairment of, or disturbance in the functioning of their mind or brain?

Is it permanent or temporary?

*If there is a permanent impairment continue with Stage 2*

*If temporary wait till condition improves*

**Stage 2**

Can he / she understand the relevant information needed to make the decision?

Can he/she retain information long enough to make a decision?

Can he / she weigh up the information in order to make a decision?

Can he / she communicate their decision [this could be non verbal]?

If the answer to any of the questions in section 2 is “no” the person does not have capacity.

If you are not sure seek advice from a more experienced assessor.

Does the person have capacity to make an Advance Care plan which include specific decision re health care needs e.g cardiopulmonary resuscitation, insertion of a PEG or Intravenous therapy.

<table>
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<tr>
<th>Name of Assessor</th>
<th>Date &amp; Time</th>
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ALLOWING A NATURAL DEATH

Relatives and Carers Information Leaflet

This leaflet is to help you discuss with the Care Home staff or GP the Best Interest End of Life care decisions.

What is resuscitation, or CPR?

Cardiopulmonary arrest means that a person’s heart and breathing stop. When this happens, it is sometimes possible to try and restart the heart and breathing with emergency treatment called CPR (this stands for cardiopulmonary resuscitation. “Cardio” relates to the heart, “pulmonary” relates to the lungs. CPR might include:

- Repeatedly pushing down very firmly on the chest
- Mouth to mouth’ breathing
- Using “electric shocks” to try and restart the heart
- Inflating the lungs through a mask over the nose and mouth or tube inserted into the windpipe.

Is CPR tried on everybody whose heart and breathing stop?

When the heart and breathing stop unexpectedly, for example, if a person has a serious injury or heart attack, the healthcare team will try CPR if it might help. A person’s heart and breathing also stop working as part of the natural and expected process of dying. If people are already very seriously ill and near the end of their life, there may be no benefit in trying to revive them each time their heart and breathing stop. This is particularly true when patients have other things wrong with them that mean they don’t have much longer to live. In these cases, restarting the heart and breathing may do more harm than good by prolonging the pain or suffering of someone who is soon to die naturally.

Do people get back to normal after CPR?

Unfortunately, most attempts at CPR do not restart the heart and breathing despite the best efforts of everyone concerned. The chance of CPR reviving your relative will depend on:

- Why the heart and breathing stopped
- Any illness or medical problems you relative has (or has had in the past)
- The overall condition of your relative’s health.
- How quickly the heart and breathing can be restarted

Attempted CPR is successful in restarting the heart and breathing in about 4 out of 10 patients. On average, 2 out of 10 patients survive long enough to leave hospital. The figures are much lower for patients with serious underlying conditions, such as cancer or heart disease. They are also much lower for patients who suffer the cardiopulmonary arrest outside the hospital. It is important to remember that these only give a general picture and not a definite picture of what can be expected.

Patients who are revived are often still very unwell and need more treatment, usually in a coronary care or intensive care unit. Some patients never get back the physical or mental health they enjoyed before the cardiopulmonary arrest. Some have brain damage or go into a coma. Patients with many medical problems are less likely to make a full recovery. The techniques used to restart the heart and breathing sometimes cause side effects, for example, bruising, fractured ribs and punctured lungs.
Who will decide about CPR?

Your relative’s GP will decide whether the CPR should be attempted if he / she has a cardiopulmonary arrest. The GP and care team looking after your relative will look at:

- All the medical issues weighing up the benefits and burdens of CPR
- The resident’s own wishes if known, e.g. any Advance Care Plan
- If the resident has appointed a Lasting power of attorney for health and welfare they will be involved in the discussion
- What you think.

However, if it is felt that resuscitation will not be successful then it will not be offered.

If it is decided that CPR won’t be attempted, what then?

The care home staff will continue to give your relative the best possible care. The doctor in charge of his / her care will make sure that you, the care home staff, and other friends and family that you want involved in the decision, know and understand the decision not to offer CPR. There will be a note in your relative’s health records that she / he is ‘not for cardiopulmonary resuscitation’. This is sometimes called a ‘do-not-attempt-resuscitation’ or DNAR decision.

A DNAR order is about CPR only and your relative will still receive necessary treatment. It is very important to understand that a DNAR order does not mean that treatment stops or is withdrawn. The doctor looking after him / her will actively treat symptoms in order to ensure that he /she remains comfortable.

This is based on the information about resuscitation taken from the British Medical Association website (www.bma.org.uk)
9. **Prompts for Palliative Care meeting**

Update your Supportive Care Register as you go through the meeting.

Make brief meeting notes – example given in pack.

Remember to update patients’ records and care plans if needed at end of meeting.

**Review residents on Supportive Care Register – think:**

- Physical – pain, nausea etc
- Emotional – understanding and reaction to condition, any fears
- Social – family friends, including their needs
- Spiritual – what's important to them? What helps them cope? Eg faith, music, family
- Communication – with resident, family, staff, wider MDT

**Do any residents need to be added to the Register?**

- Residents whose health is deteriorating
- New residents

**Review of deaths**

- If they were NOT on the register, think - why not?
- If LCP /TCP not used think – why not?
- On register identify learning points and bereavement care issues & record place of death [use Significant Event Analysis if need more space]

**Significant Events**

Anything not already covered eg emergency transfer to hospital, difficulty with symptom control.

Use the SEA sheet to identify learning / action points & most importantly to give positive feedback to staff when they have done well.

**Any other business**

Education or communication issues eg update on available services, use of syringe drivers, audits

**Date and time of next meeting**

Make sure it is clear who will follow up any action points between meetings.
<table>
<thead>
<tr>
<th>Significant event Analysis</th>
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<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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</thead>
<tbody>
<tr>
<td><strong>What went well?</strong></td>
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<td><strong>What didn’t go so well?</strong></td>
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<tr>
<td><strong>What could have been done better?</strong></td>
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</tbody>
</table>
RightCare® Management Plan

PLEASE BE AWARE RIGHTCARE PLANS WILL ONLY BE ACCEPTED WHEN ALL FIELDS ARE POPULATED. THANK YOU.

<table>
<thead>
<tr>
<th>Patient Details</th>
<th>Surname:</th>
<th>First Name:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender:</td>
<td>Ethnicity:</td>
<td>DOB:</td>
</tr>
<tr>
<td>Address:</td>
<td>Postcode:</td>
<td>Tel No:</td>
</tr>
<tr>
<td>NHS No:</td>
<td>Patient's GP:</td>
<td>Patient's Surgery:</td>
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<tr>
<td>Diagnosis:</td>
<td>Known Allergies:</td>
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Current Medication (Correct at time of plan)

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<thead>
<tr>
<th>Anticipatory drugs are supplied: YES/NO</th>
<th>Family Contact:</th>
<th>Tel No:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant:</td>
<td>Hospital:</td>
<td>Tel No:</td>
</tr>
<tr>
<td>Social Services input:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Care Plan (If your patient contacts us out of hours, you would like us to ……..)

<table>
<thead>
<tr>
<th>Patient aware of diagnosis: YES/NO</th>
<th>Patient agreed to and aware of plan: YES/NO</th>
<th>Carers aware of the plan: YES/NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consent to share with DHU and other health and social care services: YES/NO</td>
<td>If consent not given please state reason:</td>
<td></td>
</tr>
<tr>
<td>Patient on Gold Standard Framework Register: YES/NO</td>
<td>On Terminal Care Pathway: YES/NO</td>
<td>Preferred place of death?</td>
</tr>
</tbody>
</table>

EMAS require their own End of Life Decision Forms

Review Date (MUST BE SPECIFIED – MAX 6 MONTHS)

Form completed by:

<table>
<thead>
<tr>
<th>Address:</th>
<th>Position:</th>
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</table>

<table>
<thead>
<tr>
<th>Date:</th>
<th>Contact Tel No:</th>
<th>Return Email Address:</th>
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</table>

On completion of the form please email to rightcare.referrals@nhs.net

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12. Pain Assessment Chart

Name
DOB
NHS Number

<table>
<thead>
<tr>
<th>Date &amp; Time</th>
<th>1-10 Scale</th>
<th>Comments</th>
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</thead>
<tbody>
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</tbody>
</table>
The doctors and nurses will have explained to you that there has been a change in your relative or friend’s condition. They believe that the person you care about is now dying and in the last hours or days of life.

The LCP is a document which supports the doctors and nurses to give the best quality of care. All care will be reviewed regularly.

You and your relative or friend will be involved in the discussion regarding the plan of care with the aim that you fully understand the reasons why decisions are being made. If your relative or friend’s condition improves then the plan of care will be reviewed and changed. All decisions will be reviewed regularly. If after a discussion with the doctors and nurses you do not agree with any decisions you may want to ask for a second opinion.

Communication

There are information leaflets available for you as it is sometimes difficult to remember everything at this sad and challenging time. The doctors and nurses will ask you for your contact details, as keeping you updated is a priority.

Medication

Medicine that is not helpful at this time may be stopped and new medicines prescribed. Medicines for symptom control will only be given when needed, at the right time and just enough and no more than is needed to help the symptom.

Comfort

The doctors and nurses will not want to interrupt your time with your relative or friend. They will make sure that as far as possible any needs at this time are met. Please let them know if you feel those needs are not being met, for whatever reason.

You can support care in important ways such as spending time together, sharing memories and news of family and friends.
Information sheet to be given to the relative or carer continued:

Reduced need for food and drink

Loss of interest in and a reduced need for food and drink is part of the normal dying process. When a person stops eating & drinking it can be hard to accept even when we know they are dying. Your relative or friend will be supported to eat and drink for as long as possible. If they cannot take fluids by mouth, fluids given by a drip may be considered.

Fluids given by a drip will only be used where it is helpful and not harmful. This decision will be explained to your relative or friend if possible and to you.

Good mouth care is very important at this time. The nurses will explain to you how mouth care is given and may ask if you would like to help them give this care.

Caring well for your relative or friend is important to us. Please speak to the doctors or nurses if there are any questions that occur to you, no matter how insignificant you think they may be or how busy the staff may seem. This may all be very unfamiliar to you and we are here to explain, support and care.

We can be reached during daytimes at: .................................................................

Night time at: .................................................................................................................................

Other information or contact numbers (e.g. palliative care nurse / district nurse):

............................................................................................................................................................
............................................................................................................................................................
............................................................................................................................................................
............................................................................................................................................................
............................................................................................................................................................
............................................................................................................................................................

This space can be used for you to list any questions you may want to ask the doctors and nurses:

............................................................................................................................................................
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14. What is the Derbyshire End of Life Quality Award?

The National Gold Standards Framework [GSF] was set up in 2003 in response to the NHS Cancer Plan 2000: “The care of the dying must be raised to the level of the best”. Although the GSF was originally developed for Primary Care the national team adapted it for use in Care Homes. However, there was a cost involved for care homes who wanted to take part in the GSF Programme. Therefore locally we have developed our own programme which is free:

**Derbyshire End of Life Quality Award**

Like the GSF our local programme focuses on “living well till you die” and “hoping for the best but preparing for the worst”. The programme helps you to develop a proactive approach to end of life care with support from the local Primary Care Trust team. We will help you implement the Derbyshire End of Life Guidance.

The local facilitator, Kathy Gorman, will help you to develop systems to:

- **Identify** residents thought to be in the last year of life working with GPs and specialist nurses, as appropriate
- **Assess** those residents needs using a systematic approach
- **Plan** care involving residents and family, including offering Advance Care Planning
- **Communicate** at a high standard throughout resident’s journey
- **Coordinate** care working with GPs & other healthcare services as appropriate

Homes that fully implement this system can gain the Derbyshire End of Life Quality Award. The criteria for gaining this Award are attached. Most Homes will take at least a year to achieve this Award.

**Support available:**

- An End of Life Care folder that has a range of information to support you to gain this Award
- Places on the Foundations in Palliative Care course
- Participation in the Action learning set
- At least 1 visit to the Home to support progress with work toward the Award.

**Derbyshire End of Life Quality Award Competencies**

<table>
<thead>
<tr>
<th>After Death Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline and following implementation</td>
</tr>
<tr>
<td>Evidence of use of findings</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>All Staff Aware of Derbyshire End of Life Guidelines</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discuss with a range of staff including non-clinical staff</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Partnership working with GPs/District Nurses / Community Matrons /Macmillan Nurses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discuss with GP or Macmillan Nurse how are they working with Home.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Clinical Staff understand their End of Life Care role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discuss with Manager, deputy and Senior Care assistants, cover each part of process.</td>
</tr>
<tr>
<td>Discuss Symptom Control, pain assessment tools, holistic approach &amp; use of anticipatory drugs</td>
</tr>
</tbody>
</table>

| Information to Families |
| **Supportive Care Register** | 
| Check Register  up to date |
| **Advance Care Planning /Best Interest** | 
| See examples of ACP, discuss process |
| Expect documentation of discussion or attempted discussion for all residents in Home for 1 month or longer |
| **DNACPR Form** | 
| What is the process of discussing DNAR with resident, relatives & GP |
| **RightCare** | 
| As above + have they been used and what has the outcome been? |
| **Monthly Meetings in Home** | 
| See record of meeting[every 8 weeks minimum] |
| **Significant Event Analysis** | 
| Evidence of use and follow up of issues eg link to training or praise for staff. |
| **Use of End of Life Pathway** | 
| Out of last 5 deaths in Home how often used? |
| **Palliative Care Education*** | 
| Minimum of 4 Staff [including 2 senior staff] in last 2 years + rolling programme |
| **Bereavement Care** | 
| Relatives; Residents; Staff |
| How is care provided for each of these groups? |
| For staff are they using PC meetings etc? |
| **Sustainability** | 
| Evidence the Home has been working on the Derbyshire End of Life Guidelines Approach for at least 9 months. |
| Evidence that even if the EoL champions were to leave the Approach would continue. |

*Palliative Care Education – acceptable courses : Foundations in Palliative Care; Distance learning; 2,3 or 4 day End of Life Course based in Hospice; university based course eg OU Death and dying Course

For more information about this award contact Kathy Gorman Assistant Head of clinical quality southern Derbyshire CCG Kathy.gorman@nhs.net

If you would like to find out more information about National Gold Standards Framework Programme please contact the National GSF Centre Tel: 01743 291895 or email carehomes@gsfcentre.co.uk
15.

End of Life Care information and support for people with dementia and their relatives and carers in Derby

Local support services

- Making Space Derby City Dementia Support Service and Dementia Cafes
  [www.makingspace.co.uk/DerbyCity.htm](http://www.makingspace.co.uk/DerbyCity.htm)  01332 623700
- Derbyshire Carers Association
  [www.derbyshirecarers.co.uk](http://www.derbyshirecarers.co.uk)  01332 200002
- Age UK Derby and Derbyshire [www.ageuk.org.uk/derbyandderbyshire](http://www.ageuk.org.uk/derbyandderbyshire)  Tel. 01332 343232

Your care home, GP, District Nurse or Social Services Care Manager are also there for you to speak to.

Leaflets books and guides

The following organisations offer leaflets:

- Age UK Derby and Derbyshire  01332 343232
- Dementia UK use the link above or call 0845 257 9406
- The Alzheimer’s Society use the link above or call 0300 222 1122

Your care home, GP, local library, social services care manager or dementia support worker can provide you with or tell you were to find information leaflets.

The following books are available from the National Council for Palliative Care

‘Exploring Palliative Care for people with Dementia’

‘Difficult Conversations for Dementia’

‘Dying to know: Bringing death to life’

Your library will have or can source books for you. Derby City Library Service
[www.derby.gov.uk/leisure-and-culture/libraries](http://www.derby.gov.uk/leisure-and-culture/libraries)  Tel. 01332 641702
The Internet

Examples of websites to visit for information about end of life care and dementia:

- Dementia UK  www.dementiauk.org
- Alzheimer’s Society  www.alzheimers.org.uk
- Making Space  www.makingspace.co.uk
- National Council for Palliative Care  www.ncpc.org.uk
- Carers Direct information on carers and end of life  www.nhs.uk/CarersDirect/guide/bereavement/Pages/Overview.aspx
- Dying Matters  www.dyingmatters.org

You can access the internet free of charge at your local library.

Advance planning for end of Life Care

These organisations will help you to plan ahead

- Age UK Derby and Derbyshire  Age UK Life Book and advocacy
- Dying matters  Web and leaflet based information including a Face Book based interactive tool ‘5 things to do before you die’
- Dementia UK  Admiral nurses

All contact details above

Support after bereavement

- ‘What to do after a death’ web and leaflet based information from the government  www.direct.gov.uk/en/Governmentcitizensandrights/Death/WhatToDoAfterADEath/DG_10029667
- Cruse Bereavement Care  www.crusebereavementcare.org.uk  01332 332098
### Useful Web Sites

<table>
<thead>
<tr>
<th>Website</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><a href="http://www.endoflifecare.nhs.uk">www.endoflifecare.nhs.uk</a></td>
<td>The National End of Life Care Programme, it will provide you with a wealth of information and resources. This source may be removed or relocated during summer 2013.</td>
</tr>
<tr>
<td><a href="http://www.mcpcil.org.uk/liverpool_care_pathway">www.mcpcil.org.uk/liverpool_care_pathway</a></td>
<td>This is the main site for information around the Liverpool Care Pathway.</td>
</tr>
<tr>
<td><a href="http://www.dyingmatters.org">www.dyingmatters.org</a></td>
<td>Posters and information available to encourage people to discuss death and dying.</td>
</tr>
<tr>
<td><a href="http://www.goldstandardsframework.co.uk">www.goldstandardsframework.co.uk</a></td>
<td>The main site for the Gold Standards Framework,</td>
</tr>
<tr>
<td><a href="http://www.adrtnhs.co.uk">www.adrtnhs.co.uk</a></td>
<td>Advanced Decision to Refuse Treatment is an educational website, there are various teaching sessions you can work through.</td>
</tr>
<tr>
<td><a href="http://www.macmillan.org.uk">www.macmillan.org.uk</a></td>
<td>Macmillan Cancer Support website provides a range of information to support residents with cancer.</td>
</tr>
<tr>
<td><a href="http://www.be.macmillan.org.uk">www.be.macmillan.org.uk</a></td>
<td>Provides a range of resources for professionals, including an out of hours toolkit.</td>
</tr>
<tr>
<td><a href="http://www.cancernursing.org">www.cancernursing.org</a></td>
<td>An educational website has a range of teaching modules.</td>
</tr>
<tr>
<td><a href="http://www.alzheimers.org.uk">www.alzheimers.org.uk</a></td>
<td>Provides information on dementia, there are also a whole range of fact sheets you can download.</td>
</tr>
<tr>
<td><a href="http://www.crusebereavementcare.org.uk">www.crusebereavementcare.org.uk</a></td>
<td>The website for Cruse provides a range of information about bereavement. You can also download a bereavement booklet produced jointly with Help the Aged for older people.</td>
</tr>
<tr>
<td><a href="http://www.pallcare.info">www.pallcare.info</a></td>
<td>Palliative Care Matters is a website intended for health-care professionals working in palliative care or related fields.</td>
</tr>
</tbody>
</table>

17. Route to Success for Care Homes (National End of Life Care Programme) click on icon below to access.