Welcome to the eighth issue of NHS Gloucestershire’s newsletter *End of Life Care*.

The purpose of this newsletter is to raise the profile of end of life care by informing you about local and national end of life care issues and developments, promoting the message that end of life care is *everyone’s business*.

Through the sharing of best practice, together we can achieve high quality care for patients and their carers.

In this issue:

- National and regional news
- Gloucestershire EoL conference
- Updates for Gloucestershire
- Education and training
  - Care Home Education packages
  - Social care – community steps
  - Meet the new County-wide Education coordinator for EoLC
- EoLC tools/Care Planning:
  - Advance Care Planning Document – NHS Gloucestershire
  - Liverpool care pathway county-wide
- Involving and supporting carers – Bereavement policy
- Raising awareness
- Co-ordination of care
- Rapid access to care
- Sharing best practice
- Conferences, courses and study days

To improve the quality of care at the end of life for all patients and enable more patients to live and die in the place of their choice.
NHS South West

The NHS South West is part of a National End of Life Intelligence Network to explore accessible systems that identify:

- Profiles for End of Life
- A system for analysing date of age/disease groups etc
- A measurement of progression
- Improvements on monitoring
- Place of death
- Inequalities
- Disease specific analysis
- Data available for
  - Needs assessment
  - Mortality rates
  - Numbers
  - Projections.

QIPP (Quality, Innovation, Prevention and Productivity) & EoLC - Southwest

- Working groups have been set up with a lead (Chief Executive) from each PCT
- Project plan includes:
  - Best practice
  - Submission of a coherent set of key initiatives.

The key emphasis is to ensure patients are not remaining in hospital and or being admitted unnecessarily.

EoLC register for unscheduled care

The roll out is in progress with North Somerset, Bristol and South Gloucestershire and Somerset. Gloucestershire is part of the phased approach, dates are yet to be confirmed.

The Strategic Framework for the South West can be viewed on www.nhssouthwest.nhs.uk in ‘Publications.’

Gloucestershire will be represented at quarterly South West meetings to ensure progress is reported and updated appropriately, and that best practice is shared across the region to the benefit of patients and carers.

CRiSCRoS

CRiSCRoS - is being adapted to include Quality Markers for each organisation.

The system should be accessible for organisations to upload their own information/activity against the specific quality markers independently.

The purpose of CRiSCros is 3-fold:

- A PCT self-assessment tool
- A centralised place to share models of working, good practice etc across the South West
- An SHA monitoring tool – an overview of activity at each PCT against the 4 Ambitions will be presented at SHA Board level.

The new Self Assessment will contain:

- 59 instead of 79 compulsory objectives
- To be completed on a quarterly basis.

End of Life Care in Gloucestershire

The EOLC Steering Group operates on a quarterly basis and is commissioning led. Membership aims to be representative of a wide variety of key stakeholders to provide the following:

- Equal engagement and collaborative partnership working
- Continued commitment to develop and deliver an EOL strategy for Gloucestershire
- Leadership and sponsorship
- Robust systems for evaluation and Reporting
- Coordination and direction for effective cross-boundary working
- Establish and support sub-groups to ensure all associated work streams are fully implemented and sustainable.

Membership includes leading representatives from a wide range of sectors at both commissioning and provider level: primary care, secondary care, social services, specialist palliative care, hospices and other charitable organisations, mental health and learning disabilities, clinical networks, ambulance, Out of Hours, service users, Higher Education Institutions, private and independent partners.

The importance of involvement from organisations and departments with specific disease areas is recognised and representatives will be invited to attend for specific agenda items. Circulation of minutes will be widespread.

The next Steering Group Meeting will be held on 7th June 2010.

End of Life Care Facilitators

Karen English (Please note on maternity leave)
Karen is covering Cheltenham, Tewkesbury, North and South Cotswolds. Karen works on Mondays, Tuesdays and Wednesdays.

Contact details:
Email: karen.english@glos.nhs.uk
Mobile: 07990 802047

Gina King
Gina King is covering Forest of Dean, Gloucester, Stroud and Dursley. Gina works on Mondays, Wednesdays and Thursdays

Contact details:
Email: georgina.king@glos.nhs.uk
Mobile: 07990 803221

Stop press......

Karen is a proud mum of Heather Grace who arrived safely on April 15th. Baby and mum are both doing well.
NHS Gloucestershire has held its first End of Life Care conference ‘One chance to get it Right’.

The day was very successful with speakers including the National Programme Director for End of Life Care, Claire Henry; the National lead for the Liverpool Care Programme, Deborah Murphy; retired consultant psychiatrist and author Dr Colin Murray Parkes OBE; professor of sociology, Professor Allan Kellehear and Barbara Pointon, MBE and Ambassador for the Alzheimer’s society.

Jill Crook, Director of Clinical Development at NHS Gloucestershire, opened proceedings at the Cheltenham Chase Hotel, welcoming guests and speakers.

She also introduced Graham Oglivie from Oglivie Design, who scribbled unique artwork based on the conference’s key themes throughout the morning.

Claire Henry, National Programme Director for the National End of Life Care Programme, was the first speaker, touching on why End of Life Care needs to be personal.

“This is not some abstract concept,” she said. “It is about real people and making a difference. It could be our own families we want these services for.”

Claire was followed by Deborah Murphy, National Lead Nurse for the LCP and Associate Director of the Marie Curie Palliative Care Institute in Liverpool.

She spoke about how the LCP, which is now being implemented county-wide in Gloucestershire, to facilitate the transferability of communication and coordination of care of dying patients and their relatives.

Guest speaker Dr Colin Murray Parkes OBE, a consultant psychiatrist specialising in bereavement, spoke about the personalisation of grief. Dr Murray Parkes, who has worked with families affected by disasters including the Lockerbie bombing, 9/11 and the Capsize of the Herald of Free Enterprise, described how bereavement and loss affects the individual in different ways.

Other speakers included professor of sociology, Professor Allan Kellehear and Barbara Pointon, MBE and Ambassador for the Alzheimer’s society.

Gina King, Clinical Facilitator for End of Life Care, said feedback from the event had been overwhelmingly positive.

She said: “People have been inspired and motivated. They felt the speakers really made a difference. Having people like Allan Kellehear there and Barbara Pointon who gave the carer’s perspective was very important.

“It was the first time we have held this sort of event in Gloucestershire and the key point was about challenging people’s practices. We wanted to get people to think outside the box and look at how they can improve End of Life Care.

“The discussion groups had some great feedback and having a mix of disciplines and professions really worked. It gave people a chance to hear about how other people are working and gave them a different perspective on End of Life Care.”

Feedback from the event will now be used to shape how NHS Gloucestershire tackles End of Life Care in the county.
### Summary

- 120 delegates attended and 96 evaluation forms were returned.
- A wide variety of professionals and organisations from across the county were represented including clinical (Nursing, AHP, medical), managerial, community, acute and mental health, OOH, care homes, social services/county council, carers, hospices, other charities.
- Speakers were very well received, with the vast majority scoring: Good, Very Good or Excellent.
- 66/96 delegates’ learning objectives either were exceeded or fully met. (69%)
- Formal evaluations and informal messages received since the conference reflect the overall success in achieving the objectives of the day and beyond.
- Discussion groups highlighted the need to improve communication, education and partnership working at all levels.

### What changes can you make in your workplace?

Communication – with patients, carers, wider team, other professionals and organisations, raising awareness  
Education  
Training  
Involvement of patients and carers

### What are your future needs for training and support in EOLC?

- Use of LCP, ACP  
- Social Services & Health closer together/ Acute & Community  
- Training for county council domiciliary carers  
- Bereavement  
- Dementia  
- Knowledge of all agencies involved in supporting EOLC / signposting  
- Staff release for training  
- Regular training & updates  
- Non-cancer & EOLC  
- Support and training for care homes  
- e-learning

### Other comments


### Suggested future events/topics

- Encouraging MDT involvement in EoLC  
- Diagnosing dying  
- Tackling difficult conversations  
- Breaking bad news  
- Bereavement  
- LTC /other diagnoses  
- Psychological and emotional care  
- Dementia care  
- Acute hospital perspective on EoLC  
- Mental Capacity Act.

### Summary of Discussion Groups

- Need for partnership working between providers especially at ground level  
- Issues relating to organisational boundaries “working in silos” affecting continuity of care  
- Improve communication – written & verbal, use of IT, between professionals, with patients & carers  
- Education – EOLC tools, diagnosing dying, difficult conversations, disease specific, prognostic indicators, competencies & skills  
- Improve discharge planning and OOH  
- Expand skilled services eg. Dementia Link Workers  
- Health and social care to work more closely  
- Carer involvement and support  
- Practical solutions offered. Eg. Directory of services, patient letters  
- Improved measurement of outcomes, audits & research.
Local Service Updates

²gether Trust

The ²gether Trust has now set up an End of Life Care steering group with representatives across the Trust.

We are enjoying working with the End of Life facilitators and have prioritised implementing the Liverpool Care Pathway and the training required to ensure its success.

We are also involved in the roll out of the county wide Advanced Care Planning initiative and are keen to see one county wide document.

We have undertaken some case review work to examine End of Life Care experiences of our service users in order to help improve the End of Life Care offered to our service users.

Tim Coupland
Business Development & Governance Manager, ²gether NHS Foundation Trust

Gloucester Royal Hospital Foundation Trust

The Steering Group has been meeting monthly.

A draft document has been produced called “Discharge Planning for Terminally Ill Patients” which will be piloted in both GRH and CGH. It will have the Do Not Attempt Resuscitation (DNAR) sticker incorporated into it and metrics will be identified which will measure its success.

The Advanced Care Planning document which has been piloted in the community has been accepted by various teams and triggers need to be established for a wide range of conditions.

The Critical Care team in GRH has been running Bereavement follow up care for some time and this has now started in CGH. Bereaved relatives are telephoned 6-8 weeks after a death, if they express an interest in this follow up.

This gives them the opportunity to ask questions about care both in ITU/HDU and other hospital wards and about their relative's illness.

Audit results are positive.

The Diagnosing Dying Group is making progress. An Unwell/Deteriorating Patient management plan has been piloted on the Oncology wards and has proved very helpful for both Nursing and Medical Staff. It will be audited after 3 months so that it can be used more widely.

Work is continuing with the Respiratory and Cardiology Teams to recognise the dying patient and to know what to do.

Education is a major issue for the Trust but continues to move forwards.

NHS Gloucestershire Care Services

New documentation (FACE) for District Nurses is being implemented from September.

This should improve consistent record-keeping and had been developed from the former common assessment framework.

This will be the first documentation to include documentation of the patient's preferred place of death.
Gloucestershire Dementia and End of Life Care Strategies - Pain Assessment for Cognitive Impairment

Dementia is a progressive, neurological Long Term Condition that carries a significant demographic and economic impact.

Both the Dementia and End of Life National Strategies promote:

- Raising professional awareness and skills
- Use of prevention strategies to support care closer to home
- Advanced care planning
- Pathway and care plan approach
- Maintaining dignity and respect.

Looking at the relationship between the two strategies, the potential for joint work on pain assessment tools has been identified as an important development opportunity that could also support Transforming Community Services Quality Framework and CQUIN indicators.

The older person has an increased incidence of pain due to co-morbidities, but the person with dementia has difficulty communicating pain due to a combination of memory loss, receptive and expressive dysphasia. Unresolved pain may lead to:

- Increased irritation
- Anxiety
- Aggression
- Resistance to care
- Depression
- Loss of sleep
- Wandering

Hospital admission is often perceived as the only option for a medical or social crisis involving a person with dementia or their carer. However, inappropriate hospital admission is distressing, harmful and costly. Studies also suggest that professional care tends to focus on physical needs rather than being holistic and person-centred, and that empathy can be lacking where there is a perception of "no cure no hope."

Initial review of current literature on pain assessment shows that there are a number of tools that could be effective for people with cognitive impairment since they use nonverbal interpretation of pain; physiological signs, facial expression and behaviour.

The CRT is represented on the Gloucestershire Respiratory Steering Group that meet bi-monthly. The main work stream of this group is to develop a local COPD pathway and this will include the End of Life and Palliative phase. It is expected that the draft pathway will be available for open consultation in June with a launch and supportive educational event in the autumn and End of Life issues will form part of this.

Currently there is collaborative working between the Hospital teams and the CRT in developing an Advanced Care Planning Diagnostic tool for use in COPD and Interstitial Lung Disease (ILD). This tool will be based on NICE and BTS Guidance and supported by the National Clinical Strategy for COPD when it is launched later this year. The tool will set the criteria to identify patients who are approaching a stage in their disease where ACP should be discussed. It is hoped that this will be a quick guide that can be easily adopted into General Practice as well as the hospital setting which will try to improve the care given to patients nearing the end of their life and for those who are caring for them.

The CRT currently offers Pulmonary Rehabilitation (PR) in the Forest of Dean delivered at Great Oaks Hospice which has proved to be a very effective and comfortable site. The teams there have been very accommodating and though one might question the choice of using a Hospice in this patient group the feedback has been very positive from all involved. As we enter our third year at Great Oaks we hope it will continue on this very encouraging note. In the future the PR service is expected to be expanded to cover the county and we will offer this course at other sites such as Great Oaks and we are hopeful that Cotswold Care Hospice can work with us to integration this service into other care providers.

Kathy Cambell, Respiratory Specialist Practitioner, Community.
An End of Life Education package has been developed for care homes and is now reaching its final stage. It has four modules and has been designed using the common core competencies for end of life care developed by the End of Life Care Programme in partnership with Skills for Care and Skills for Health, supporting the National End of Life Care Strategy (2008).

The four modules are:
- Communication
- Assessment
- Symptom Management, comfort and wellbeing
- Advance Care Planning (ACP).

It will be recommended that the communication module be completed first as good communication skills are essential in order to provide high quality End of Life Care.

At present the communication and ACP modules are being trialled by 5 care homes within the county and following the review in May the final modules will also be tested by the same homes.

The package is to be used as a foundation tool for End of Life Care which can be built on as the learner desires further knowledge. Both registered and unqualified staff will be testing out the modules in order for the package to be assessed fully and this will also give us broader critique.

Following the recommendations, any changes/alterations will be made and an implementation plan then agreed for the roll out to homes wishing to make use of the tool.

Amongst the questions required of the trial leads is an important one relating to the training package’s use across other care services, including hospitals and community settings. We are hoping for a positive response and be able to make the finished package available to the wider community.

The draft package was shared at the Trust’s recent first Healthcare Assistant Conference in March and anecdotal it was well received by all who viewed. Thankyou!

The draft package was shared with the Strategic Health Authority and has been forwarded to other Trusts and hospices for their own use. We will keep you up to date with its progress.

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The aim is to improve multidisciplinary working between Health and Social Care at the bedside and improve the skills and confidence of care workers in caring for dying patients and their families is still ongoing at Gloucestershire County Council Education Department. In November all Home Support Officers from the Community Steps Team have been trained to train their Home Support Workers in how to use the LCP within their role.

However, problems that arise especially at referrals so have attached questions that I have set for managers to ask when a referral is made, hopefully this will enable a smooth transfer and prevent any crisis occurring.

The World Health Organisation sets 9 firm guidelines for the care of people with a life limiting illness. One of these states ‘to use a team approach to address the needs of the patient and their families’.

Communication appears to be a barrier in allowing this guideline to be met and carers have to sometimes go in with very little information, except to know they are a ‘palliative case’. Some carers then feel that this word means they have very little time left, in fact they can have many years left as palliative care should be put into place from the onset of the life limiting disease.

I appreciate that Home Support Workers are involved when the disease has progressed to an extent where the person needs assistance with personal care, and some of them have reached the terminal stage. With very little information given carers are finding this care stressful, especially around the issues of ‘what does the person and their family know of their disease and condition,’ ‘is the person for resuscitation if they reach end of life’.

To help alleviate these concerns and allow better communication to enable a team approach, I have set some questions that managers may need to ask when a referral is made so that the information can then be given to the carers.

- Is the person palliative care or terminal care (palliative means that care is provided from the onset of the disease and can have many stages, where terminal care is the care provided in the last hours or days of a person’s life. It has become confusing as Health Professionals today still class the terminal stage as palliative care to avoid using the word terminal.
- If they are terminal care and are in the last 7 to 10 days of life, is the LCP (Liverpool Care Pathway) in place.
- Is there written evidence of DNR (do not resuscitate) in place. If LCP plan in place would be the ‘yellow sticker’. If not written information needs to be in place re the procedure in the event of a crisis. Perhaps the GP or D/N needs to be contacted.
- What does the person and their family know of their condition and what have they been told. Again G.P or D/N may need to be contacted.
- I think you will agree that by gaining this information, provides the carers with the information that are at present causing them great concern and most importantly enables a holistic approach to the needs and wishes of the person.

Mo Wells from the GCC Education Department has just started the 2nd Accredited palliative care course for a further 12 staff. Also, Independent Home Life Agency are also setting dates for the Introduction to Palliative Care and other agencies are showing interest There is also a further 3 sessions for the introduction to Palliative Care in May for GCC staff, so most will have now attended.

Mo Wells
Contact: pat.williams@glos.gov.uk or mo.wells@glos.nhs.uk
My name is Sue Goold and I came into post on March 8th as the countywide End of Life Education Coordinator on an 18 month secondment from Cotswold Care hospice. I work under Gina King and Karen English, End of Life Care Facilitators.

At present there are pockets of end of life education happening throughout the county held by a variety of education providers but not everyone knows about it or has access.

All staff involved in providing End of Life Care (EoLC) need to have a baseline knowledge in order to provide equitable and standardised care regardless of the setting therefore be competent.

The EoLC Strategy (2008) defines the workforce into three areas each with a minimum skill and knowledge level relating to the four common core competencies for End of Life Care.

- Communication skills
- Assessment and planning
- Symptom management, comfort and well being
- Advance Care Planning.

The 3 workforce areas are:

Group A - Specialist Palliative Care (SPC) staff, work entirely focussed on people at the end of their lives.

Group B - Staff who frequently deal with EoLc as part of their role (generalists)

Group C - Staff working in other services who are involved in End of Life Care infrequently.

Education and training will be targeting Group B in order to promote the End of Life Care Strategy’s work to provide high quality End of Life Care for all adults.

We will, therefore, ensure that End of Life Education is included in all relevant induction and training programmes for all Health and Social Care staff.

Coming soon….

Plans are underway for you to be able access relevant EoL training in a variety of ways.

Within each newsletter there will be an education article to keep you updated. Look for this symbol!

Meanwhile if you have any questions regarding EoL education please email me

sue.goold@glos.nhs.uk
Liverpool Care Pathway for the Dying (LCP) county-wide

2Gether Trust

The 2Gether Trust as part of the EoL Steering Group has identified that the Liverpool Care Pathway (LCP) is a clear and concise tool for documenting the delivery of care in the last days of life. Plans are being developed in rolling out the use of the LCP and the Education and Training that underpins the framework.

This will ensure the LCP becomes a county-wide document which should facilitate the transferability of communication and coordination of care of dying patients and their relatives. It will also support best practice of care of the dying irrespective of where the person dies.

Peter Fitzpatrick has been appointed to develop a training package to focus on the Liverpool Care Pathway and underlining principles of care.

Contact: Tim Coupland Tim.Coupland@glos.nhs.uk or Peter Fitzpatrick Peter.Fitzpatrick@glos.nhs.uk

Care Homes Pilot

The pilot has now been completed with a positive response from the 7 participating homes. Comments at the review meeting included:

- The LCP document was very straightforward to use.
- When introduced some staff were initially nervous, but once familiar were happy with the document.
- One home had informal review meetings following its completion which staff found particularly helpful.
- The DN team, in some instances, were also supportive as were some GPs. Other homes still experienced issues around GPs and anticipatory prescribing, whilst others had full support.
- The spiritual section was sometimes difficult to complete, but felt combined with Advance Care Planning this would improve.

The plan now is to roll out the LCP to other homes across the county and this will be led by the Care Home Support Team. Date for the start of the implementation to be confirmed. Further details will follow.

This is being supported by Maggie Martin, Care Home Education Project Nurse, the Care Home Support Team and EOLC Facilitators.

Contact Maggie Martin on 07824 837201
Maggie.martin@glos.nhs.uk

If you would like to contribute to the newsletter in any way then please email either georgina.king@glos.nhs.uk or Karen.english@glos.nhs.uk.

To improve the quality of care at the end of life for all patients and enable more patients to live and die in the place of their choice.
NHS Gloucestershire developed its own Advance Care Planning (ACP) document as nationally the only tool available was the Preferred Priorities of Care (PPC) document which did not encompass all aspects of Advance Care Planning.

The document adapted information from the Weston Hospicecare Advance Care Plan as well as the PPC.

Involvement from key stakeholders has been vital to the development of the document therefore the draft was shared from its initiation to completion with the following parties:

- Primary Care
- Acute Trust
- Voluntary Specialist Palliative Care
- Specialist Palliative Care
- Community Nursing
- Care Home Support Team
- Unscheduled Care – medical and nursing
- Education & training – health and social care
- Patient/public involvement
- Ambulance Service.

The document has been divided into five sections including the introduction. Each section also contains signposting for individuals to gain further information and guidance.

**Introduction**

An overview of the document, explaining that the design is to encourage discussions with family and friends re an individual’s own wishes and preferences regarding their future care if, for whatever reason, they are unable to express those wishes for themselves.

It is emphasised that the document can be completed over a period of time, as and when an individual feels comfortable.

Also explains that ACP is a voluntary process and if the document is completed needs to be regularly reviewed.

**Preferred Priorities for Care (PPC)**

This section provides examples of information which should/could be recorded and also includes the questions in the national PPC document.

**Putting affairs in order**

This section lists information which should be stored in a safe place with the name of a trusted nominee who can access this.
It provides an example form for recording funeral planning preferences.

**Appointing decision makers**

This section describes the two types of Lasting Power of Attorneys (Property & Affairs and Personal Welfare Lasting Power of Attorney).

Explains the benefits of making a will to ensure personal outcomes are met as well as reducing the stress and anxiety already felt by family and friends still living.

**Advance Decisions**

Detailed description of the definition of an Advance Decision:

- Legal document
- About refusing and not requesting certain treatments
- Requires specialist input
- Only comes in to place if capacity is lost
- Requires a signature
  - Individual
  - Witness

The document was piloted in Care Homes within the Stroud locality and supported by the locality practice based commissioning group. The leads received training and support throughout the pilot period (September 2009 to January 2010) and targeted new and existing residents.

Head of Care, at Moreton Hill Care Home, Trish Pyne stated on the use of the ACP document: “There are very few things in this world we can hang onto. By using the choice to our residents to make decisions about their future care, no matter how small.”

We are now at the stage of setting up a short life working group to finalise the document and implement a phased approach for its implementation.

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**Sharing excellence in EOLC in Gloucestershire....**

**The Liverpool Care Pathway Update**

It has been a year (February 11th 2009) since the Liverpool Care Pathway (LCP) was launched in the Community Hospitals and Community. The LCP champions undertook a re-audit of the document to ascertain how the document was being cemented into practice. This time the audit was divided into three parts to capture data that will influence how education and training will be developed, identification of gaps in completion, patient's preferences and the provision of information.

1. How many patients had died in the last year (February 09 to February 2010) and whether or not the LCP was used.
2. A repeat of the National LCP Baseline audit
3. An adaptation of the National audit of the Dying:
   - Preferred place of death/actual place of death?
   - Who documented in the LCP?
   - Was the LCP transferred with the patient?
   - Was a Allow a Natural Death (DNAR) been applied?
   - Has the patient received any written information?
   - Has the family received any written information?

The next steps are to analysis the results and present them to the relevant Clinical Governance Groups for action and using the data to determine further education pathways to support the sustainability of the LCP and the delivery of high quality EoLC care.
A baseline audit last year of services in the community and community hospitals revealed there was no standardised community bereavement follow-up as well as a lack of information provision. A survey commissioned by the bereavement charity CRUSE also indicated that the PCT’s referral activity was patchy.

As a result a working group was formed in September 2009 consisting of CRUSE, hospice and specialist palliative care representation and a cross-section of community nurses from all localities in Gloucestershire. The group’s purpose was to develop a bereavement protocol that would support community nurses in their practice and would be in line with the Liverpool Care Protocol ‘Care after Death’ Section. It was hoped the protocol would standardise practice so that all bereaved relatives and carers would receive an equitable service.

The aim was to develop a standard that concentrated on bereavement support and not the provision of counselling. Community Nurses are skilled professionals who can provide follow-up support whereby the bereaved and nurse can discuss their experience and add clarity and provide closure to the episode of care. Counselling maybe required if there are identified issues relating from the bereavement and a trained counsellor can enable reflection and resolution. Using a framework developed by a Gloucestershire GP surgery, the group first agreed the key principles of care:

- Respect for the individual
- Recognising and acknowledging loss
- Provision of information – LCP Resource Pack
- Support
- Ensuring the environment and facilities are appropriate for the bereaved
- Review and audit.

The second section of the protocol focused on the essential practicalities of community bereavement follow-up, including contact information, access to ongoing support and communication pathways across a multidisciplinary team.

To support the community nursing teams in using the protocol two tools were developed to help assessment and to document the follow-up visit. An audit tool was adapted from the Acute Trust Critical Care Unit. This document structures information recorded surrounding the death so that vital information is documented between the identified key worker and bereaved relative that would provide evidence for signposting. A prompt sheet was created to support the nurse in asking key questions that would indicate if the relative/carer was at risk and needed further support from CRUSE or another identified bereavement service. Answers would be recorded on the audit tool for future reference.

In addition a standardised letter for those who did not respond or who had left the area was devised and a contact card to inform the bereaved of the planned follow-up. A resource file was produced with all the necessary documentation and information leaflets for when the Liverpool Care Pathway was begun.

The protocol and the supporting documentation have now been approved by the Clinical Governance and the District Nurses Operational Group. The LCP resource packs are being reproduced so all district nurses in Gloucestershire will have supplies to ensure standardised practice.

Responses to the protocol have been positive. Operational Development Manager Sue Aldous said: ‘It is very comprehensive and will prove valuable to our staff.’ It also offers a best practice template that other organisations can follow.
Dying Matters awareness week was held between 15th and 21st March. The aim was to raise awareness and generate debate on death, dying and bereavement; to increase media and public attention on these issues and increase membership and coalition. As well as encouraging individuals to start the conversation, it was also aimed to highlight the importance of End of Life Care to the main political parties at a key time.

The National Launch Event and National Forum, ‘Dying to Talk’ was held in London with other national activities including

- ‘Dying to know: Bringing Death to Life’ book launch
- A tea party in the House of Commons
- Marie Curie Cancer Care & Kings Fund ‘Achieving the end of life care pathway, what works’ Conference, London
- Cancer Network Development Programme Conference, Heathrow.

A new awareness campaign is encouraging people to talk to their loved ones about their dying wishes.

The drive, launched earlier this year as part of Dying Awareness Week, comes after a survey revealed 81% of people have not written down their preferences around their own death.

Research by the Dying Matters Coalition also shows only a quarter of men and just over a third of women have told family and friends about any funeral arrangements they would like after death.

Dying Matters Chairman Dr Mayur Lakhani said it was time to put social taboos aside and discuss dying.

He said: “It goes against our instincts to talk about death, but we must overcome our reticence. People should ask themselves: ‘If I were to die, what would I want my loved ones to know? Would they be aware of your wishes? If we don’t talk about what we want it will directly impact on our experience at end of life.

“This is vital as there is a major mismatch between people’s preferences for where they would like to die and their actual place of death. The End of Life Care Strategy noted that most people would prefer to die at home, but 60% die in an acute hospital. It is important to start the conversation early when people are well so that people are not caught unawares as dying and death is much harder to talk about when someone is ill.”

Eve Richardson, Chief Executive, National Council for Palliative Care and Dying Matters, added:

“Without communication and understanding, dying can be a lonely and stressful experience, both for the person who is dying, and for their friends and family. Dying people can experience a tremendous sense of isolation and can feel shut out.

“It’s clear that people need help starting this important conversation around dying, death and bereavement with loved ones. The thing many people fear most about it is the loss of control – it’s often the process of dying rather than death itself that causes anxiety. We can reduce the fear of dying by encouraging more open discussions.”

Dying Matters believes that promoting greater openness and communication are the first steps towards helping people exercise greater choice at the end of life, and has developed a range of information on death and dying, and supporting materials to provide:

- advice on how to start a conversation and how to deal with people’s reactions
- help around the timing of starting the conversation so that ‘too soon’ doesn’t turn into ‘too late’, and
- techniques that enable people to raise the subject with different individuals in different settings.

To find out more visit: www.dyingmatters.org
We are a team of nurses with a variety of nursing experience in the primary and secondary care and rehabilitation sectors. We are supported by a group of administrative staff who have an extensive knowledge of our role within Gloucestershire.

Our role with End of Life care is to facilitate care provision, whether that be in the patient’s own home or a care home. The Fast Track tool (FTT), is the Department of Health document for simplifying access to care provision for patients with a ‘rapidly deteriorating’ condition. It’s predecessor was CHC3 which Gloucestershire used for the last eight weeks of life.

The difference with the FTT is that it can be completed by the nurse responsible for the patient, once they have completed the training. All relevant information, including a clinical diagnosis, prognosis and details of the patient’s condition is required. This is sent to the CHC team and must be accompanied by a comprehensive care plan and diary sheet. Care is provided appropriate to health needs. If the patient’s condition improves they may no longer meet the CHC criteria.

With regard to nursing homes and both Long Term and End of Life Care, Nurse Assessors offer on-going support and advice as well as signposting to the care home staff for support from other health professionals such as the Care Home Support Team, Tissue Viability and Palliative Care.

We may also provide support and reassurance to the patient and their family and will work together with the care home staff to enable, as far as is possible, pain-free, holistic, supportive and dignified End of Life Care.

Application for the End of Life Care can be made through the usual CHC route. If the FTT is not the appropriate route to health care provision and the patient has significant health needs, they may meet the CHC criteria.

Nurses complete the Specialist Assessment of Care Needs (SACN), by completing a thorough and holistic assessment of the patient’s physiological, psychological, social, emotional and spiritual needs should be recorded. Gathering evidence from all health, clinical and social care professionals involved with the care of the patient and discussion with their loved ones will ensure a fair result. It is expected that the referrer discusses the assessment and the process with the patient’s relatives wherever possible.

This can be time-consuming but is intended to try and ensure that the patient has been fairly ‘screened’ for CHC which, without the evidence, may result in a delayed decision.

Unfortunately, the media and some organisations have misinterpreted CHC. It is health needs based and not diagnosis based and is interpreted as such that the patient has a primary health need which is complex, unstable, unpredictable or intense, resulting in the requirement of skilled care workers to fulfil the complex health care of the patient.

It is one of our duties to make best use of public money. We work together with health and social care professionals and care providers to try and deliver a fair and consistent service to patients in Gloucestershire.

For further information please see the DoH website on Continuing Health Care, the Decision Support Tool, Checklist and the Fast Track Tool.

Sandra Burns BSc (Hons)
Adult Nursing Nurse Assessor CHC Team, Commissioning, Gloucestershire PCT, Edward Jenner Court, Brockworth, Glos 08454 220302
Gloucestershire Care Services implemented a countywide single point of clinical access (SPCA) on March 1, 2010. It has already coordinated services for a number of GPs across the county looking for alternatives to admission including emergency respite or combined health and social care solutions as well as coordinating community hospital beds.

GPs who have accessed the service have been able to find a range of solutions to enable their patients to remain in their homes.

This has included:

- provision of an emergency care package to start the same evening
- emergency respite using a block bed at a local nursing home
- a joint OT and District nurse visit, resulting in the installation of equipment to prevent an admission that day.

Gloucestershire Care Services and the PCT commissioners are using this feedback on from GPs on this new service to make constant improvements in the way services are delivered.

We are also collecting information from the SPCA to identify gaps in provision or where we might need a more rapid response or better coordination to enable patients to remain safely at home.

The SPCA will continue to be developed to support urgent care pathways and to ensure integration across different services, based on feedback from those using the service. As further pathways are developed, the SPCA will use these to advise GPs, care homes, the ambulance service and acute services of alternatives to acute care.

The capacity management system (CMS) is being implemented in Gloucestershire to support the SPCA. This system will, by September 2010, provide access to a directory of urgent care services available in the community and “live” capacity and availability information for community services, beds in the community and acute care bed capacity.

We are about to embark on joint work with the palliative care strategy group to see how the SPCA might, in the future be able to support End of Life Care pathways both by providing a single point of access linked to palliative care teams and services, and through the development of the directory of services.

If you have any queries or feedback regarding this new service, please contact:

**Justine Rawlings**
Tel: 08454 221867/07765 627965
Email: justine.rawlings@glos.nhs.uk
Cancer survivor Nina Hickman is challenging women to pull on their walking shoes and take part in the Cotswold Midnight Walk.

The 10-mile women-only event raises vital funds for Cotswold Care Hospice.

Nina has a personal reason for taking part – the hospice supported and helped her as she went through chemotherapy, a mastectomy and reconstructive surgery.

“I often sit and wonder if Cotswold Care Hospice hadn’t been there to support help and guide me, where would I be today,” said the 49-year-old. “I got so low some days that I wanted to end it all. Cotswold Care kept me going.”

Every year Cotswold Care, based in Minchinhampton, helps more than 500 people with life-limiting illnesses, their families and their carers. All of its services are provided free of charge. It costs £2.3 million a year to run the hospice. The charity receives less than 10 per cent funding from the Government.

This year the charity is staging two Midnight Walks: one in Cirencester on Friday June 25 and one in Gloucester on Friday September 3.

Women can register online for both walks by logging on to www.fancyagirlsnightout.com. It costs £12 to register - £10 if you register before March 31. You must be registered in advance to take part.
Promoting Independence and Choice through Personalised Care

Established in Cheltenham 30 years ago, Sue Ryder Care - Leckhampton Court Hospice supports people with cancer and other life limiting conditions across Gloucestershire to live well, and when the time comes, to die with dignity and in their preferred place of choice.

To provide people personalised care and choice as their end of life care needs change, the hospice provides a continuum of services including: a 16 bed in-patient unit, day hospice, family support service including a bereavement programme and a hospice at home service.

In-line with many people's preference to be cared for at home, Sue Ryder Care is increasingly focusing on developing community based services that support people to retain independence and live well in own homes for as long as possible. In Gloucestershire less than half of those people who wish to be cared for and die at home actually achieve this. Sue Ryder Care is working collaboratively with the local Primary Health Care Trust and other providers to provide choice for patients wishing to be cared for in their own homes.

Hospice at Home

Leckhampton Court Hospice’s Hospice at Home service is now well established and working to meet the needs of people with life-shortening conditions who express a wish to be cared for and die at home. After an initial successful six month pilot, the service has gone from strength to strength in providing support for people and their families across Gloucestershire.

It is a flexible and responsive service designed to compliment existing health and social care services and support, with the District Nursing Team remaining the key worker and decision maker.

Hospice at Home aims to:

- Enable people who want to remain at home during their last few weeks of life to do so
- Complement and support Primary Healthcare Teams e.g. GPs, District Nurses and social care professionals
- Offer emotional support and appropriate nursing care to people and their carers during the day and night
- Aid discharge home from an in-patient unit or hospital
- Prevent unnecessary admissions to hospital

Lorraine Dixon, Palliative Care Services Manager at Sue Ryder Care – Leckhampton Court Hospice, said: “There is a wealth of experience and knowledge within the team at the hospice, all of whom are committed to supporting local Primary Health Care Teams to develop end of life care services that ensure people are well supported, regardless of their diagnosis, and have choice on where they are cared for.”

For information on any of Sue Ryder Care – Leckhampton Court Hospice’s services and to refer patients to the Hospice at Home service call 01242 230199 or email sandra.flanagan@suerydercare.org. Or visit www.suerydercare.org.
“Call for contributions – Case Studies, Letters, Question and Answers, New Posts”? If you would like to submit an entry for the next issue of the newsletter, please contact Gina King mobile: 07990 803221 or georgina.king@glos.nhs.uk and Karen English mobile: 07990 802047 or karen.english@glos.nhs.uk