Welcome to the third issue of 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.

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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.
The National End of Life Strategy

The National End of Life Care Strategy: promoting high quality care for all those at the end of life was published in July this year. The strategy has provided a framework for Gloucestershire on which local health and social care services can build. The key areas for end of life care addressed in the strategy are as follows:

1. Raising the profile
2. Strategic commissioning
3. Identifying people approaching the end of life
4. Care planning
5. Coordination of care
6. Rapid access to care
7. Delivery of high quality services in all locations
8. Last days of life and care after death
9. Involving and supporting carers
10. Education and training and continuing professional development
11. Measurement and research
12. Funding

The full document can be viewed on the Intranet A-Z Listings: End of Life Care/End of Life Care Strategy see page 11 for details.

The National Dementia Strategy

The awaited National Dementia Strategy will be launched in the New Year. There has already been extensive consultation on the draft strategy, and we know that there are key messages we will need to focus on - these include:

- the importance of early diagnosis to assist people in planning for their future
- raising standards of quality of care, both at home and in care homes and hospitals
- training and education for all on dementia

We are already working together with partners in the county to develop and improve our services, and we recognise the vital role that carers play in caring and supporting friends and family who are diagnosed with dementia. We know that the prevalence of people aged 65 and over predicted to have dementia in Gloucestershire in 2008 is 7,881 and this rises to 12,544 by 2025. Most of this increase will be in those people aged 80 and over, and reflects the ageing population of the county. There are currently around 75 younger people (under 65) known to services in the county and whilst this number will remain relatively small, it will increase.

We will be working on all aspects of the pathway of care, and are keen to work with all staff involved in supporting End of Life care. This is a key area, and we need to make sure staff are knowledgeable and feel equipped to support individuals and their families.

Advanced Directives are an essential part of Advanced Care Planning (ACP) and are important in supporting decisions made earlier on in the patient’s journey. So we need to make sure that in managing early diagnosis well and providing the right support at the right time, we are also managing to support
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.

The National End of Life Care Programme

Claire Henry End of Life Care (EoLC) Programme Lead came to Gloucestershire to meet with Jill Crook, Karen English and Gina King to be updated on our developments in EoLC. Claire was impressed with our accomplishments and that our current plans were in line with the national agenda. However it highlighted the need to be involved with the Department of Health’s and EoLC Programme forthcoming initiatives and work streams to enable Gloucestershire to be a Beacon Site in EoLC.

Key Points for future collaborative working

- Explore ways of improving communication targets within an operating Framework
- Looking at ways of testing out communication skills training with G.Ps
- Developing an Action Pack sets for education in EoLC
- Pilot of the patient’s experience in ACP based on G.P Practices
- Commissioner Framework

Partnership of Older Person’s Projects (POPP)

A Partnership of Older Person’s Projects (POPP) is a government initiative with funding given to a range of projects supporting older people. Ours in the PCT is the only one that’s focuses on Care Homes and there are different work streams within our project such as the Care Homes Support Team. We are multidisciplinary and consist of general and mental health nurses, Physiotherapists, Occupational Therapists, medicines management, SALT, Dieticians and dementia education nurses.

The areas we have focussed on are Nutrition, Dementia and Person centred care and End of Life Care. A main focus has been on training and equal opportunities for homes to access training, and ultimately improve the standards of care in homes through empowerment. We would like to work with homes to improve end of life care through advance care planning and integrating the PCT’s pathways around end of life.

For further information contact: Mandy.Barnard@glos.nhs.uk

End of Life Care in Gloucestershire

A Strategy for End of Life Care in Gloucestershire

There was agreement at the EOLC Steering Group on 8th December to adopt the National Strategy for use in Gloucestershire. The Group are currently clarifying local priorities in line with previous work and aim to develop a clear ‘vision’ for EOLC across Gloucestershire. These will be published in a supporting document to the National Strategy.
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.

The EoLC Steering Group operates on a quarterly basis. Membership aims to be representative of all key stakeholders in EoLC. Its purpose is to implement the EoLC strategy with local key priorities.

To view the minutes please go to the webpage on the intranet (see page 11 for details).

The next Steering Group Meeting will be held on Monday 9th March 2009.

End of Life Care Facilitators

Karen English

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 covers Forest of Dean, Gloucester, Stroud and Dursley and works on Mondays, Wednesdays and Thursdays

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

End of Life Care Steering Group Membership

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
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<tbody>
<tr>
<td>Jill Crook (Chair)</td>
<td>Director of Clinical Development</td>
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<tr>
<td>Karen English</td>
<td>EoLC Facilitator</td>
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<td>Gina King</td>
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<tr>
<td>Helen Hodgson</td>
<td>Head of Community Service/CHC</td>
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<tr>
<td>Jane Smith</td>
<td>Community Hospitals lead</td>
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<tr>
<td>Jane Steel</td>
<td>Manager (OOH)</td>
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<tr>
<td>Mary Morgan</td>
<td>Commissioning Lead</td>
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<tr>
<td>Linda Piontek</td>
<td>POPP Care Home Support Team</td>
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<td>Ted Quinn</td>
<td>Mental Health &amp; Learning Disabilities</td>
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<tr>
<td>Dr Helen Miller</td>
<td>GP (PEC Member)</td>
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<td>Dr Tim Healey</td>
<td>GP</td>
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<tr>
<td>Jon Burford</td>
<td>Head of Nursing GRH</td>
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<tr>
<td>Debra Clark</td>
<td>Clinical Nurse Manager Community SPC</td>
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<tr>
<td>Dr Colette Reid</td>
<td>Palliative Medicine Consultant</td>
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<td>Dr Paul Perkins</td>
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<td>Dr Cath Blinman</td>
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<tr>
<td>Dr Ian Donald</td>
<td>Consultant Physician (Medicine)</td>
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<tr>
<td>Sian Cole</td>
<td>Head of Care Services, Cotswold Care Hospice</td>
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<tr>
<td>Jane Hamilton</td>
<td>Clinical Nurse Manager Great Oaks Hospice</td>
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<td>Lorraine Dixon</td>
<td>Palliative Care Services Manager: Sue Ryder</td>
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<td>Annie Young</td>
<td>Nurse Director 3CCN</td>
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<td>Vicki O’Leary</td>
<td>Great Western Ambulance Service</td>
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<tr>
<td>Nick Baker</td>
<td>Manager Carers Glos</td>
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<td>Sue Dale</td>
<td>General Manager</td>
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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.
County-wide Palliative (EoLC) Care Link Forum

Nominated representatives from the Community Hospitals, Localities, POPP and Specialist Palliative Care met on the 15th October to discuss extending current Forums county-wide using the link nurse model approach. Thus to develop an overarching, equitable approach in accessing information, improving links and communication, providing education, and support thereby improving care in Palliative Care and End of Life (EoL) in Gloucestershire.

The next steps for the Core Group are to integrate the Forum into current work streams and provision of education so not to overlap current practices.

Gloucestershire Do Not Attempt Resuscitation (DNAR) Policy

Do Not Attempt Resuscitation (DNAR) discussions are a vital part of Advanced Care Planning as it enables individuals to have a choice about their death. DNAR decisions in End of Life Care (EoLC) are difficult enough for the patient and family/carerers because of the obvious emotional meanings of making their choice. Therefore both Gloucestershire PCT and Foundation Trusts have decided to have a joint policy which would enable the DNAR decision to be transferable in order to minimise the trauma of going over the decision with the patient again if moved from one location to another especially if the person was nearing the end of life.

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You can download the full document from www.resus.org.uk/pages/dnar

Gloucestershire’s policy has been passed by the ratification group in November. Please contact Alan Keyte or Andrea Darby for more information.

Alan.Keyte@glos.nhs.uk, Andrea.Darby@glos.nhs.uk
Tel: 01242 548800

Marie Curie supporting packages of care at home

Our referral centre is open from 0800-2200hrs 7 days a week, and will take referrals on 0845 0567899 up until 2100hrs. Our referral process has been made shorter and you can ask to do a rapid referral to see if we can provide a nurse for that day, before you proceed further.

Our remit is the last 6 months of life, and we now fund 49% of the direct cost of all shifts, for all End of Life patients, not just cancer. There are two locality codes you will need when referring a patient, under Gloucestershire PCT, they are ‘Chelt’ and ‘Chelt CHC’. If your patient needs care from us before they are eligible for CHC funded care you should use ‘Chelt’ and then add CHC when this funding has been agreed. This helps identify the correct budget to be used to pay for care.

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Marie Curie Direct is a free phone line, (0800 634 4520), open from 0900-2230hrs for patients and families only, to enquire if they have cover, and can make comments about the service. We send them a welcome pack once they have been referred to us containing this information and also a ‘Partners in Caring’ book and a complaint form should it be needed.

Please ensure that your patients have an up to date care plan, manual handling assessment and that the families are told our nurses need a comfortable chair, heating, and good lighting available so they can read, study and stay awake. The nurses also need a handover from you about the patients, especially for their first shift and any subsequent change in the patients’ condition. They will also handover to you any concerns or changes that have occurred whilst they are on duty.

Pandora Slinger is available to help, on 07798637972 from 0830-1730hrs Monday to Friday, with any aspect for your referral, especially if, on referral, a shift is not covered. Pandora will ring around to find cover from her team and make every effort to help. Any concerns should be directed to her so a service that helps you meet the needs of your patients and their families can be put in place.

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.

Useful websites

- www.endoflifecareforadults.nhs.uk
- www.goldstandardsframework.nhs.uk
- www.lcp-mariecurie.org.uk
- www.cancerlancashire.org.uk/ppc
- www.ncpc.org.uk
- www.doh.gov.uk
- www.nice.org.uk/
- www.carers.org/
- www.the3ccancernet.org.uk
- www.palliativedrugs.com/

Is it a Myth or Fact?

Please let Karen or Gina know if there is a Myth you would like to dispel with a Fact!

In the next issue:

- The launch of the LCP
- Clarification of terms
- Quality outcomes in EOLC
- Syringe Driver Policy
- Update on medication charts
- Education in EoLC

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Stoke Road Surgery Bereavement Pack

Following a significant event meeting held at the surgery, we felt we needed to improve the support we gave our patients following the loss of a loved one, an experience all of us will have to deal with at some point in our lives.

For most of us, just coming to terms with the loss is a traumatic experience, without having the added stress of knowing what to do, who to contact, and how to cope with our own feelings.

To this end we have put together a pack with all the relevant telephone numbers and information that are needed, from registering a death to details of support organisations, right down to what to do with old medication and equipment.

We have also included booklets from agencies such as Cruse, Marie Curie and The Bereavement Register, together with an excellent publication from the Department of Health.

To make sure the admin process of registering a death is “managed” efficiently at the Surgery we have devised a tick list system to ensure all the processes are carried out in order. This includes advising all staff members at the surgery, arranging a bereavement visit by the family’s GP, contacting the hospital and ensuring all medical records are returned to the Health Authority.

Each member of the surgery team is committed to helping the bereaved family through the difficult journey that lies ahead with support and understanding.

Any enquiries regarding ‘The Bereavement Pack’ - please contact Stoke Road Surgery on 01242 672007 and ask for Jane Tillotson or the Practice Manager, Lester Pygott.

There are some excellent ideas and initiatives in End of Life Care in Gloucestershire. This newsletter is an ideal resource to share such developments and spread best practice.

If you would like to share your local progress then please contact either Karen or Gina on Karen.english@glos.nhs.uk or georgina.king@glos.nhs.uk

New Horizons supporting EoLC

New Horizons are a team of children’s community nurses and support workers. We provide a countywide nursing service to children aged 0-18. We support children and their families to make an informed choice regarding end of life care. If a child or family choose home as their location for end of life care, then
New Horizons will support the family in this decision by providing a 24 hour on call service.

Recently we supported a family with a young baby – Baby A who had been diagnosed with a neurometabolic disorder with a very poor prognosis. Initially, the team provided the family with support following diagnosis. As the baby deteriorated, the team discussed end of life options for the family. We worked with the family to access a local hospice. We liaised closely with the children’s and young people disability team to provide extra support to the family.

Baby A had a short period of stability for 6-8 weeks. During this time she was reviewed regularly by nursing staff who visited her and her family at home. New Horizons also provided a support worker on a weekly basis to offer some respite or short break to the family. We strived to maintain links between the GP and consultant paediatrician during this time to ensure a good basis for working relationships.

Baby A then began vomiting and it became difficult to manage her symptoms with oral medications. She was commenced on a once a day anti-emetic medication to be given subcutaneously. Symptoms became well controlled once twice daily injections were given. To minimise trauma and upset to Baby A, an insuffion was sited into the skin. This meant that once the insuffion inserted, the needle was placed into a port not directly into baby A. New Horizons commenced a 24 hour on call service for the family along with twice daily visits. As a team we were supported by Baby A’s consultant who was happy for us to discuss anything with him.

During this time, we tried to plan for any future deterioration. Pain control was discussed and we ensured that Paracetamol suppositories were available if Baby A couldn’t tolerate oral analgesia. Other analgesics were obtained and pre-emptive prescriptions were written so that we could respond quickly to any change in condition.

Baby A died peacefully at home in her parent’s arms which was exactly how the family wanted it. The family were very grateful that they were supported fully in their decision to keep baby A at home. The New Horizons nurse supported the family when then Gp visited and carried out the verification of death.

As a team we will continue to support the family with bereavement support. All members of the New Horizons team receive regular clinical supervision and we will also have a team reflection.

The future of children’s end of life care

Better Care, Better Lives is a recent publication by the Department of Health that focuses on the future development of children’s palliative care. It is striving to drive forward joint approach to supporting children and their families.

There is currently no medical lead for Children’s palliative care. In the case of Baby A, the family were supported medically out of hours purely by the goodwill of the consultant paediatrician.

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As a team we are currently involved with developing countywide strategies which will provide a seamless service to children and their families across acute and community trusts. This strategy will include the development of a steering group.

For further information contact Kerry O’Reilly, Community Children’s Nurse on kerry.o’reilly@glos.nhs.uk

EoLC in HMP Gloucester Prison

HMP Gloucester is a local male prison with a population of approximately 300. The ages range from 18-70 years approximately. Most of the population are reasonably fit people, and until recently we have not had, or perceived the need, for a policy covering End of Life care.

This changed earlier this year when a patient died in GRH, after being diagnosed with a life-limiting illness.

Although this diagnosis was not made until after our patient had been admitted into hospital the subsequent inquiry highlighted our lack of policy surrounding this area.

Efforts have been made to increase awareness surrounding the complex, holistic needs of patients with life-limiting illness, with some staff attending courses and workshops around grief and bereavement. We hope with greater understanding and knowledge, we may become better advocates for our patients. These courses also identify what services are available within our locality; we are then better able to advise not only our patients, but their families on what facilities are available to support them during this difficult period.

We are also in the process of developing an agreed policy to help staff access appropriate services to ensure best practice for any patient fitting these criteria. This is made difficult due to the obvious security implications surrounding our patient-group, whether the patient needs to attend hospital, or if any practitioners visit their patient within the Prison environment. There can, therefore, be a delay in accessing appropriate services and facilities.

The healthcare and the Prison services at HMP Gloucester are committed to working together to ensure excellent evidence-based best practice to all of our clients.

For further information contact Karen English on Karen.english@glos.nhs.uk

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Conferences, courses and study days

**Seventh National Conference: A Practical Guide to Developing, Measuring and Maintaining (Competence in New Nursing Skills and Advanced Practice)**

Tuesday 24th February 2009
Manchester Conference Centre
For more information contact Hannah on 020 8541 1399 or email hannah@healthcare-events.co.uk

**National Council of Palliative Care’s forthcoming conferences:**

**Dying Differently: the ethical dimensions of how and where we die - Conference**

31st March 2009.
Guys Hospital Suite, London
www.ncpc.org.uk/events

**Recognising Complex Grief**

Tuesday 13th January 2009 1.30-4.30pm.
Cotswold Care Hospice, Minchampton
Ring Diane Ponting on 01453 733702

**Celebrate District Nurses Day in Gloucestershire PCT**

Tuesday 11th February 2009
To be held at Kingsholme Rugby Club, Gloucester
**Guest Speakers:** Professor Christine Moffat and Karen Logan

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**Palliative Care Education** also offered by the following local providers (list not exclusive):

- Gloucestershire Acute NHS Trust
- Adult Social Care Services
- University of West of England
- University of Gloucestershire
- Sue Ryder Care
- Cotswold Care Hospice

Please contact organisation directly for further details.

**New way to find page: End of Life Care on the PCT Intranet**

To access a wide rage of local and national information about End of Life Care go to the **Home page** of the **Glos PCT Intranet**, click on **Clinical Information** on the top menu, and then make your selection from the End of Life Care menu. These pages are currently under construction so do contact Karen or Gina if you can’t find what you are looking for or for comments and suggestions!

We also plan to extend this work to Gloucestershire County Council intranet and develop a website for the wider audience.

**And Well Done to…**

…Heather Mitchell from Kate’s Care Home, and Helen Ballinger on receiving the Queens Nurse award on 14th October 2008.

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