

# Nottinghamshire County LINK



## End of Life Care in Broxtowe Improving Choices in Care



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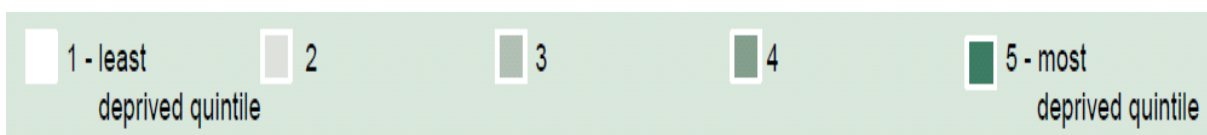
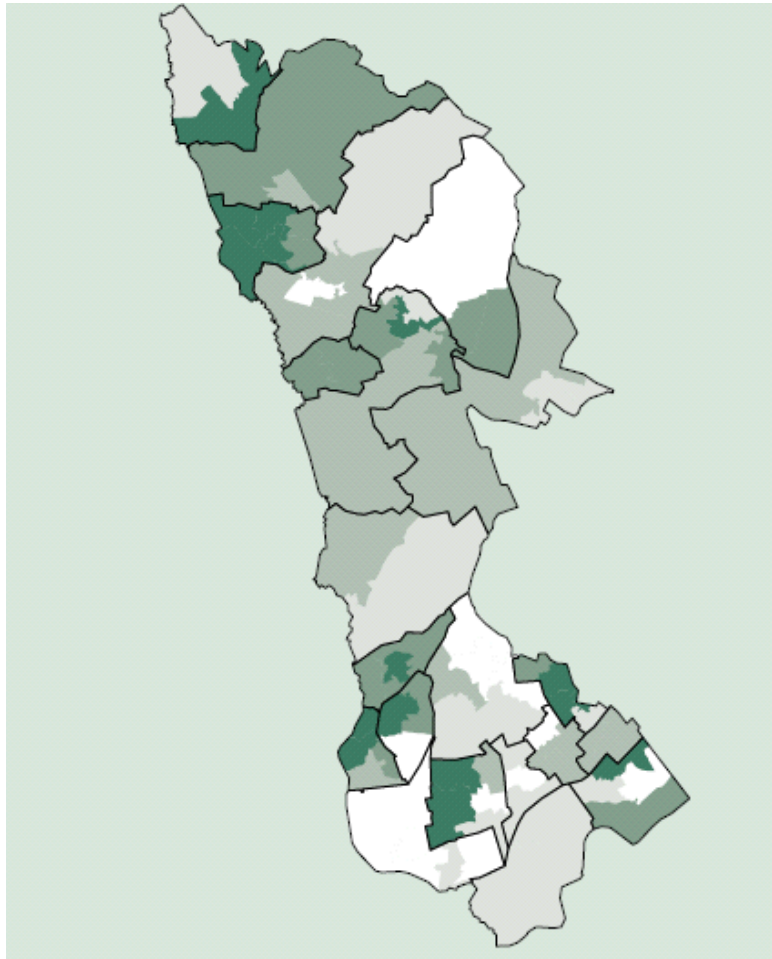
### **Origination of Issue**

Nottinghamshire County LINK held workshops across the county in January/February 2010. The aim of workshops was to allow communities to come together to identify gaps in health and social care services that they experience in the community. From this, the LINK can identify a priority issue where they can initiate positive changes.

All issues raised to the Nottinghamshire County LINK are analysed by the Issues Panel (a group of LINK participants). Set questions are used to score or prioritise the issues. The same questions are used for every issue, as approved by the Nottinghamshire County LINK Executive Board in April 2010.

Broxtowe has a population of 110,000. At the Broxtowe workshop an issue was raised that End of Life care choices were not currently being met in the area. Residents felt that relatives had not had appropriate end of life care and a death in a place of their choice. Examples were given of hospitals, emergency respite placements and ambulances where a death had occurred outside of the patients wishes; this could have been avoided with better planning.

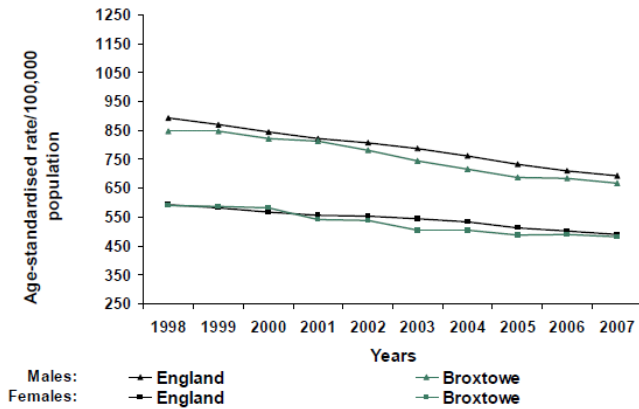
Broxtowe Area illustrating the deprivation levels across the district (Index of Multiple Deprivation 2007).



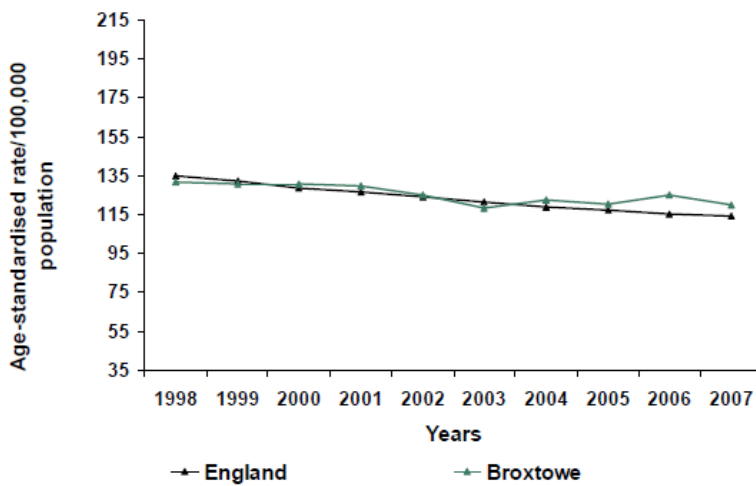
(Source: Association of Public Health Observatories).

This reflects that there is not widespread deprivation in Broxtowe or more to the north of the district than the south which is a common assumption.

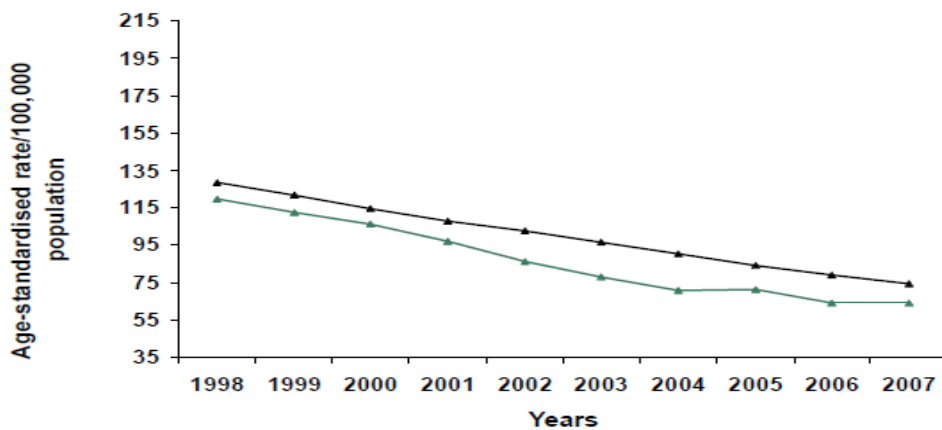
### **Trend 1 .All ages death rate in Broxtowe.**



### Trend 2. Early Death rates from Heat Disease and Stroke.



### Trend 3. Early death rates from cancer.



The death rates from heart disease, cancer, smoking and road traffic accidents are in line or slightly lower than the national average.

(Association of Public Health Observatories 2010). This suggests that services in Broxtowe do not have to provide more End of Life care than other areas of England and Nottinghamshire. If the area does not have higher demands then it should run alongside national policy. Currently, there is a large amount of media attention on End of Life Care provisions. This suggests that this issue although raised in Broxtowe will be affecting many residents in Nottinghamshire.

### **Focus**

To determine what information provisions need to be put into place to ensure patients have chance to plan their End of Life care and this can be communicated with service providers.

To ensure death is avoided in a place that was not the patients choice where possible. This will be to look into current practice adopted particularly by hospital staff to enable patient's wishes to be met with discharge planning and relationships with community services.

<b>Participants and partners involved.</b>	<b>Organisation (If applicable)</b>
<b>Jane Stubbings</b>	LINK Executive Board Member
<b>Shirley Inskip</b>	LINK Executive Board Member
<b>Josie Forest</b>	LINK member
<b>Margo Heyhurst</b>	LINK member
<b>Alison Rae</b>	LINK Support Team
<b>Laura Thomas</b>	LINK Support Team

### **Activities, Sources and Correspondences**

The group first sent statutory 20 day letters out to all the organisations they felt were central to the start of the projects research, and to gain direction. The letters were sent to Nottingham University Hospitals Trust (NUH) (appendix 1) and to General Practitioners (GP's) with a questionnaire (appendix 2).

Following the statutory letter the group received an invitation to attend a meeting at the hospital with a discharge coordinator and end of life specialist nurse.

The group attended the meeting at Queens Medical Centre (QMC) with the intention to have an easy discussion to see what provisions were currently made by NUH staff to make end of life decisions. They also wanted to give staff an opportunity to be honest about restrictions on what they can provide.

### **End of Life meeting at NUH QMC.**

Present at the meeting were a Team Leader Macmillan Nurse Specialist and a Service Improvement Nurse.

The Task and Finish group explained project outcomes and how this relates to hospital admissions and discharge procedures.

The staff at NUH explained end of life discharge planning has just been aimed at complex and high level need patients. They advised there is only 5.4 specialist nurses for both hospitals so cannot reach every patient who is on an end of life pathway.

They are currently looking to address this to ensure every patient receives the same discharge package even if a specialist nurse is not available. The pro forma is in its third draft stage and should be available for sign off at trust level. The team will pass on the finalised document to the LINK.

The staff commented and gave indication of communication barriers between them and community services staff. It is often difficult to know which member of staff they need to be contacting and who is coordinating the care package to liaise each time someone is admitted.

The care coordinator and ward staff may change each time someone is admitted making the ongoing communication challenged. This results in it being imperative that good records are kept from universal forms.

Following this, NHS Nottingham City is piloting a one number referral system for End of Life care planning systems. With this there is only one place staff needs to contact to be able to find out who is in charge of a patients care planning and contacting the multi disciplinary team.

Another aspect to improve is if a patient has an uncertain diagnosis, this may lead to staff being unable to offer advance care planning to the patient. The care pathway that needs to be followed is often not defined. Once again this puts emphasis on having good relationships with community services so changes can be put in place efficiently if a late diagnosis changes care planning.

A higher amount of training needs to be offered to nurses and health care professionals, so they are well educated within End of Life health care provisions. Often nurses are constantly analysing how care can be tweaked or new plans implemented to create health improvements, when efforts and attention should be making someone comfortable and relieving symptoms for a 'good' death.

There are also restrictions on the beds available in a hospice for people suffering from long term conditions, as cancer patients receive the majority of places in hospices from up to 96%.

NUH provided the group with a discharge care plan (appendix 3) currently used in the hospitals.

The group visited the Patient and Public Involvement manager at Nottinghamshire NHS County to discuss and review results they had from a survey taken of residents in Nottinghamshire looking at End of Life choices. The results had shown the majority of people wanted to die at home.

Literature reviews were also conducted to look into what information is offered and available to people.

## **Literature Review**

<b>Resource</b>	<b>Description</b>	<b>Available</b>
NHS End of Life care The Nottinghamshire End of Life Care Pathway for All Diagnoses. A Patient's Journey A guide for Patients.	A booklet designed to give help and advice to patients and carers to access practical and emotional support, available during the last 12 months of life.	Through the NHS. Group did not find any available in GP surgeries, libraries or community centres in the area. Head of End of Life Strategy for the NHS provided copies.
NHS online Information Prescriptions.	A website designed to provide information and signpost patients to services. Provides specific information matching a patient's needs and demographics.	Online. Printable fact sheets. Internet dependant.
Marie Curie Patient Information Card.	Give information for a patient referral to ensure all needs have been assessed. Ask for this information to be updated each time there is a need for referral. Ensure they provide effective care.	Through Marie Curie for cancer patients.
Mid Trent Cancer Network. 'My Little Blue Book'	Journal for cancer patients to record details of illness and plan care and support. Offers the chance for reflection and time to assess how patients want their needs to be met.	Available to cancer patients.

**Table 1. Resources found for End of Life Care support.**

## **Results**

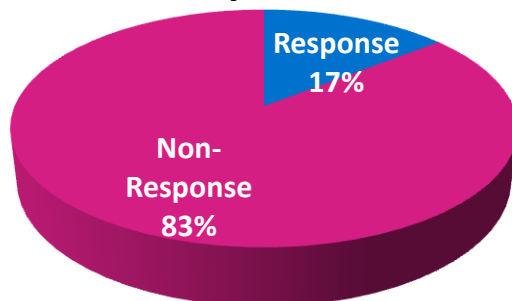
### **End of Life Questionnaire**

Following careful consideration, the task and finish group decided to design a questionnaire on End of Life Care to be distributed to staff in nursing and residential care homes, and to all General Practitioner's (GP's) in the Broxtowe area (appendix 3). Questionnaires were sent to GP's through the post with a Statutory 20 Day letter, which gives LINK the power under legislation to request information within 20 working days of receipt of that request. Questionnaires were delivered and collected by hand to each of the care homes, which enabled a dialogue between the task and finish group and each individual care home. Respondents had a month to respond to each questionnaire from delivery.

### **Residential & Nursing Care Homes in Broxtowe**

Questionnaires were delivered to a total of 18 care homes all in the Broxtowe area throughout September 2010, with copies of the questionnaire for each member of staff. One month later responses were collected.

#### **No. of Care Homes Responses**



A total of three care homes submitted responses, which is a total of 17% of the care homes surveyed. Within the three care homes that responded, a total of ten members of staff responded collectively.

Staff were asked a series of six questions and made the following responses;

*1. Please specify which policies and procedures you yourself use for a patient approaching the expected last 12 months of life?*

The following table shows a list of the policies and procedures that care home staff specified they used when working with a patient approaching the expected last 12 months of life.

<b>Policy/Procedure</b>	<b>No. of respondents using this document</b>
<b>Administration of Controlled Drug policy</b>	1
<b>Anticipatory Drugs for End of Life</b>	5
<b>Advanced Care Planning</b>	5
<b>Advanced Directives</b>	1
<b>Advocacy Services</b>	3
<b>Bereavement</b>	2
<b>Care Plans policy</b>	1
<b>Confidentiality policy</b>	5
<b>Consent for Treatment</b>	3
<b>Data Protection Act</b>	2
<b>Dignity in Care policy</b>	3
<b>End of Life Care Toolkit</b>	3
<b>Financial policy</b>	2
<b>Health and Safety policy</b>	2
<b>Liverpool Care Pathway</b>	7
<b>Medication policy</b>	2
<b>Mental Capacity Act</b>	5
<b>Mental Capacity policy</b>	1
<b>Prevention of Pressure Sore policy</b>	2
<b>Privacy and Dignity policy</b>	3
<b>Record Keeping</b>	5
<b>Resident Care Plan policy</b>	2
<b>Residents Charter</b>	1
<b>Resuscitation policy</b>	3
<b>Residents own Care Plan</b>	4
<b>Rights and Responsibilities Act</b>	2
<b>Support Plans and Risk Assessments</b>	2
<b>Terminal Illness policy</b>	2
<b>Try to care for patients if they choose to remain in the home</b>	1

The above table shows that within care homes a wealth of different policies and procedures are being used, however this is not necessarily consistent amongst all staff. It is clear that the most commonly used policies, procedures and tools are; Anticipatory Drugs for End of Life, Advanced Care Planning, and Confidentiality policy, Liverpool Care Pathway, Mental Capacity Act and Record keeping.

*2. Please specify which policies and procedures you yourself use for a patient during the expected last week of life?*

The second question asked care home staff to identify the policies and procedures they use during the expected last week of a patients life. The following responses were given;

<b>Policy/Procedure</b>	<b>No. of respondents using this document</b>
Liverpool Care Pathway	8
Care Plans Policy	5
Advanced Directorates	2
Privacy & Dignity	1
Support Plans	2
Mental Capacity Act	2
Confidentiality	2
Risk Assessments	1
Medication Policy	2
Health & Safety	2
Bereavement	2
Data Protection Act	2
Terminal Illness Policy	2
Advanced Care Planning	3
All policies provided by Heritage Care	1
Palliative Care	1
Support and reassurance for resident & family	1
Ensure resident is comfortable and pain free	1

This table highlights that there are much fewer policies, procedures and tools used by care home staff within the expected last week of life. Again

the Liverpool Care Pathway again is the most widely used followed by Care Plans Policy.

*3. Do you have end of life care training?*

The next question asked staff to identify if they have completed end of life training. Those members of staff that responded said that they had not received any end of life training. This may identify a real need for training for staff working directly with patients on end of life care.

*4. If, so has this taken place in the last 18 months?*

This question could not be answered as no member of staff that responded had received end of life training.

*5. Please specify the ways in which you communicate end of life care choices to your residents and their families/carers?*

Question five asked respondents to identify the ways they communicate end of life care choices with residents, families and carers.

<b>Methods of communication</b>	<b>No. of responses</b>
During admission process	6
Review on regular basis	1
Complete an advanced care plan	3
Keep families and service users informed of changes	2
Discuss choices	4
Care plans	4
When needed	1

The table above shows that the most popular response was to discuss end of life care plans on admission, this was followed by constantly discussing choices and updating care plans.

*6. Please specify the actions taken to ensure end of life choices are met?*

The final question asked respondents to identify the actions taken to ensure end of life choices are met.

<b>Actions taken</b>	<b>No. of responses</b>
Discussion/requests with resident & family	8

Advanced directives	1
Care plans/ advanced care plans	6
Involvement of professionals	8
Meet religious beliefs	2
Staff awareness	1

The above table shows much fewer responses than previously received. The most popular choices are discussions and requests from residents, families and carers, and the involvement of outside professionals such as MacMillan Nurses and GP's.

To conclude, the above data highlights the wealth of policies, procedures and tools available for care home staff regarding end of life care, but also highlights that staff within the same care home are not necessarily consistently using the same tools when working with residents. It has also highlighted a real lack in training for staff.

### **Best Practice Sharing Event.**

After research commenced the group decided they wanted to hold an event to bring professionals together to discuss the gaps in services identified and to form recommendations for improvements.

There were two workshops designed to produce recommendations for community services and rapid discharge planning from hospitals.

### **Workshop 1 Community Services**

Participants were asked to discuss:

1. Roles and responsibilities of community based professionals.
2. Information provisions in the community.
3. How professionals can follow and allow a patient to reflect on their care and choices in the last 12 months of life.

Below is a summary of the discussions held by workshop members.

### **Roles and responsibilities of community based professionals.**

Examples given of numerous roles: care home staff, District nurses, practice nurses, ambulance staff, hospice staff, local authority carers, specialist nurses, family, friends, GPs, religious leaders and neighbours.

It was suggested the roles outlined above are responsible for implementing the following recommendations to provide improved End of Life information provisions and planning in the community.

### **Recommendations:**

- There should be a nominated Key Worker that is responsible for ensuring the patients have a chance to discuss End of Life and make plans.
- The Key Worker will ensure all professionals are aware of the patients care plans.
- The Key Worker is responsible to start each patient with a folder and help them find and organise information. The Key worker should also have a contract agreement with expectations and pre-plan their visits to keep in the folder.
- The patient should be able to choose who their Key Worker is from those already involved in their care.
- Every End of Life care patient should be provided with an empty folder for them to be able to create a personal End of Life care record and plan. This should be offered in a paper or online version in the correct language and format.
- The folder should have sections for patients to store information they collect from different providers, agencies, health libraries and professionals.

### **Suggested sections:**

- Fact Sheets about specific illnesses.
- Regionally specific information about groups, contact names and finance.
- Diary/calendar to record appointments.
- Care plan (homecare, daycare, respite care).
- Reflection journal to record thoughts, feelings, experiences.
- Funeral and will planning.
- Carer and service provider record section.
- Jargon Buster.

The folder should be based on the 'My Little Blue Book' given to Cancer patients and Information Prescriptions by NHS.

### **Easy communication pathway for staff from primary and secondary care.**

- Admission and Discharge check list to ensure all staff members have been contacted from the community care support team. This can ensure community staff can voice their concerns and discuss care plans prior and when planning discharge.
- Information to be given to the patient about their hospital stay to help them communicate any implications to community care staff:

Summary of ward notes of stay.

- Care plan changes.
- Long term care plan interview.
- Nominated key worker in the community to receive this information. Keeps care plan updated on a weekly basis after discharge and care decisions.

Information sharing between primary and secondary care health and social care services.

- Common IT System- 'Closing the Gap' Project Electronic through GP. This pilot for the NHS should take specific consideration for End of Life planning.
- Sharing notes with social workers and community care officers to assist discharge planning.
- Summary of homecare notes pre admission and transfer letter from carers at home. This should provide hospital staff with a clear picture of what was happening to lead to an admission.

### **Way for secondary care staff to keep in contact with patient after discharge for a period of time.**

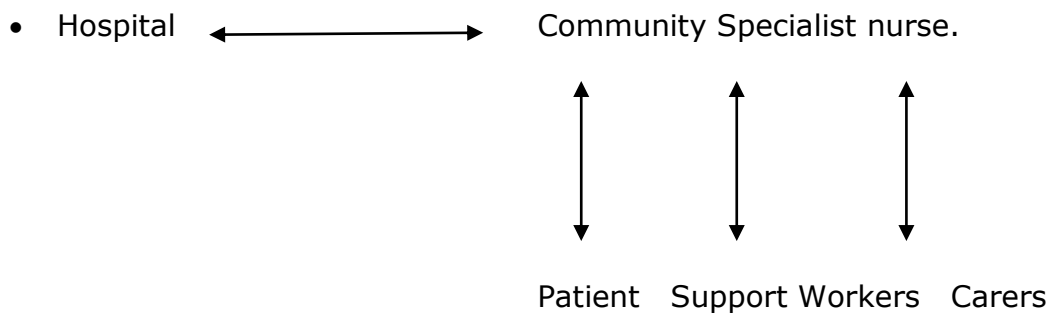
- Patient able to contact ward.
- Hospital to keep in contact for 28 days. This is due to come into place as legislation from April 2011.
- Weekly intervals patient can call a member of ward team after discharge if required.
- Family and carer conference pre discharge, this will enable them to form a contact on the ward should they have any queries or need to contact the ward afterwards.

### **Admission assessment and patient interview changes to integrate End of Life care considerations.**

Staff should be able to design and implement a quick care plan into place should the patient require urgent support due to a decline or new diagnosis. Health professionals should be quick and straight talking about a prognosis so decisions can be made.

- Rapid deterioration support.
- End of Life patients to automatically receive intermediate care involvement.
- Shared notes between homecare notes, care plan, carers, previous hospital summary. This would save time having to ask information again if it has already been gathered.
- Consent form stating wishes at End of Life. Copy available in all note formats.

### **System suggested to enable successful partnership working.**



The following were suggested areas of professionals that needed to be brought into the system to also work in closer partnership.

- Co- ordination of local capacity- hospice bed spaces use.
- EMAS- End of Life policy.
- A&E medical emergency admissions policy.

The group also suggested more provisions needed to be made to meet the emotional needs of patients in hospitals a clear admission interview could provide this opportunity.

- Preferred place of death.
- Maintain a preferred routine.
- Faith group and spiritual care support.
- Access to emotional support once leaving hospital.
- Trained specialists in emotional support should provide this service in a hospital.
- Support during visiting hour includes family.

## **Appendix 1**



25/05/10

Dear Sir/Madam,

The LINK is an organisation which aims to help local people to improve health and social services in their local area. The LINK receives issues from members of the public in each district and form Task and Finish Groups to address these.

One issue raised was the concern of choices in care for End of Life patients. People in Broxtowe have reported that they are not receiving the care they require at the end of life. People suffering from long term illness are dying in hospitals, care homes or at home when they would have preferred an alternative. Carers are struggling to cope with the pressures of caring for someone at this stage of an illness.

LINKs is looking to investigate and make recommendations to help improve health and social care services in Nottinghamshire. The group would appreciate your help by providing information about the discharge policy and provisions made on all wards in the hospitals to provide dignity in care for patients in the end stages of an illness. Also any reports and figures about unnecessary admissions that could have been avoided if other care places had been found would be beneficial to the LINK.

Thank you for your help and time with this matter, we look forward to hearing from you.

Yours sincerely,

Jane Stubbing

Chair of the LINK Issues panel

On behalf of the Nottinghamshire County LINK

## **Appendix 2**

Ref: 20 day Statutory Letter: End of Life Care Choices Broxtowe

Date: 6<sup>th</sup> September 2010

Dear Medical Practice,

### **Nottinghamshire County LINK**

I am writing on behalf of the Nottinghamshire County LINK, an organisation of volunteers set up by the Government to promote their 'Duty To Involve' agenda. It is the responsibility of the LINK and its participants to look at community issues in relation to health and social care, and to investigate and offer suggestions to service providers if the LINK is able to suggest any improvements.

Following feedback from the community, Nottinghamshire County LINK has established a Task and Finish Group looking into End of Life care choices in Broxtowe.

**Individual End of Life Care choices are not being met in the Broxtowe area. LINK needs to investigate to identify gaps with information provision and joined up working between professionals in primary and secondary care.**

The LINK has been spending time working alongside service providers to identify and start planning solutions to ensure everyone is treated with dignity and receives the care they wish for at the end of life. The group are holding a best practice sharing event as an opportunity for providers in Broxtowe to meet and discuss this further.

The group would appreciate if you could provide information by asking each GP to fill out the questionnaire attached. Please return the completed forms to

[a.rae@carersfederation.co.uk](mailto:a.rae@carersfederation.co.uk). You are invited to attend the event. Please see flier attached and invite any practice staff.

We are hoping that we can use the powers given to us by government legislation (Local Government and Public Involvement in Health Act 2007) in order to assist our local community.

We look forward to hearing from you within twenty working days of this letter, and hope to work alongside you in relation to this issue.

Yours faithfully

**Jane Stubbings**

**Chair**

**On behalf of the Nottinghamshire County LINK**

### **Appendix 3**

Date: 8<sup>th</sup> September 2010

Dear Care Home,

#### **Nottinghamshire County LINK**

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There is an invitation to the event included.

The group would appreciate if you could provide information by asking all members of staff to fill out the questionnaire. We will come and collect these questionnaires on **Wednesday 6<sup>th</sup> October**.

We look forward to coming to collect the results and making important changes to providing End of Life care. All answers are completely confidential and staff can make additional comments if they wish.

Yours faithfully,

Alison Rae  
Community Engagement Worker  
On Behalf of Nottinghamshire LINK

Jane Stubbings  
Chair  
Nottinghamshire LINK

**Appendix**

EDWARD      Rosewood House Care Home  
End of Life Plan

Name of Resident: \_\_\_\_\_ Date of Birth: \_\_\_\_\_  
Date: \_\_\_\_\_

Name(s) of those involved and relationship to service user:  
\_\_\_\_\_  
\_\_\_\_\_

Contact details:  
\_\_\_\_\_  
\_\_\_\_\_ telephone: \_\_\_\_\_

Name of healthcare professional involved in this discussion: \_\_\_\_\_  
Role: \_\_\_\_\_

In the event of deteriorating health where would you prefer to be cared for? E.g. home, hospital or care home?  
\_\_\_\_\_

What would be important to you at such a time? E.g. not in pain, comfortable.  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Is there anything you would not like to happen? E.g. not left alone  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Is there anything you are particularly worried about regarding your future?  
\_\_\_\_\_  
\_\_\_\_\_

Is there anything you would want us to make sure happens (future wishes)?  
\_\_\_\_\_  
\_\_\_\_\_

Important contacts:

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In the event of deteriorating health or death who would you like us to contact first?

Name:

Relationship:

Telephone:

Name:

Relationship:

Telephone:

**Special wishes at end of life**

Are there any special wishes that you would like us to know about y/n?

Details:

Are there any special people/pets that you would like present/to see other than family y/n?

Details:

Would you like a priest, minister or other religious person to attend y/n?

If you were unable to communicate is there anything you would want to say to your loved ones?

Is there anything you wish you had done in your life that you have not yet had chance to do?

Funeral arrangements

Name and address of funeral director:

Telephone number:

In unknown is there someone else you would like to discuss this with and then advise us? Y/N

Would you like any particular flowers or a donation to somewhere?

Would you like any particular songs or hymns?

Would you like a particular reading prepared for your service?

Would you like to be buried or cremated?

If cremated – is there anywhere in particular you would like your ashes to be scattered?

If buried – where would you like to be buried?

Would you be interested in organ donation or would like further details on it?

**If a service user is unable to fully convey their wishes on decision making then the above form will be completed in their best interests by care staff/healthcare professional and or/attorney/next of kin/carer etc.**

Service user signature: \_\_\_\_\_

Care staff/healthcare professional signature: \_\_\_\_\_